First Nations of
Quebec and Labrador
Health and Social Services
Commission

Assessing Continuing Care Requirements in First Nations and Inuit Communities

Quebec Regional Report

July 2006

First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)
250, place Chef Michel Laveau, Wendake, Quebec, G0A 4V0
Telephone : (418) 842-1540
Fax : (418) 842-7045
Website : www.cssspnql.com

Report content and Editing : FNQLHSSC Research Team
Quebec Continuing Care Regional Table
Design by : Indiana Marketing
Printed by : Imprimerie Laurentide

This document is also available in French at www.cssspnql.com.
ISBN 0-9687619-5-X

Acknowledgements

We wish to thank the communities that accepted the invitation to participate into this pilot assessment and opened their door to us. We also wish to express our appreciation to the interviewers who took on the mandate to conduct interviews and collect the information presented in this report. We would like to acknowledge the clients and family caregivers who agreed to share their impressions and took some of their own time to fill out the questionnaire. Finally, let us underline the work accomplished by the Quebec Continuing Care Regional Table; they have supported us and brought their precious contribution all along the research process.

On behalf of the First Nations of Quebec and Labrador Health and Social Services Commission, the Research Team wishes to thank all those who were involved and contributed to the success of this community research project.

Meegwetch!

Nia:wen!

Tia: wen!

Merci!

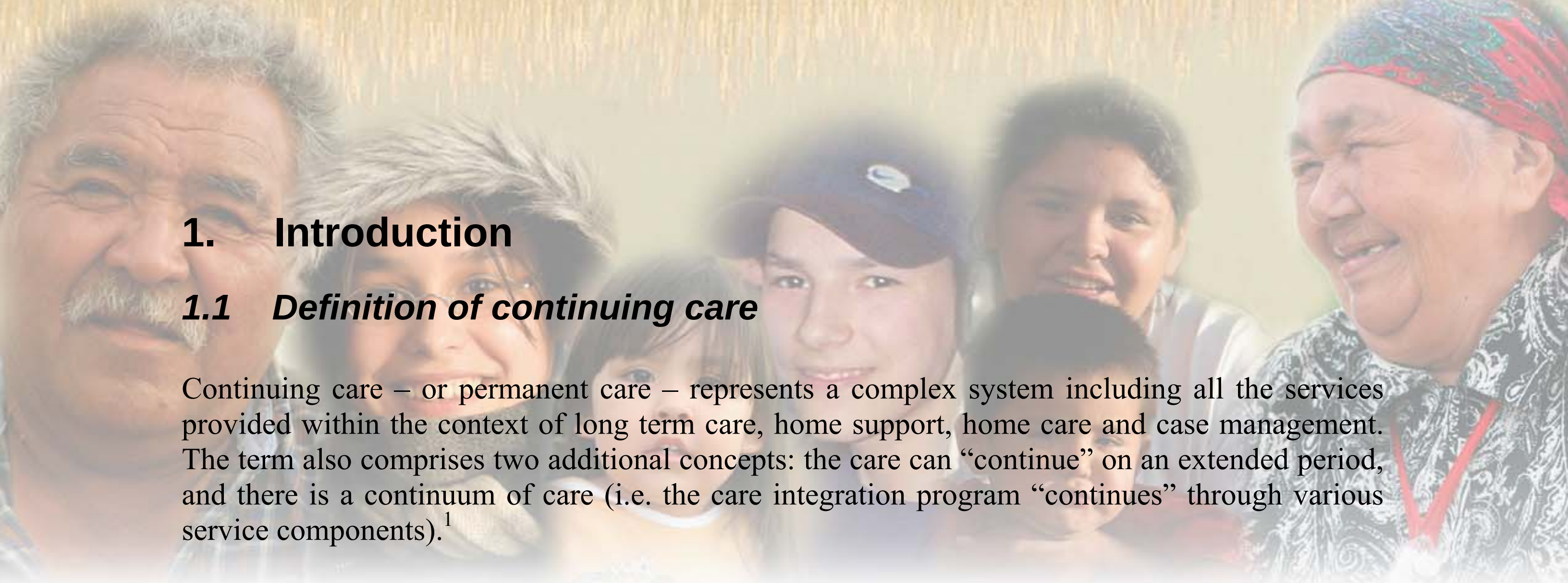
Thank you!

Note to the reader: The masculine gender is used throughout the text without any intent to discriminate but solely to make the text easier to read.

TABLE OF CONTENT

LIST OF MAP AND CHARTS

LIST OF TABLES



1. Introduction

1.1 Definition of continuing care

Continuing care – or permanent care – represents a complex system including all the services provided within the context of long term care, home support, home care and case management. The term also comprises two additional concepts: the care can "continue" on an extended period, and there is a continuum of care (i.e. the care integration program "continues" through various service components).[1]

Within the context of this research project continuing care designates a range of medical, nursing, social and therapeutic services intended for people who have lost part of their ability to care for themselves. Here are the groups of people targeted in this research project:

- *Elders* – People aged 55 and over who do not have or have lost, part or all of their ability to care for themselves due to their physical or mental health (for example, elders with diabetes, with cardiovascular problems and dementia type disorders).
- *Adults with chronic diseases* – People aged between 18 and 54 who do not have, or have lost, the ability to care for themselves and whose physical abilities are impaired by a disease or chronic health condition (for example, diabetes, cancer, cardiovascular and respiratory diseases, musculoskeletal conditions such as arthritis, etc.).
- *Adults with mental health problems* – People aged between 18 and 54 who do not have, or have lost, the ability to care for themselves and whose mental/intellectual abilities are impaired by a disease or a health condition (for example, depression, neurological sequelae consequent to alcohol or drug abuse, etc.).
- *Children and teenagers with special needs* – People aged between 0 and 17 who do not have, or have lost, the ability to care for themselves due to an impairment of their physical or mental/intellectual abilities related to a given health condition (for example, developmental delays, physical impairment, psychiatric disorders, etc.). Children and teenagers with an attention deficit and/or foetal alcohol syndrome are not included in this category.

Continuing care services may be provided at home, in a supervised environment, in an institutional environment and in a long-term care facility. It may be long-term or short-term care. Long-term care is usually required when the person can no longer stay at home due to increasing medical needs and security. However the client may receive long-term services and personal care in his own home, such as personal care, foot care, meals, laundry, house-cleaning, etc.

Short-term care services are limited in time (up to three months). They are intended for people recuperating from an acute episode of illness, surgery or to help anyone recently discharged from

---

[1] Health Canada, 2004, *Frequently asked questions: Continuing care*. Government of Canada, available at http://www.hc-sc.gc.ca/hcs-sss/home-domicile/index_e.html

the hospital (post-hospital care). These services aim to prevent the person from being admitted or readmitted in a short-term care facility and/or to shorten the stay in a short-term care facility[2].

1.1.1 Historical overview of the organization of health services among Aboriginals in Canada

In the last decades, several events have shaped continuing care among First Nations in Canada. Here is a brief historical overview of those main events.

In 1979, the Government of Canada adopted the *Indian Health Policy*. It recognizes that the circumstances under which many Aboriginal communities exist have placed Aboriginal people at a grave disadvantage compared to most other Canadians in terms of health, as in other ways.[3] Hence, the goal of this policy is to achieve an increasing level of health in Aboriginal communities, generated and maintained by the Aboriginal communities themselves.

The policy is built upon three pillars: “community development, the traditional relationship between Aboriginals and the Federal Government, and the Canadian health system”.[4]

The first and most significant pillar is community development, both socio-economic development and cultural and spiritual development. Under this policy, this pillar will help remove the conditions of poverty which prevent the members of the community from achieving a state of physical, mental and social well-being.

Maintaining the relationship between Aboriginals and the Federal Government is the second important component of the policy. This relationship must be strengthened by opening up communication with the Aboriginal people and by encouraging their greater involvement in the planning and implementation of health programs.

Finally, the policy’s third pillar is the Canadian health system. Although Aboriginal communities play a major role in the promotion of health and the adaptation of health services to their own needs, the Federal Government is committed to maintaining an active role in the Canadian health system as it affects Aboriginals. Through this policy, the government indicates its commitment to helping Aboriginal communities play an active and more positive part within the Canadian health system and in the decision-making process affecting their health.

Within the context of this policy, Health Canada has the mandate to assist communities in the delivery of continuing care, particularly with an emphasis on fostering community development and maintaining the traditional relationship between Aboriginals and the Federal Government.

---

[2] Canadian Health Information Institute, 2002, *Development of National Indicators and Reports for Home Care, Phase 2*, Ottawa, p. A-1.

[3] FNQLHSSC, 2006, *Indian Health Policy*, available at www.cssspnql.com.

[4] *Ibid.*

In the ‘80s and at the beginning of the ‘90s, the Federal Government developed health and social services initiatives among First Nations in line with the intent of the 1979 *Indian Health Policy*. Among those initiatives were the *Quebec Region Community Health Representative Program* (1981), the *Native Alcohol and Drug Abuse Program* (1984), the *Family Violence Initiative* (1990), and other community development programs. Although these programs are not intended specifically for Elders, they are part of the continuum of care that involves all community members: children, teenagers, adults and Elders.

In 1984, a memorandum of understanding between Health Canada and the Department of Indian and Northern Affairs Canada (DINAC) set the areas of responsibility of each department in order to ensure different and complementary continuing care services to the First Nations and Inuit community members and residents through their respective programs. This memorandum of understanding gave DINAC limited responsibilities with regards to non-medical institutional care provided in communities: type 1 and 2 levels of care.

The following is the federal classification of types of care:

- Type 1: Institutional care for individuals requiring supervision and assistance with daily living activities as well as social and recreational services. Usually independently mobile, they may have decreased physical or mental faculties;
- Type 2: Continuing care for individuals with a relatively-limited need for diagnostic and therapeutic services in a hospital but who require some personal care on a 24 hour basis under medical and nursing supervision. They have a relatively stabilized chronic disease or physical or mental functional disability;
- Type 3: Care provided to the chronically ill who require a complete range of therapeutic services, medical management and specialized nursing;
- Type 4: Rehabilitation care to restore or improve the functional ability. Depending on the situation a psychiatric treatment may complete the physical rehabilitation;
- Type 5: Intensive care for people requiring investigation, a diagnosis or treatment and who are seriously ill or recovering.

In 1986, the Federal Government introduced the *Health Transfer Initiative*, designed to transfer administrative authority for community health services over time to reserves in the provinces. The communities in the territories became involved in a similar transfer process through the devolution of responsibility for health services to the territorial governments. The Inuit and some First Nations people in Quebec achieved a considerable level of community control over health and social services through the *James Bay and Northern Quebec Agreement* (1975) *and the Northeastern Quebec Agreement*[5] (1978). These initiatives promise to provide opportunities for Aboriginal communities to assume greater responsibility for developing health services and programs at the community and regional levels. At the time, provincial governments had also recognized the value of decentralization, community involvement and integrated service delivery.

---

[5] DINAC, 1991, *Royal Commission Report on Aboriginal Peoples*. Available at http://www.ainc-inac.gc.ca/ch/rcap/sg/si27_e.html

In 1987, DINAC proceeded with the inventory of adult care and services in First Nations communities. At the time, no governmental program was designed to specifically meet the needs of people requiring continuing care. Moreover, very few data was available on the community needs in terms of continuing care, which made it difficult to develop strategies to address those gaps. In order to develop a model for the delivery of continuing care in First Nations and Inuit communities, DINAC and Health Canada decided to join their efforts. This collaboration avoided having adult care entirely taken over by DINAC.

In 1988, a moratorium was imposed by DINAC on the construction and implementation of new residential services in the communities. However, DINAC increased the resources to offer home support services to Elders living at home.

1989 was a milestone in the development of a home and community care program. Health Canada and DINAC created a joint working group to assess the needs of First Nations community members. The findings of the working group lead the developments to come by asserting the existence of significant gaps in home and community care in most First Nations communities. At the time, the absence of an authority responsible for continuing care curbed the development of a national policy in addition to creating ambiguities with respect to the responsibilities of both organizations (Health Canada and DINAC) involved. This absence of a responsible authority also created structural obstacles and fragmentations in the development of services and standards for the quality of care.

In 1991, Health Canada and DINAC's joint working group – created in 1989 – made the following recommendations based on the *National Strategy for the Integration of Persons with Disabilities* form the early '80s:

1- comprehensive continuing care services should be established which would include assessment, single source entry, case management and evaluation;
2- Health Canada should be given the mandate and resources to provide home nursing care;
3- one federal department should take sole responsibility for the delivery of services in this area;
4- case managed funding options should be developed which recognize regional and community diversity;
5- improved training, programs and resources should be established.[6]

The joint working group also acknowledged the existence of several gaps in terms of continuing care in First Nations communities: personal care, meals on wheels, housekeeping, alternatives to institutional care (for example, group homes, day care services, and Elders homes).[7]

In 1996, in the wake of events, the *Royal Commission Report on Aboriginal Peoples* was published. This voluminous document contains a significant amount of information on the culture, economy, education, health and well-being of First Nations in Canada. It also mentions the importance of developing a new strategy for the health and well-being of First Nations. This

---

[6] Katenies Research and Management Services. 2002. *A First Nations Continuing Care Policy- an Intergenerational Perspectives*, p. 23.

[7] Ibid, p. 23.

strategy must focus on the family, community and nation in which individuals live. It is therefore a holistic approach to health specific to First Nations communities. This approach will be developed later.

From June to November 1998, a working group, comprised of representatives from Health Canada's First Nations and Inuit Health Branch (FNIHB), INAC, the Assembly of First Nations (AFN) and the Inuit Tapirisat in Canada (ITC), worked on the development of the *Continuing Care Framework*'s first phase. For the first time, Aboriginal organizations were invited to participate in the development of strategies for continuing care in the communities. A first conference on home care was also held in 1998, during which several issues around service delivery, national policy development and resources requirements were highlighted. At the conference, the Federal Minister of Health stated that "we [the Federal Government] have a long way to go before we meet our responsibility of funding home and community care […] in First Nations and Inuit communities"[8]. It is reasonable to say that this conference accelerated the developments in continuing care that communities had been waiting for so long.

The following year, in 1999, the *First Nations and Inuit Home and Community Care Program* (FNIHCCP) was announced and was expected to be operational in all regions by 2001. It was set up by Health Canada in order to complete the service offer by DINAC's 1986 *Assisted Living Program*.

1.1.2 Health Canada's involvement: *First Nations and Inuit Home and Community Care Program* [9]

In 1998, a Continuing Care Working Group was formed and included representation from Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), Health Canada's First Nations and Inuit Health Branch (FNIHB), and the Department of Indian Affairs and Northern Development (DIAND). This group laid the foundation for the *First Nations and Inuit Home and Community Care Program* Program (FNIHCC), which was launched by Health Canada at the end of 1999.

Managed by FNHIB, the FNIHCCP is intended for members of all ages living in a First Nations or Inuit community. The program funds essential home and community care service elements, such as case management, nursing, in-home respite care and personal care. The funding is allotted based on the number of residents and the location of the community (Appendix 1).

The objectives of the FNIHCCP are to:

- build the capacity within First Nations and Inuit to develop and deliver comprehensive, culturally sensitive, accessible and effective home care services;

---

[8] Katenies Research and Management Services. 2002, p. 25.

[9] Health Canada, 2004, *First Nations and Inuit Home and Community Care Program – Annual Report 2002/2003*, Minister of Public Works and Government Services, available at http://www.hc-sc.gc.ca/fnih-spni/pubs/home-domicile/2002-2003_rpt/index_e.html).

- assist First Nations and Inuit living with persistent and acute illness in maintaining optimum health, well-being and independence in their homes and communities;
- facilitate the effective use of home care resources through a structured, culturally-defined and sensitive assessment process to determine service needs of clients and the development of a care plan;
- ensure that all clients with an assessed need for home care services have access to a comprehensive range of services within the community, where possible;
- assist clients and their families in participating in the development and implementation of the client's care plan to the fullest extent and to utilize community support services where available and appropriate in the care of clients; and
- build the capacity within First Nations and Inuit to deliver home care services through training and evolving technology and information systems to monitor care and services and to develop measurable objectives and indicators.[10]

The essential elements of the FNIHCCP are:

- a structured client assessment process that includes on-going reassessments and determines client needs and service allocation. Assessment is a structured dynamic process of continuous information gathering and knowledgeable judgements that attach meaning to the information being gathered. Assessment and reassessment processes can involve the client, family and other care givers and /or service providers;
- a managed care process that incorporates case management, referrals and service linkages to existing services provided both on and off reserve/settlement;
- home care nursing services that include direct service delivery as well as supervision and teaching of personnel providing personal care services;
- the delivery of home support personal care services that are determined by the community needs assessment plan and that do not duplicate, but enhance existing DINAC adult care services (e.g. bathing, grooming, dressing, transferring, care of bed-bound clients including turning, back rubs and routine skin care, etc);
- the provision of in-home respite care;
- established linkages with other professional and social services that may include coordinated assessment processes, referral protocols and service links with hospital service providers, physicians, nurse practitioners, advanced practice nurses, respite and therapeutic services;
- provision of and access to specialized medical equipment, supplies and specialized pharmaceuticals to provide home and community care;
- the management and supervision of the program regarding the capacity to manage the delivery of the home and community care program in a safe and effective manner, if existing community infrastructure exists; and
- a system of record keeping and data collection to carry out program monitoring, ongoing planning, reporting and evaluation activities.[11]

---

[10] Health Canada. *First Nations and Inuit Home and Community Care Program – Annual Report 2002/2003*. Available at www.hc-sc.gc.ca/fnih-spni/pubs/home-domicile/2002-2003_rpt/1_background-contexte_e.html.

[11] Health Canada, 2004, *First Nations and Inuit Home and Community Care Program – Annual Report 2002/2003,* Minister of Public Works and Government Services, available at http://www.hc-sc.gc.ca/fnih-spni/pubs/home-domicile/2002-2003_rpt/index_e.html

The Program may expand to include supportive service elements based on community needs and priorities, existing infrastructure and availability of resources. Supportive elements that may be provided within a continuum of home and community care might include, but are not limited, to:

- rehabilitation and therapy services;
- respite care in a facility;
- adult day care;
- meal programs;
- mental health home-based services for long-term psychiatric clients and clients experiencing mental or emotional illness. These services might include traditional counselling and healing services, and medication monitoring;
- support services to maintain independent living, which may include assistance with special transportation needs, grocery shopping, accessing specialized services and interpretative services;
- home-based palliative care;
- social services directly related to continuing care issues; and
- specialized activities to promote health, wellness and fitness.

In order to determine if an individual is eligible to these services, the community health centre is responsible for systematically assessing the client's needs and physical condition. These results will be used to establish the care and essential services required. This process takes into account the client's medical history and is carried out with the collaboration of the client, his family, physician, and any other person involved in the provision of care. Before authorizing home care and services, the security of the client and his family caregiver is assessed to make sure their health is not compromised. The range of care and services must also be in accordance with the pre-established standards through the FNIHCCP and Aboriginal health authorities. To this effect Health Canada indicates that "an integral part of the *First Nations and Inuit Home and Community Care Program* (FNIHCC) Program in Quebec is ongoing collaboration with the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) and Nunavik Regional Board of Health and Social Services (NRBHSS). These two organizations play vital roles in the planning, implementation, and monitoring of the program"[12]. Let it be noted that with the exception of the nine Cree communities, the other First Nations communities operate the program independently.

Following the client's assessment, the case management committee ensures that the care plan corresponds to the client's needs and that it is carried out in an efficient and timely manner by the care provider. The home and community care include the delivery of the following services:

- nursing care: provided in a home or community setting, nursing care may include teaching the client and his family about self-care. It may also include the supervision of workers providing the personal care services;
- personal care: maintaining the client's personal hygiene through bathing, foot care, etc.;

---

[12] Health Canada, 2004, *First Nations and Inuit Home and Community Care Program – Annual Report 2002/2003,* Minister of Public Works and Government Services, p. 49, available at http://www.hc-sc.gc.ca/fnih-spni/pubs/home-domicile/2002-2003_rpt/index_e.html

- home support, which includes two components:
    - personal care services: bathing, personal hygiene, dressing, transfers, care of bed-bound clients including turning, back rubs and routine skin care;
    - housekeeping services: light house cleaning, laundry, meal preparation,
- in-home respite care services: caring for someone ill while family members have a rest.

The FNIHCCP's target clientele includes the following individuals who:

- have been discharged from the hospital;
- have an illness or disease requiring follow-up care;
- are unable to live alone while waiting for care in a long-term care facility;
- have a disability requiring assistance to live on their own;
- need nursing care in the home;
- choose to live at home instead of in a long-term care facility as long as it is safe, affordable and services are available;
- are part of the family and friends of someone receiving continuing care services and who need support to continue to care for people in the home.

Finally, let it be noted that the FNIHCCP will not fund the construction and/or delivery of long term care institutional services.

1.1.3 Department of Indian Affairs and Northern Canada's involvement: *Assisted Living Program*

Complementary to Health Canada's *First Nations and Inuit Home and Community Care Program*, DINAC provides continuing care services under its *Assisted Living Program*. This program funds in-home support services, adult foster care and institutional care, based on the reimbursement of actual expenses. The objective of the *Assisted Living Program* is to provide non-medical social support programs that meet the special needs of infirm, chronically ill and disabled people at standards reasonably comparable to the reference province or territory of residence[13].

The *Assisted Living Program* is threefold:

1. In-home support: allows for financial assistance for the delivery of non-medical personal care such as light housekeeping, short-term and long-term respite care, home care day care meal preparation and medical transportation.

---

[13] In the province of Quebec, " [any] person living in a single house, an appartment, a group home or a private facility is entitled to home support. The needs assessment and the intervention plan or personal service plan will take into account the services provided in these facilities. The people living in a public facility (hospital, rehabilitaitn centre or public long-term care facility), in a private long-term care facility or in a private conventionned long-term care facility are not eligible since they already receive services from these facilities. It is also the case for people living in public facilities created under other provincial or federal departments." - Ministère de la Santé et des Services sociaux, 2003, *Chez soi: Le premier choix- La politique de soutien à domicile,* Government of Quebec, p. 16.

2. Institutional care: allows for the reimbursement of the expenses associated with non-medical type I and II levels of care services in a facility recognized by the province. The resident is expected to pay the provincial/territorial government established co-insurance or user fee for care and maintenance, and clothing and personal expenses to the extent that his individual circumstances permit. The following services may be covered: normal accommodation, meals and therapeutic diets, laundry, emergency and everyday equipment required for the treatments, the care provided under professional supervision, planning of a social and recreational activity program, clothing, old age benefits, benefits to cover the costs of living as well as guide dogs.

Let it be noted that these services may also be provided in a foster family located in or outside a community.

Institutional care may be long-term or short-term care. Long-term care facilities offer housing to people requiring day and night supervised care, including professional health care and personal care (meals, laundry, housekeeping). Short-term care is provided over a limited period of time (up to three months) and is intended for people recovering from an acute episode of illness, surgery, or who have been discharged from the hospital.

3. Adult foster care: allows for financial assistance to provide care and supervision, in a family setting, to people who are not independent due to physical or psychological impairments but who do not require constant medical follow-up. It is an alternative solution to institutional care. A foster home must obviously be operated in compliance with the guidelines governing authorization or accreditation in the province. In Quebec, the Intermediate Resource Reference Framework (*Cadre de référence sur les ressources intermédiaires*) (2001) stipulates that a foster home may be comprised of “one or two people who take in a maximum of nine adults or elderly people entrusted by a public facility in order to meet their needs and provide them with living conditions that are as close as possible to a natural setting”.[14]

In 1988, restrictions were imposed on constructing new institutional care facilities on reserves because of escalating costs and INAC’s unclear authorities in that area. The restrictions were intended to be temporary until a national policy framework was put into place. Even though no national policy was implanted, INAC has agreed, since 2000, to approve the construction of new facilities under the following conditions:

- construction of the facility will not require a Ministerial Loan Guarantee;
- the facility will operate within provincially established rates for types 1 and 2 levels of care, for which INAC has authority;

---

[14] Ministère de la Santé et des Services sociaux, 2001, *Cadre de référence sur les ressources intermédiaires*, *Direction générale des services à la population*, p.14, available at http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2001/01-801-01.pdf

- where required, types 3, 4 and 5 care will be provided by another authority (provincial, territorial or regional health authority);
- the facility will be economically viable (for example, projected bed demand and funding partnerships will be specified);
- the facility will be licensed and/or recognized and monitored by a recognized authority (province, territory or other licensing or recognition body);
- operational funding must be available within existing regional allocations.[15]

The *Assisted Living Program* is intended for any person living in a First Nations community who has undergone a formal assessment by a social worker, who requires services and who does not have the resources to obtain them himself. The assessment focuses on the client's needs, the family composition, his age and the financial resources of his household.

The reimbursement of in-home support care may take the form of compensation to the family or the individual who then pays the selected family support worker himself. This compensation is established at an hourly rate of $9 and may not exceed 40 hours per week. Let it be noted that families living below the poverty line, on social assistance and the people 65 and over only receiving the Old Age Security Benefits (and the Guaranteed Income Supplement in some cases) are not subject to an evaluation of their financial capacity. Finally, applicants with an annual net income of $47,001 and over are not eligible to the program. The recipient's financial contribution is calculated based on the following scale[16]:

Table 1.1: Client's financial contribution based on net annual income

Gross income scale	% of the client's contribution
$15,000 Poverty line (December 1999)	**0%**
$19,000 Poverty line	**10%**
$19,001 to $23,000	**20%**
$23,001 to $27,000	**30%**
$27,001 to $31,000	**40%**
$31,001 to $35,000	**50%**
$35,001 to $38,000	**60%**
$38,001 to $41,000	**70%**
$41,001 to $44,000	**80%**
$44,001 to $47,000	**90%**
$47,001 and more	**100%**

As a comparison, the province of Quebec proceeds differently to establish the recipient's financial contribution. People with a low income receive daily living activity services at no cost. The main difference lies in the fact that the establishment of the low income cut-off value takes into consideration the size of the family. For example, in a rural zone, the low income cut-off value is $14,000 for a person living alone. This cut-off value increases by $3,000 to $4,000 for each additional person up to a maximum of $37,050 for a family of 7 persons and more. If the

---

[15] DINAC, 2004, *Assisted Living Program – National Manual — Overview*, available at http://www.ainc-inac.gc.ca/ps/mnl/alp/bkg_e.html.

[16] *Ibid*.

income is superior to the low income cut-off value, the people in need are referred to a social economy enterprise in their area.[17]

Taking into account the size of the family allows for a greater number of people to access attendant care.

In the province of Quebec, regarding the services provided by social economy enterprises, the Financial Assistance for Domestic Help Services Program was created in 1996. Managed by the RAMQ (*Régie d'assurance-maladie du Québec*), the program's objectives are to help build a strong network of businesses providing domestic help services and to encourage people to use the services offered by these businesses. The services provided by these businesses are light housekeeping work (laundering, vacuuming, dusting, cleaning), heavy housekeeping work (major cleaning jobs and clearing snow), cleaning clothes, preparing non-diet meals, Shopping for groceries and running other errands.[18] This type of organization does not exist in First Nations communities.

In order to better understand the differences between Health Canada's FNIHCCP and DINAC's *Assisted Living Program*, here is a table illustrating their main components[19]:

Table 1.2: Synthesis of Health Canada' FNIHCCP's and DINAC's *Assisted Living Program*'s main components

Home and Community Care Program (Health Canada)	Assisted Living Program (DINAC)
Home support – provides medical personal care (for example, wound bandaging).	**Home care – provides non-medical personal care (for example, washing hair, preparing meals and housekeeping).**
Nursing – provides nursing care (for example, administering medications and changing IVs).	**Foster care – provides supervision and care in a family setting.**
Community support – includes a process evaluating how the HCC Program is functioning.	**Institutional care – provides services in Type I and II institutions.**

Both programs vary when it comes to eligibility criteria. Health Canada's *Home and Community Care Program* is open to all residents of First Nations communities, whether they are members or not. Whereas DINAC's *Assisted Living Program* is open to all First Nations members living in the community. For non-aboriginal residents, the delivery of services covered by DINAC's Program is at the discretion of each community's local authorities.

---

[17] This information was obtained at the Timiskaming Health and Social Services Centre

[18] RAMQ, 2006, available at http://www.ramq.gouv.qc.ca/en/citoyens/contributionetaidefinancieres/exonerationaidedomestique.shtml

[19] DINAC, 2004, *Assisted Living Program – National Manual - Overview*. Available at http://www.ainc-inac.gc.ca/ps/mnl/alp/bkg_e.html.

1.1.4 Family Caregiver

Consequent to the political and social trend that aims to relieve health facilities and within the context of a shift to ambulatory care, an increasing number of people are cared for at home instead of in a facility. Hence the contribution of and need for family caregivers is increasing significantly.

A family caregiver is a person who provides care and support and assists a close or extended family member, a friend, a neighbour or any person requiring assistance. The family caregiver provides individual assistance to carry out various tasks or activities on a daily, weekly, monthly or seasonal basis, without any remuneration. A report from the Canadian Institute on Health Information (2002) indicates there is an increased recognition of the "role and importance of family caregiver and support networks in the delivery of home care. In research reports, the absence of support by family caregivers was identified as a significant risk factor in the placement in a facility of non-autonomous elderly people and people with disabilities living in the community. The availability of family caregivers is categorized as important when evaluating the needs that family caregivers may address, as well as the capacity of family caregivers and service providers to meet the client's physical, psychological and social needs"[20].

According to the Quebec Health and Social Services Ministry (MSSS) (*Ministère de la Santé et des Services sociaux du Québec)*, a family caregiver plays the following roles:

1) A **family caregiver**:

- «The family caregiver's commitment is voluntary and results from the freedom to make informed choices. It is possible for any person, at any time, to re-evaluate the nature and scope of his commitment. This recognition however should not eclipse those normal and usual obligations between parents and children or between spouses, provided for under Civil Code;
- the support to family caregivers has one objective, and that is to enable the family caregiver to maintain his current and usual personal relationship with the person he assists;
- in view of this, the family caregiver is considered both as a client, a partner and a citizen who fulfills his usual obligations.

2) A **client**:

The family caregiver needs to be supported and accompanied in his role. Services and measures aiming to support them must progressively be implemented in each region to meet their own needs

---

[20] CIHI, 2002, *Development of National Indicators and Reports for Home Care. Phase 2: Description of indicators – National Pilot,* p. 10.

3) A **partner**:

> The family caregiver must receive all the information (with the previous consent of the person he is assisting), the training and the supervision required to master the tasks he freely accepts to carry out; he must also know who to contact in case of an emergency and have immediate access to assistance. With regards to long-term care, the family caregiver takes an active part in the development of the intervention plan or the personal service plan, always with the recipient's consent.

4) A **citizen** who fulfills his /her social and family obligations:

> Measures must be taken for the family caregiver regarding his normal and usual obligations (labour standards, employment-insurance, fiscal measures…)"[21].

At the following point - 1.2.1 *Delivery of Continuing Care: the Province of Quebec Versus First Nations communities* – we will see that the range of services, measures and support to family caregivers is not fully implemented in First Nations communities, partly because of a lack of resources. Let it be noted that these findings precede the study and the various continuing care players and there is consensus on most of them among stakeholders.

1.2 Issues in the Delivery of Continuing Care among First Nations

1.2.1 Delivery of Continuing Care: the Province of Quebec versus First Nations communities

In Canada health care services are under provincial jurisdiction. The Canadian Heath and Social Transfer[22] ensures the funding per capita of health care services covered by provinces and territories. Most provinces and territories however do not deliver these services in First Nations communities.

In the province of Quebec, continuing care services are delivered in compliance with the orientations of the *Politique de soutien à domicile « Chez soi: le premier choix »* (Home Support Policy "At home: my first choice") (2003) from the *Ministère de la Santé et des Services sociaux (MSSS)* (Health and Social Services Ministry). The policy's priorities are as follows:

- any person with a significant and persistent disability must be able to live in his home and take part in his community life in conditions that he considers satisfying both for him and his family;
- any person recovering at home or receiving care, treatments or support there must be able to count on the required security guarantees;

---

[21] MSSS, 2003, *La politique de soutien à domicile: Chez soi le premier choix*, p. 6-7, available at http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2002/02-704-01.pdf

[22] Department of Finance Canada, 2005, *Transfer Payments to Provinces,* available at http://www.fin.gc.ca/transfers/transfers_chst_e.html

- any person has the right to be treated fairly, notwithstanding his status or income;
- the residence is a private place. The people's decisions always prevail when it comes to their daily living choices and the choice of resources to support them;
- home interventions must be carried out in a manner respectful of the cultural values and the family and social situation. The intervention is founded on a relation of trust. "“Overprofessionalization”[23]of the home must be avoided". [24]

<u>Home care services ensured by the Government of Quebec</u>

The four following points list the range of home care services ensured by the Government of Quebec[25]. Brief comments in the situation of First Nations communities clearly demonstrate a shortfall in the services that are delivered to them.

A. Professional care and services:

- medical services;
- nursing care;
- nutrition services;
- rehabilitation services (physiotherapy, occupational therapy, speech therapy and audiology);
- respiratory therapy services;
- psychosocial services;
- consultation services (psychogeriatrics, geriatrics, psychiatry and pediatrics);
- specialized rehabilitation services.

In the communities medical services are provided by the RAMQ. Nursing care is under Health Canada's responsibility while the delivery of psychosocial services is ensured by DINAC. The other care and services (nutrition, rehabilitation, respiratory therapy) are extended health care services and depend on each community's service delivery plan.

Access to services varies from one community to another. Specialized services frequently require staying in a facility located outside the community and some other services are available only on a periodic basis, depending on the visiting specialists who come to communities located in more or less remote areas.

B. Home support services:

- personal assistance services (hygiene, meals, transfers, etc.);
- housekeeping services (cleaning, meal preparation, shopping, etc.);
- community support services (manage a budget, fill out administrative forms, meals on wheels, accompaniment, friendly visits, etc.);

---

[23] To avoid the "overprofessionalization" of the home means to avoid having an overly strong professional presence at home.
[24] MSSS, 2003, *La politique de soutien à domicile*, p. 5.
[25] *Ibid*, appendix.

- learning assistance (training and stimulation activities, occupational and rehabilitation activity support, personal activities, etc.).

Heath Canada's FNIHCCP is responsible for the personal assistance services whereas DINAC's *Assisted Living Program* is in charge of the housekeeping support services. The two other services (community activities and learning assistance) are note covered by these two programs. Although these services are not covered by the governmental programs, many communities ensure their delivery themselves.

C. Services to family caregivers:

- babysitting or « presence-surveillance »: in the case of an adult, the normal babysitting activities when a family caregiver living with a disabled person must leave home occasionally for various daily living activities;
- respite: allows for rest to compensate for the additional stress and fatigue that result from the special needs of a child or an adult with a disability. Respite may be provided at home or outside of the home (temporary stay in a public facility, an intermediate resource or a community intake organization or a stay in a foster family, a respite home or any other resource offering this service);
- ad hoc help: allows the family caregivers to deal with unpredictable situations. Temporary and usually for a short period of time, it aims to plan and organize needs in case of emergency;
- daily living activity support: various measures enabling the family caregivers to relieve each other in their daily living activities (child care, material life organization support and accompaniment);
- psychosocial services: allows the family caregivers to deal with the adaptation required when accompanying a person with a disability, frail or going through an episode of acute care, at all stages (diagnosis, treatment, rehabilitation, palliative care, etc.). Theses services are also intended for the brothers and sisters and the close ones;
- community organization services: provided by the local entity, they support the development of personal assistance services to the person and services to family caregivers.

In First Nations communities DINAC's *Assisted Living Program* provides respite care to family caregivers, babysitting and assistance with activities of daily living. In the case where other services are available in the communities, they are funded through the allocations intended for health services. However, resources are often very limited in several communities, which reduces the possibility of offering support to family caregivers. The other services to family caregivers are not available in First Nations communities.

D. Technical support (required for a person to stay at home):

- medical supplies;
- various equipment;
- technical aids.

Technical support is an essential service element by Health Canada's FNIHCCP. Let it be noted that DINAC will cover the costs of technical aids when the person receives benefits from the income security program.

The comparison between the services delivered in First Nations communities and those ensured by the Government of Quebec allows us to draw a first conclusion: significant gaps exist in First Nations communities regarding the continuum of services delivered, particularly when it comes to the support provided to the family caregivers. One of the main heath issues for First Nations communities, more specifically with regards to continuing care, is the ambiguities when it comes to the responsibilities of Health Canada and DINAC in the organization and the delivery of services. Although Federal departments fund some continuing care services, currently they do not have the required authorizations and authorities to deliver the complete range of continuing care services in First Nations and Inuit communities.

1.2.2 Contextual Issues

A. Demographic context

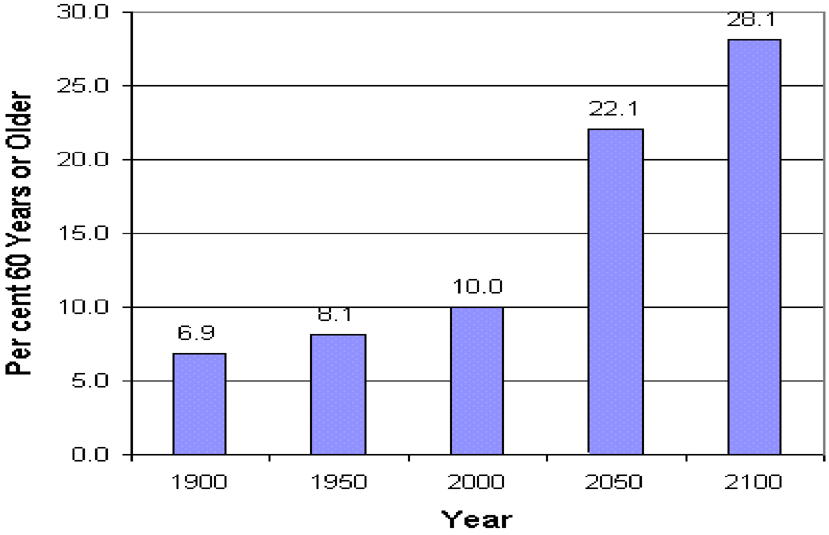
- **Demographic changes to come**

The current demand for continuing care for First Nations is growing and will grow rapidly over the next several decades due to increases in the number of First Nations members aged 55 and older in the next 25 years. The 55- 64 year age group will increase by 236% and the 65+ group by 229% in this period. Life expectancy of First Nations males will increase from 59.2 to about 72 years and from 65.9 to 79 years for First Nations females.[26] These increases follow demographic trends world-wide. In 2002, 1 person out of 10 was aged 60 and over; in 2050, it will be 1 person out of 5, while in 2150, 1 person out of 3 will be aged 60 and over.

---

[26] Assembly of First Nations, 2005, *First Nations Action Plan on Continuing Care*, p. 1.

The following chart illustrates this world-wide trend among people aged 60 and over[27]:



There are real needs in continuing care and the lack of resources to meet those needs put constant pressure on First Nations communities. In the next few decades, that pressure will increase significantly due, among other things, to the increasing prevalence of chronic health conditions that limit their autonomy level. Based on the current morbidity rate, it is expected that the demand for type 1 and 2 levels of care in First Nations communities will be between 2,000 and 2,500 beds by 2011, and between 3,000 and 4,000 beds by 2021. It is further expected that the demand for type 3, 4 and 5 levels of care will be 2,700 beds in 2011 and 4,500 beds in 2021[28]. Let it be noted that for all the First Nations communities in Canada, the total capacity for type 1 and 2 levels of care was 700 beds in 2003 and type 3, 4 and 5 are not funded by federal programs.

These projections are quite unsettling given the lack of resources of the continuing care program in First Nations communities. The current continuing care governmental programs do not have the long-term vision required for the planning of continuing care services. Other factors such as the changes in the context and composition of families must be taken into account in the equation.

- **Family context**

Traditionally, for First Nations, the family has always been much more than the biological unit comprised of the parents and their children. The family has a much broader meaning and is comprised of an extended network of grand-parents, aunts, uncles and cousins. In some First Nations communities, the family includes other clan members, even though kinships are sometimes hard to trace back. This complex structure of bonds and obligations creates a very dense network of relations in which the duty of sharing and helping constitutes an efficient

---

[27] United Nations. 2003. *The Ageing of the World's Populations: a demographic revolution*, available at www.un.org/esa/socdev/ageing/index.html

[28] Katenies Research and Management Services. 2002, p. 11.

security net.[29] As stated by the *Royal Commission Report on Aboriginal Peoples* (1996), still nowadays, families play an essential part in the individual and collective healing process in First Nations communities.[30]

However, in the last few decades, the traditional concept of family has undergone significant modifications. Several factors can influence the family harmony, and consequently impact the health and well-being of its members. Quite a few families are scarred by violence and disintegration. Overcrowded and inadequate housing, the high unemployment rate (20.2%), income below the poverty line (approximately 20.0%), the significant number of people living off social assistance (23.7%)[31], the various abuses and the reduction of traditional family mutual aid are factors that also have negative impacts on the health and well-being of community members. These disorders can also affect the family members' capacity to care for a close one requiring continuing care.

The decreasing size of families is another factor that can influence the members' capacity to care for a close one requiring continuing care. The family increasingly seems to be limited to the biological unit rather than an extended network. Moreover, the number of children per family tends to decrease, thus reducing the number of potential family caregivers in the future. In DINAC's report entitled *Registered Indian Population Projections for Canada and Regions 2000/2021*, indicates that in 2000, young people 19 years of age and under made up 42% of the registered Indian population. By 2021, the 19 and under group is expected to decline to approximately 32%. Finally, in the same report, the total fertility rates of registered Indians is projected to decline from 2.89 children per woman in 2000 to 2.35 children in 2021.[32]

Although First Nations members recognize the responsibility of families and close ones in the delivery of continuing care to people who need them, and appreciate the importance of maintaining family mutual help, too much pressure on family caregivers is to be avoided. The transformations within families clearly show that the number of family caregivers will not follow the increasing needs in the next few years. It is therefore necessary to adopt a short, mid, and long-term vision in the planning of continuing care services.

- **Role of women**

Most family caregivers and care providers are women. Several factors such as poverty, single-parent families, family violence, difficult living conditions and the lack of resources for women make it difficult for these women to assume the role of family caregiver. Moreover, they play a vital role within families and are most inclined to provide children care. Given the increasing pressure on family caregivers and the lack of resources to provide them with support, women have to bear a workload that is far too great. Their particular situation must be examined in order to provide women with the support and assistance they need.

---

[29] Government of Canada, 1996, *Royal Commission Report on Aboriginal Peoples,* vol.3, chap. 2.

[30] *Ibid*, p. 3.

[31] This data was extracted from the 2002 Quebec Region First Nations Regional Longitudinal Health Survey – Report on the health of individuals living on reserve (in press).

[32] DINAC, *Registered Indian Population Projections for Canada and Regions, 2000/2021,* Government of Canada, p. 5, available at www.ainc-inac.gc.ca/pr/sts/ipp_e.pdf.

B. Sociocultural context

➢ Notion of health: The Aboriginal perspective

The notion of health reveals a fundamental difference in the context of continuing care for First Nations. Health Canada and DINAC's governmental programs mostly offer health services that aim to improve the physical health. However, First Nations consider health to be as much a physical well-being, as a mental, emotional, spiritual and environmental well-being. The people in charge of continuing care in First Nations communities are concerned with the narrowness of the health perception in governmental programs. One of their concerns regards the mode of remuneration based on the number of care services provided instead of the period of time spent with the client. The time spent with the client has a significant impact on his general well-being, particularly in the case of clients with no family caregiver or with a poor social network.

According to the Aboriginal perspective, health is related to the natural and human environment, the family, the clan, the community, the nation and Earth. The following Circle of health illustrates the First Nations holistic vision of health[33]:

THE FIRST NATIONS HEALTH CIRCLE

Governmental programs do not sufficiently address the importance of the fundamental aspects of health for First Nations and minimize the negative impacts that having to leave the community to access higher levels of care (type 3 to 5 levels of care) has on the physical, mental, emotional and spiritual health of the clients. Moreover, when the client has to leave the community, he is confronted with other issues of the provincial health network such as long waiting lists and the increased need for places in long-term care. These issues add up to the pressure already present in the communities. Some clients, who do not find any place to receive care, sometimes have to access care in other provinces, which is not without challenges. Among them are the isolation from the community, care that is not culturally-adapted, linguistic difficulties, priority given to

---

[33] FNQLHSSC, 2006, website, available at www.cssspnql.com

the clientele from other provinces, etc. Respecting the First Nations approach to their health involves respecting the people's will to receive care in their community up until the end.

- **Role of Elders**

The *Royal Commission Report on Aboriginal Peoples* defines Elders as "individuals who have amassed a great deal of knowledge, wisdom and experience over the period of many, many years. They are individuals who have also set examples, and have contributed something to the good of others. In the process, they usually sacrifice something of themselves, be it time, money or effort »[34]. Elders play a vital role on the transmission of traditional knowledge to the younger generations and act as resource persons for many community members.

With this perspective, diseases can have significant social, family and personal repercussions for Elders who require continuing care. An Elder who has no other choice than to leave his community sees himself cut from his family's support and his social environment. At the social level, the community loses an important member and at the personal level, the Elder may experience a loss of self-esteem, a feeling of rejection or social isolation, and thus see his health condition further reduced.

It is therefore of paramount importance to implement measures to assist and support continuing care recipients and their families, by taking into consideration the vital role played by Elders and the values specific to the various Aboriginal peoples.

- **Context of social mobilization**

One element to consider to better understand the dynamics of continuing care in First Nations communities is the context of social mobilization among Elders. It consists of the gathering of community strengths in order to change things. Although this information has not been documented, most First Nations stakeholders agree to say that the context of social mobilization among Elders is distinctive. According to those stakeholders, the gratitude for all services received and any expression of mutual aid is omnipresent among First Nations Elders. The latter are not inclined to criticize or mobilize themselves to change situations that do not suit them. They tend to be satisfied with what they have instead of requesting additional services and care or questioning the services they have. Still according to the stakeholders, some Elders are concerned they will lose what they have if they question certain services.

In the research entitled *Assessing Continuing Care Requirements in First Nations and Inuit Communities* (2006), this tendency probably explains, first, the reason why such a high proportion of Elders indicate they are happy with the continuing care they receive at home, in the community and in a facility and, second, the discrepancies between the needs identified by the key stakeholders and those identified by the clients.

---

[34] Government of Canada, 1996, *Royal Commission Report on Aboriginal Peoples*, vol.4, chap. 3.

1.2.3 Organizational Issues

A. Duplication of authorizations by Health Canada and DINAC

The integration of care and services represents a major challenge for First Nations, particularly given the fact that two different federal organizations are responsible for the provision of continuing care. DINAC's report, entitled *Evaluation of Adult Care Services 01/25* (2003), states: "INAC, Health Canada, provincial governments and First Nations: there is no clear division of roles and responsibilities for providing adult care"[35]. The report also recognizes that the division between the services by DINAC and those by Health Canada may hinder the implementation of a comprehensive continuum of services in First Nations communities. The evaluation also indicates that the participation of First Nations members in the development of adult services was superficial, contrary to the objectives set out in the 1979 *Indian Health Policy*.

The findings of the *Evaluation of Adult Care Services 01/25* (2003) recommend some lines of action in order to solve the ambiguities that result from the entities' shared responsibilities. The following are the main points:

- DINAC must clearly define the roles and responsibilities of each entity in collaboration with First Nations, Health Canada and provincial and territorial governments;
- It is recognized that DINAC and Health Canada must consider integrating their respective programs (Adult Care Program and Home and Community Care Program). This would be in line with the informal integration already implemented in several First Nations communities;
- DINAC proposes developing a national policy for adult care services. This policy would set "the standards in terms of services delivery while recognizing the range of regional and community needs"[36];
- DINAC also proposes to further lead the continuing care file in order to ensure that special needs in terms of adult care are met in First Nations communities.[37]

It seems that the integration of Health Canada's and DINAC'S programs may be carried out in the near future. At a meeting of the Quebec Regional Table on Continuing Care in January 2006, DINAC'S representative indicated that negotiations concerning the integration were ongoing. The First Nations representatives who sit on the Table indicated they were open to such integration, although it does raise some concerns such as the quality of service and funding, which currently do not meet the immediate needs of First Nations members.

---

[35] Departmental Audit and Evaluation Branch, 2003, *Evaluation of Adult Care Services, Project 01/25*. Indian and Northern Affairs Canada – Corporate Services, p. iii.
[36] Departmental Audit and Evaluation Branch, 2003, p. iv.
[37] Ibid, 2003, p. iv.

B. Integration of continuing care services

Concerning the service integration, efforts must be made to establish a well-integrated continuing care program that incorporates a management framework and that supports adaptation to regional and local conditions.[38] The creation of a single-window service approach could foster access to services while reducing the structural constraints that result from having service delivery stem from several Ministries and programs. A first fundamental exercise could be to develop, in close collaboration with First Nations members, a common definition of continuing care and the list of all the services that should be available in communities.

The organization of services must also be based on a short, mid and long-term vision in order to ensure a continuum of care for people suffering from a decline of their functional capacity. In the province of Quebec, integrated continuing care networks are considered to be a promising approach to improve the service continuity and efficiency through the adoption of a long-term vision to anticipate the needs to come. With the fragmentation of services available, the lack of certain continuing care services in some communities and the lack of funding, work must be pursued in First Nations communities in order to ensure a continuum of care, i.e. that the care integration program ensures access to all services the client might need.[39]

The First Nations health professionals are in favour of improving continuing care services. In a national survey conducted in 1999, the professionals indicated they strongly supported a change in current policy that would enable the construction and operation of a First Nations Elders Lodge, extended care homes and facilities, as well as adult day cares and facilities for complex continuing care.[40]

C. Absence of systematic approach

Although the Federal Government has established guidelines for levels of care, there are no functional status assessment tools at the national level. In other words, there is no systematic approach to the assessment of clients' needs in terms of continuing care in First Nations communities. Moreover, there is no systematic assessment tool to determine the needs in terms of home care or institutional care. Although some First Nations health systems use provincial assessment tools, each province has its own classification code for levels of care, which usually does not correspond with the federal one. This is an obstacle to the comparison between various regions as well as to establishing a global portrait of the needs in all of the First Nations communities.

In order to standardize the needs assessment tools in the various communities, it would be preferable to develop tools that are culturally adapted, easy and fast to use by health professionals in First Nations communities. These tools should be developed in collaboration with the people responsible for continuing care and be flexible enough to be adapted to the various community contexts.

---

[38] AFN, 2005, *First Nations Action Plan on Continuing Care,* p. 8.

[39] Health Canada, 2004, *Frequently Asked Questions: Continuing Care*. Government of Canada, available at http://www.hc-sc.gc.ca/hcs-sss/home-domicile/index_e.html

[40] AFN, 2005, *First Nations Action Plan on Continuing Care*, p. 9.

The absence of a systematic approach is also noted in the organization of health services and care. The *First Nations Action Plan on Continuing Care* (2005) states that " many reports over the past few years have emphasized the need for flexibility in programs designed for First Nations to address the diverse needs of various communities which range from small and remote, to large and urban. The typical government planning concept of "one size fits all" does not work for First Nations communities. […] First Nations know what works best in their communities and they need to be an integral part of the program planning and implementation process. The need is even more critical for the small and remote First Nations communities which must deal with a variety of problems such as the lack of roads, poor housing, high cost of healthy food, high cost of transportation for medical supplies, difficulty in retaining trained professionals and inability to access rehabilitative services, adequate palliative or respite care."[41]

To summarize, First Nations communities are facing a shortfall in terms of needs assessment and the organization of health services and care. As cited previously, all of the health determinants must be taken into account when planning and implementing health programs. The successful outcome of these health programs also depends on the autonomy of First Nations communities in managing those health programs.

D. Work organization

➢ Human resources

In First Nations communities, several gaps persist in the development of human resources in the health and social services sector. The main gaps are training, competence development and the capacity to retain professionals in the communities. Here is an overview of the main issues concerning human resources in the health and social services sector, and more specifically in continuing care, in First Nations communities.

First, with regards to the training of home care staff, the evaluation report of the *First Nations and Inuit Home and Community Care Program* entitled *First Nations and Inuit Home Care* (2000) identifies certain difficulties concerning access to training for First Nations community members. The training of the people responsible for home care is essential to ensure the development of a comprehensive home and community care program and to ensure the improvement of the quality of services and care. A survey conducted by the Wendake *Centre de développement de la main d'oeuvre* in 2002 also revealed there was an urgent need to train Aboriginal home care workers to meet the increasing needs in the communities.

Adequate training offered in the community entails numerous advantages for the staff and for the whole community. First, the home care staff who has received adequate training has a better self-esteem, better performance and professionalism, and provides the client with better services.[42] It is important to note that offering training directly in the community enables the students to stay in their community, close to their family, while attending the training program.

---

[41] AFN, 2005, *First Nations Action Plan on Continuing Care*, p. 6
[42] *Ibid*, p. 43.

The new skills acquired will have a beneficial impact in the community and will enhance the capacity to provide personal care, palliative care, respite care and other home care services. Finally, the new skills will foster the transfer of new knowledge, thus ensuring continuing education and the update of the staff's skills. This will improve home care staff's capacity building.

The *First Nations and Inuit Home Care* (2000) evaluation report also identifies some difficulties concerning the training of home care staff in First Nations communities. It is often difficult to access affordable training in the community and/or training in one's mother tongue. Finally, there are some difficulties in offering training in such a way that trained staff is available at the time of implementing the home care program.[43]

Secondly, the access to health staff is also a challenge. The permanent staff shortage is omnipresent in First Nations communities. Vacancies, high staff turnover and lower requirements for positions are structural consequences to the lack of sufficiently qualified human resources in the communities. This also has repercussions on the quality of health services and care.

An important factor to consider is the requirements of the *Ministère de l'Éducation* in Quebec for the training and accreditation of the family and social assistance at home program (*Assistance familiale et sociale aux personnes à domicile*). With its 960 hours of teaching, the program leads to a professional studies diploma (DEP). Let it be noted that Quebec is the province with the highest number of hours for this training. In comparison, Ontario offers a 530-hour training and New Brunswick a 210-hour training. Moreover, admission criteria for the training may prove hard to meet for several people, particularly for those with a very low schooling degree.

In some communities, mostly those located close to the borders with Ontario and New Brunswick, some English-speaking students get their training outside of Quebec since it is available in English. Such training outside of Quebec results in additional costs for the student for, among other things, transportation, accommodation and schooling.

Since these training programs do not last as long as in Quebec (530 hours in Ontario and 210 in New Brunswick), these students must have their training evaluated in a professional studies centre upon their return in Quebec. The three evaluation criteria for a training followed outside of Quebec are: 1) training must have been followed in a recognized institution; 2) training must last at least one full-time year; 3) admission prerequisite must be clear.[44] The student may have to take up again part or all of the training to obtain the equivalency in Quebec. This is a major issue for communities at the border who have many members following training outside of Quebec. Since family and social home care workers do not have any national professional association, such as social workers, their skills are not recognized and they cannot serve their community without taking up again their training. In some cases, professional schools located near the communities offer training in French only, which is an additional challenge for these communities.

---

[43] Health Canada, 2004, *First Nations and Inuit Home Care – Final Report*, Public Works and government Services Canada, p. 44.

[44] Ministère de l'Éducation, des Loisirs et des Sports, 2006, Bureau des équivalences, personal communication.

In 2002, Health Canada funded a 3-year training. The theoretical component was offered at the *Centre de développement de la main d'œuvre de Wendake* (CDFM) and the practical component at the *Centre Professionnel Fierbourg* in Charlesbourg. At the end of the training, 21 students out of the 76 registered obtained a DEP in family and social assistance at home (*Assistance familiale et sociale aux personnes à domicile*). Among the reasons evoked by students for quitting the program, being far from their family and community and the linguistic barriers were mentioned the most. In order to continue developing these valuable resources for the communities and further adapting training, the FNQLHSSC, in collaboration with Health Canada, is planning on conducting a survey in communities to identify their needs and evaluate the possibilities in each of them.

In order to foster the success of the students, it would be appropriate to evaluate the participants' needs and to offer them financial support (paid practical training) and psychosocial support. This would help prevent school drop-out due to the loss of income that results from participating in academic training. Moreover, offering training in the communities would help avoid linguistic problems and difficulties due to being far from their family and close ones.

Access to training and sufficient financial contributions are needed now in order to train staff to address the increasing number of Elders in the next decades. In order to compensate for the shortage of nursing staff in First Nations communities, Health Canada's First Nations and Inuit Health Branch (FNIHB) has undertaken a national strategy for the recruitment and retention of nursing staff.

The main components of this strategy are:

- creating more favourable living and working environments in First Nations communities;
- improving the training for staff and supervisors in order to ensure better technical support to the staff;
- improving general living conditions in order to increase the capacity to retain health staff in First Nations communities;
- developing new funding mechanisms in order to compensate for the upcoming increasing expenses due to the recruitment of new health professionals.[45]

Finally, the health staff's acquisition of skills and knowledge is another important issue. It is essential for the enhancement of health promotion and disease prevention strategies in order to improve the population's health and well-being. Training that aims the development of skills and knowledge should cover the following characteristics:

- cultural knowledge of health and wellness;
- the strengths and currents challenges facing Aboriginal communities;
- key issues and the connections among them;
- population health, health promotion and disease prevention theory and practice;
- community development, client participation and empowerment practices; and,
- best practices in program planning, delivery and evaluation.[46]

---

[45] NAHO, 2002, *Improving Population Health, Health Promotion, Disease Prevention and Health Protection Services and Programs for Aboriginal People*, p. 33, available at www.naho.ca/english/pdf/research_pop_health.pdf.

There is a great need among managers and administrators for knowledge and skill development in order to better conceive and manage health programs. This would enhance the programs' performance and ensure a more efficient management of human resources.

To summarize, several human resources issues remain unsolved in First Nations communities. In order to achieve efficient continuing care delivery, measures must be implemented to train staff, ensure access to qualified workers in the communities and develop the skills and knowledge of the staff, managers and administrators.

➢ Accountability

Accountability is an integral part of the tasks of First Nations health and social services administrators. Since First Nations health and social services are funded by Health Canada and DINAC, administrators must produce monthly reports for each of these organizations. Several health and social services program managers have mentioned that reports are complex and time-consuming.

A report by the General Auditor published in december 2002 denounced the number of reports communities have to produce to justify their use of allocated funds. A survey of federal reporting requirements revealed that First Nations must submit a total of 168 reports annually to four main funding organizations and that most of the information is never used.[47] In communities where resources are already at their lowest, and given the 10% maximum set for administrative tasks expenses, these reporting requirements represent a great burden and true frustration for program administrators. It would be appropriate to reduce federal reporting requirements or to increase the funding allocated for administrative tasks.

Moreover, care and services are sometimes difficult to quantify, particularly when clients receive a range of services provided by several workers. Some services and care are probably not accounted for. It is also possible that workers address other needs of the clients with care and services that cannot necessarily be quantified. For example, a worker could take the time to chat with a client who feels depressed or is going through a personal difficulty related to his health condition. According to the bio-psychosocial approach to health, all components of the person must be taken into consideration when intervening with a client. One must also remember that for First Nations, health is more than physical wellness, it is also mental, emotional and spiritual well-being. The care and services provided under this approach must be considered in the accountability in order to give a true portrait of care and service delivery. Federal authorities should integrate these concepts in their administrative practices. This openness would then be reflected through more flexible funding and the adoption of accountability procedures that are less cumbersome and more respectful of the Aboriginal concept of health.

---

[46] NAHO, 2002, *Improving Population Health, Health Promotion, Disease Prevention and Health Protection Services and Programs for Aboriginal People*, p. 30, available at www.naho.ca/english/pdf/research_pop_health.pdf.

[47] Office of the Auditor General, 2002, *Streamlining First Nations Reporting to Federal Organizations,* Government of Canada, available at http://www.oag-bvg.gc.ca/domino/media.nsf/html/20021201pr_e.html.

E. Funding

> "As of September 2003, the vast majority of eligible communities [in Canada] (96%) were being funded by the [Home and Community Care] Program, while 78% of the eligible communities and 88% of the eligible population had access to full service delivery. In small and remote communities, however, even the essential services are minimal due to lack of funds. In addition, there is some indication that the essential service elements are not always those that respond to the identified needs of the communities. The main ongoing gaps are perceived to be palliative care, rehabilitative care, respite care and mental health services."[48]

This quote from the *First Nations Action Plan on Continuing Care* (2003) clearly demonstrates that some gaps concerning care funding remain unresolved, particularly in small and remote communities. Several communities face major challenges on a daily basis. One of these challenges concerns human resources, as discussed previously. Moreover, small and remote communities cannot rely as much on neighbouring communities in cases when the care is not available in their own community. Although the community's geographical remoteness and demographics are taken into consideration in Health Canada's *First Nations and Inuit Home and Community Care Program*' funding system, it does not solve all the problems specific to small and remote communities.

The funding of new facilities or the converting and restoration of existing facilities is also a major challenge in the communities. Out of the 29 First Nations communities in Quebec (with the exception of Cree communities), only 7 of them currently have a facility for Elders that provides type 1 and 2 levels of care. These communities are all medium or large communities and are located near an urban centre. One community also has a hospital on its territory. Let it be reminded that since 2000, DINAC authorizes the construction and expansion of new facilities under five conditions, including that the facility does not require any ministerial loan guarantees and that the funding required to operate the facility be taken within the regional envelope. Given the fact that essential service delivery is already at its minimal level in several communities due to a lack of resources, particularly in small and remote communities, mobilizing funds for the construction of a facility seems very difficult. In other words, DINAC's moratorium is lifted but the communities still do not have sufficient resources to cover their needs in terms of facilities.

Within this context of funding difficulties, the Assembly of First Nations points out that "Federal investments are required to provide higher levels of care in First Nations communities. Provincial health reforms which have, in some cases, resulted in hospital closures, introduction of early discharge programs and other changes, have placed serious pressures on First Nations communities. Population demographics and health status trends will also raise the critical need for continuing care services"[49]. It is therefore vital to increase the allocation of resources for continuing care in First Nations communities; otherwise they will not be able to address the demographic changes to come.

---

[48] AFN, 2005, *First Nations Action Plan on Continuing Care*, p. 3.
[49] *Ibid*, p.4.

To achieve the vision of a holistic continuum of continuing care services, the *First Nations Action Plan on Continuing Care* is premised on three key concepts: sustainable funding, flexibility in program design, and coordination towards a holistic approach. Sustainable funding requires funding to be matched to the population's growth, health needs and real cost drivers as well as effective measures to monitor and track spending.[50] Funding must also be recurrent, renewable and adjusted to the cost of living to ensure the care and service continuity and ensure employment security to workers and care providers in the communities.

Since continuing care services in First Nations communities are provided by two different programs, as mentioned previously, the funding of continuing care is more complex. Federal programs expect communities to provide care and services to all the people living on their territory. DINAC's program can fund home care for all the community residents, but the funding is allocated based on the number of Aboriginal adults and Elders registered as Band members. Health Canada's program funds care and services for all community residents (whether they are members or not). For several communities, it is therefore impossible to provide care and services to everybody when funding is not established to support this. The delivery of care and services remains to each community's discretion. This means that in some communities, non-member residents may be refused care and services due to a lack of funding. It is a major equity issue that faces First Nations communities.

Finally, on another issue, let it be noted that the situation of the Quebec Region entails a distinctive linguistic issue since both French and English are the official languages. All the documents as well as meetings and conferences must be translated, which results in significant costs for Aboriginal organizations such as the FNQLHSSC. Funding must take these expenses into account for research and the management of regional programs.

F. Missing or incomplete services

➢ Long-term care

Long-term care is usually required when a client can no longer live at home because of increasing medical needs and for safety reasons. In other cases, clients who are more independent can receive long-term personal care and services at home. Type 3, 4 and 5 levels of care are not funded by the federal programs in First Nations communities but are provided by the provincial health network. As mentioned previously, staying in a facility located outside the community can be a major challenge for people, mainly Elders, who must deal with an environment that is unknown, far from their close ones.

Considering the demographic changes to come and the increase in the prevalence of disabling diseases, governmental programs must cover long-term care in First Nations communities.

➢ Mental health services

> "In situations involving clients with mental health challenges, there is a recognized need, at the community level, for general care of clients that fit within

---

[50] AFN, 2005, *First Nations Action Plan on Continuing Care*, p. 5.

> these parameters. Unfortunately, many First Nations members suffering from the effects of foetal alcohol spectrum disorders or other mental health conditions are housed in the corrections facilities. Provincial health care reform changes with the delivery of mental health services has placed the clients' health at risk and restricted them to access necessary services to stabilize their health. There is a desperate need to address this situation and seek alternate solutions for these clients."[51]

The despair undermining several First Nations members is an unfortunate consequence of the rapid cultural change, Aboriginal residential schools and the loss of their language, religion, values, practices and traditional roles. This feeling translates into an overwhelming number of mental health problems and personal losses.

The First Nations population shows an alarming rate of self-destructive behaviours. According to the *Royal Commission Report on Aboriginal Peoples* (1996), the suicide rate among Aboriginal women, for example, is eight times higher than that of other women in Canada.[52] Family violence in some communities also puts enormous pressure on First Nations members. Finally, the prevalence of alcohol and drug abuse is also high in several communities.

There is a significant shortfall in mental health promotion services. Services that are culturally adapted, available directly in communities and provided by qualified staff still need to be developed. Moreover, the needs being so great, it is urgent to evaluate the mental health care system in order to identify the obstacles that First Nations members must overcome in order to access mental health treatment outside their community. These obstacles may include the fear of being stigmatized, systemic racism, being isolated from the family and friends and the lack of consideration for traditional healing practices. It therefore appears necessary to develop service corridors and liaison mechanisms that are well defined with the facilities in the provincial network to ensure that care and services are adapted to the needs and culture of First Nations.

Other shortfalls concern for pathological gambling, long-term alcohol and drug rehabilitation centres, intervention teams that come into communities to support local workers, services for adults and Elders who experienced residential schools, treatment of post-traumatic stress, etc.

People suffering from mental health problems represent an important proportion of the continuing care clientele. Since services are often non existent in communities, people access care and services in the provincial network where they face several challenges. One example of this is the deinstitutionalization in the provincial network at the end of '90s when several recipients in psychiatric care were taken out of the institutions. These persons were left alone and were not able to integrate society.

The duplication of authorizations, as mentioned previously, is also problematic in the organization of mental health services since there is a fine line between mental health services funded by Health Canada and social services funded by DINAC.

---

[51] AFN, 2005, *First Nations Action Plan on Continuing Care*, p. 2.

[52] Government of Canada, 1996, *Royal Commission Report on Aboriginal Peoples*, vol 3.

Finally, it is appropriate to decompartmentalize the various mental health prevention and promotion programs in order to allow communities to better define their priorities based on their reality rather than based on objectives set out by the Ministries concerned.

➢ Palliative care

The Canadian Hospice Palliative Care Association defines palliative care as "care that aims to relieve suffering and improve the quality of living and dying"[53]. In 1990, the World Health Organization (WHO) put forth a definition of palliative care, which states they are "active and complete care provided to patients whose affection does not react to curative treatment anymore. The control of pain and other symptoms, as well as the consideration of psychological, social and spiritual problems are fundamental. They do not accelerate nor delay death. Their goal is to preserve the best possible quality of life up until the end".[54]

The WHO's definition is more compatible with the traditional and holistic vision of health of First Nations, which includes the physical, mental, spiritual, emotional and social components. This approach takes into consideration the balance between the individual, his family, his community and his environment. As such, if death occurs when the person feels in balance and the suffering is reduced until the moment of death, the family, the close ones and the community can recover a state of balance since the person died with dignity.

To this date, palliative care is not covered financially by any of the continuing care programs in First Nations communities. Palliative care represents an essential component of the continuum of continuing care aimed by federal programs. Few communities have the financial, human and material resources required to provide their members with palliative care. The members therefore end up in a hospital located outside their community to receive end of life care due to the lack of resources to provide such care in the community. That is a major shortfall for First Nations.

➢ Resources for family caregivers

As mentioned previously, a family caregiver is a person who provides a member of his close or extended family, a friend, a neighbour or any person requiring assistance with care, support and assistance, without being paid. A family caregiver provides individual assistance to carry out various tasks and activities on a daily, weekly, monthly or seasonal basis.

Family caregivers can quit providing their client with assistance due to a lack of support, because they feel overwhelmed with feelings of distress, anger or depression. "The burden of family caregivers is often associated to the presence of emotional tension caused by the activities of care, problems with the family caregiver's health and difficulties in carrying out the necessary tasks. […] The exhaustion of family caregivers can impact the client's capacity to achieve the service objectives or to remain at home"[55].

---

[53] Canadian Hospice Palliative Care Association, 2006, website, available at http://www.chpca.net/home.htm

[54] Groupe coopérateur multidisciplinaire en oncologie, 2006, website, available at http://www.canceronet.com/public/conseils/conseils09.asp

[55] CIHI, 2002, *Development of National Indicators and Reports for Home Care. Phase II: Description of indicators – National pilot test,* p. 11.

As described previously, the Quebec Ministry of Health and Social Services ensures the provision of certain services to assist family caregivers in Quebec:

- babysitting or « presence-monitoring »: the normal babysitting activities when a family caregiver living with a disabled person must leave home occasionally for various daily living activities;
- respite: allows for rest to compensate for the additional stress and fatigue that result from the special needs of a child or an adult with a disability;
- ad hoc help: allows the family caregivers to deal with unpredictable situations;
- daily living activity support: various measures enabling the family caregivers to relieve each other in their daily living activities;
- psychosocial services: allows the family caregivers to deal with the adaptation required when accompanying a person with a disability, frail or going through an episode of acute care;
- community organization services: provided by the local entity, they support the development of personal assistance services to the person and services to family caregivers.

In First Nations communities, respite care, babysitting and assistance with activities of daily living are funded by DINAC's *Assisted Living Program*. In the case where the other services are available in the community, they are funded through the allocations for health services. But, as mentioned previously, the resources are often minimal in several communities, which reduces the possibilities of providing family caregivers with support.

Although Health Canada does not fund services for First Nations family caregivers, it proposes elements to take into consideration in order to foster care efficiency and to reduce family caregivers' stress. Although these means are far from the needs of family caregivers, nursing staff should take them into consideration:

- involve the family caregiver when assessing the client. This step lays the foundation of a positive and efficient relation between the client and the family caregiver;

- ensure the client and the family caregiver know how to contact the nursing care coordinator if needs change;

- develop the client's care plan in collaboration with the nursing care coordinator, the client and the family caregiver based on the needs identified during the assessment;

- review the responsibilities of the family caregiver to make sure he understands them well. If the family caregiver is not able to carry them out, he will need to find someone else to provide the care or contact the nursing care coordinator to find solutions and continue to meet the client's needs.[56]

---

[56] Health Canada, 2000, *Service Delivery,* Government of Canada, available at http://www.hc-sc.gc.ca/fnih-spni/alt_formats/fnihb-dgspni/pdf/pubs/home-domicile/handbook-guide_5_e.pdf

A lot of work still needs to be done to provide First Nations family caregivers with support services. The stated services offered to Quebec family caregivers demonstrate the gap to bridge for First Nations family caregivers. The current state of situation is not encouraging, knowing that services for family caregivers are often missing and that the pressure on family caregivers will increase significantly in the years to come, notably because of demographic changes.

- **Program for persons with disabilities**

Service delivery in First Nations communities also lack programs for persons with disabilities. The condition of persons with disabilities is crucial to First Nations members and is often influenced by distinct social, economical, cultural, political and environmental contexts in which they live. These contexts also vary among the various First Nations cultural groups.

Aboriginal persons with disabilities need the same forms of support for their disabilities as other Canadians. They need adequate income; social, community and family support; learning opportunities; access to health and social services; a physical environment that can accommodate their needs; and a system that is barrier free and culturally appropriate.[57] They also need aids, devices and adaptation accessories within the context of their daily living, accessible buildings, transportation, medical and community support, support from family or family caregivers, and housing that meets the specific needs of persons with disabilities.

Although Health Canada's *First Nations and Inuit Home and Community Care Program* and DINAC's *Assisted Living Program* both apply to persons with disabilities, they only cover a small portion of this population's specific needs.

G. Impacts of the reduction of the Non Insured Health Benefits (NIHB) reimbursement

An independent study on NIHB demonstrated that the increase of current funding levels is limited to an annual population growth rate and does not take into consideration the needs in terms of health and the cost factors.[58]

Unless new investments are announced, the Assembly of First Nations anticipates cuts equivalent to approximately $2.85 billions over the next five years in Health Canada's First Nations and Inuit health sector.

The reduction of the NIHB reimbursement is a direct result of these budget cuts. Consequently, cost reduction measures will be imposed upon First Nations communities by the Federal Government. This will seriously jeopardize the patients' safety, including the health and safety of persons requiring continuing care. The budget cuts will also affect the budget allocated for supplies and equipment, thus putting more pressure on the communities' home care budget.

---

[57] Government of Canada, 2005, *Advancing the Inclusion of Persons with Disabilities*, Social Development Canada, Chapter 7, available at http://www.sdc.gc.ca/en/hip/odi/documents/advancingInclusion05/chap7.shtml.

[58] AFN, 2005, *First Nations Action Plan on Non Insured Health Benefits*, p. 22, available at http://www.afn.ca/cmslib/general/NIHB%20Action%20Plan_Ff.pdf.

1.2.4 Recipient-related Issues

A. Accessibility

In a study conducted in 1999[59] on the persons close to persons receiving continuing care in First Nations of Canada, 85% of respondents indicated that some of their community members lived in extended care facilities located outside their community and this situation entails major inconveniences. These inconveniences include being far from the family and friends, the loss of opportunities to participate and contribute to the cultural life of their community, and the loss of their role as Elders. The fact that many Elders and other members have to leave the community to receive care means that the community loses the Elders' contribution to the preservation and vitality of their culture[60].

In the report entitled *Evaluation of Adult Care, Project 01/25* (2003), DINAC recognizes the negative social effects of transferring First Nations people in facilities located outside the community[61]. Among the negative social effects are the cut from family support, the loss of identity, social isolation and the cultural clash. These negative effects are particularly strong for people from remote communities. Because of these negative social effects, some clients decide to remain in the community as long as possible, even if it means reducing their access to care and jeopardizing their health and safety. Obviously, the desire to remain in the community increases the service needs.

Moreover, for Elders who speak their traditional language, who do not speak French or English, who have a low degree of schooling and/or who are illiterate, access to care is a major challenge. It increases when the person has to leave the community, which adds to the stress caused by the health condition or disease.

Finally, clients who return home after a stay in a hospital located outside their community may experience other difficulties once they're back. In some communities, available resources and services are limited; consequently, it is not always possible to ensure the follow-up of clients and to provide the appropriate care upon their return in the community. This situation seems particularly problematic in remote communities where resources are even more limited.

B. Characteristics of First Nations Elders

First Nations Elders are a particular group within the population for several reasons. Health Canada considers that "Aboriginal Seniors are among the most difficult seniors to reach with information related to federal programs and services"[62]. Still according to Health Canada, Elders and members of their family indicate they are not informed adequately on the options they have. This situation is problematic, especially since it makes it more difficult to assess the needs of Elders in terms of continuing care.

---

[59] Gibbons, A., 1999, *First Nations Institutional Care: A review of critical issues and trends.*

[60] AFN, 2005, *First Nations Action Plan on Continuing Care*, p. 8.

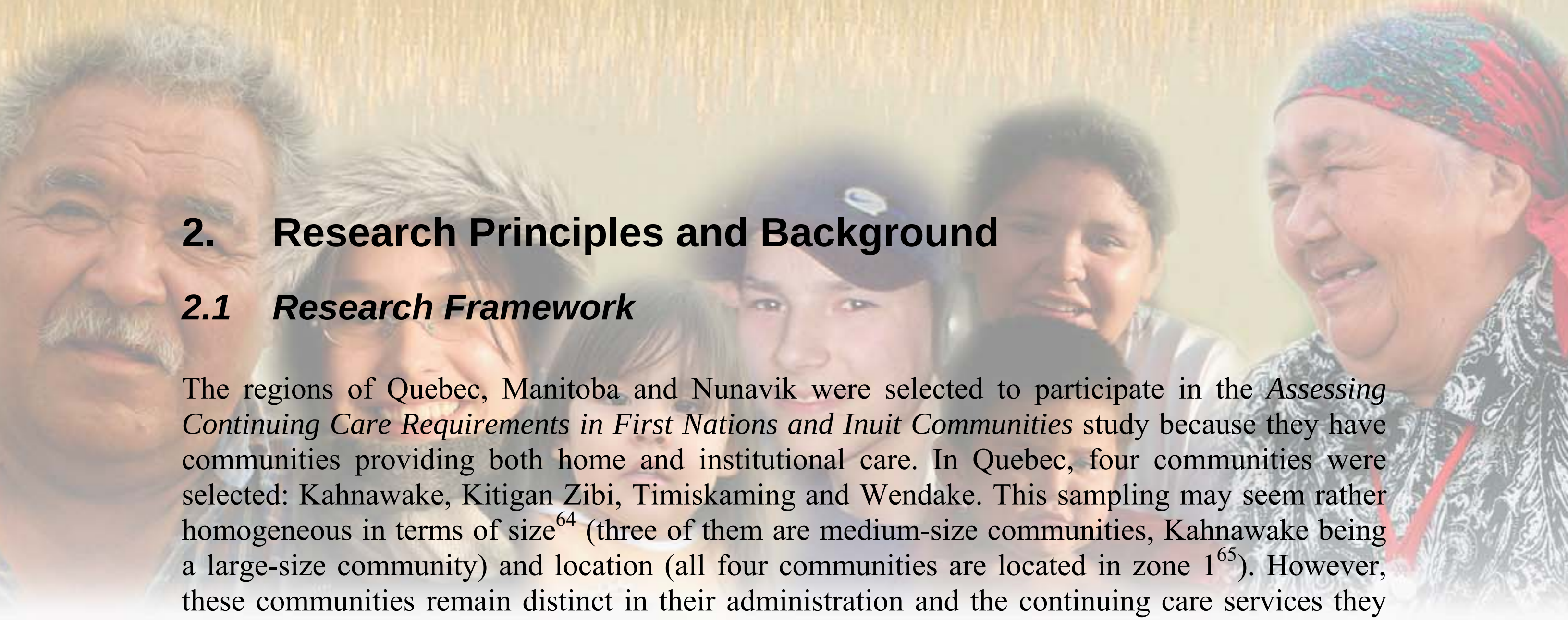
[61] Departmental Audit and Evaluation Branch, 2003, p. 18.

[62] Health Canada, 1998, *Reaching Out: A Guide to Communicating with Aboriginal Seniors,* Public works and Government Services, p. 1-2.

Another disturbing data is that almost half of First Nations Elders who live in their community rarely leave their home for more than half an hour per day.[63] This limited mobility is certainly an obstacle to access information on the care and services offered. Therefore Elders do not know all the options they have. Based on this, it is reasonable to think that if the information on care and services that are available does not reach them at home, they might not receive the range of care and services they need. It is therefore appropriate to develop communication strategies to ensure that people who are most isolated socially will not be excluded by lack of access to information on care and services offered.

---

[63] Frideres, J.S., 1994, *The Future of our Past: Native Elderly in Canadian Society*, Writings in Gerontology, vol. 15, Ottawa, National Advisory Council on Aging, p. 34.



2. Research Principles and Background

2.1 Research Framework

The regions of Quebec, Manitoba and Nunavik were selected to participate in the *Assessing Continuing Care Requirements in First Nations and Inuit Communities* study because they have communities providing both home and institutional care. In Quebec, four communities were selected: Kahnawake, Kitigan Zibi, Timiskaming and Wendake. This sampling may seem rather homogeneous in terms of size[64] (three of them are medium-size communities, Kahnawake being a large-size community) and location (all four communities are located in zone 1[65]). However, these communities remain distinct in their administration and the continuing care services they provide their respective populations. It should be remembered that these are 4 out of the 6 communities with a facility for elders in the Quebec Region.

---

[64] In this document, a small-size community means up to 500 people, medium-size means between 501 and 1,000, and a large-size community means 1,001 people and over.

[65] Zoning system developed by DINAC in order to classify the communities' level of remoteness:

Zone 1: Located within 50 km of the nearest service centre* with year-rund road access;
Zone 2: Located between 50 and 350 km from the nearest service centre with year-rund road access;
Zone 3: Located over 350 km from the nearest service centre with year-rund road access;
Zone 4: No year-round road access to a service centre.

* The nearest community to which a First Nations can refer to gain access to government services, banks and suppliers.

Source: Corporate Information Management Directorate, Information Management Branch, March 2004, *Band Classification Manual,* Indian and Northern Affairs Canada, p. 2.

The following map shows the location of the 4 communities participating in this research project:

Map 2.1: Location of participating communities

This research project is divided into five phases:

- Phase 1: Analysis of existing documentation (by Hollander Analytical Ldt.);
- Phase 2: Interviews with key informants from both Health Canada's and DINAC's head offices, representatives of those two departments' regional services as well as from First Nations and Inuit communities. More in-depth interviews with the First Nations and Inuit representatives in the participating communities allowed for a comprehensive listing of continuing care services currently delivered, an evaluation of the needs in terms of continuing care, and an estimation of the number of clients (age, gender, etc.) (by Hollander Analytical Ldt. And the FNQLHSSC in the Quebec Region);
- Phase 3: Analysis of national surveys and databases (by Hollander Analytical Ldt.);
- Phase 4: Evaluate the cost-effectiveness of continuing care in Inuit communities through individual interviews in order to evaluate the services provided, the clients' satisfaction, the tasks carried out by both family and formal caregivers, as well as to estimate the associated costs (by Hollander Analytical Ldt.);

- Phase 5: Evaluate the cost-effectiveness of continuing care in First Nations communities in the regions of Manitoba and Quebec through individual interviews in order to evaluate the services provided, the clients' satisfaction, the tasks carried out by both family and formal caregivers, as well as to estimate the associated costs (by the FNQLHSSC in the Quebec Region).

The FNQLHSSC is responsible for the planning, implementation, deployment and conduct of the collection, the integration and analysis of the data for phases 2 and 5 in the Quebec Region.

At the preliminary meetings held with the Quebec Regional Table on Continuing Care, two main concerns were raised. The first pertained to the care provided to the people requiring higher levels of care in First Nations communities. The communities see themselves having to deliver these care services despite the fact they are not funded by DINAC. The clientele gets heavier without having the funding adjusted. The second concern pertained to the ownership, control, access and possession of the data collected in the communities (i.e. OCAP principles). The First Nations representatives wish to keep the information collected in the respective communities and intervene at all steps of the research, from the participation to the dissemination of results. They also questioned themselves on the type of data collected, the mean in which this data would be used, who would be using the data and the way in which the research results would be interpreted and used. For the Quebec Regional Table on Continuing Care, respecting the OCAP principles was non-negotiable otherwise the research could not be conducted.

2.1.1 Overview of the research project's development

Background

A Joint Working Group was established in 1998 in order to develop a national framework on continuing care and eventually, develop a national policy on continuing care. The Group is comprised of representatives from Health Canada, DINAC and First Nations and Inuit. The national framework, based on the adult care services in the communities, includes two phases. The first phase was the development of Health Canada's *First Nations and Inuit Home and Community Care Program* such as previously documented. The second phase, which is currently ongoing, addresses the issues related to institutional care and other community services.

Despite DINAC's *Assisted Living Program* and Health Canada's *First Nations and Inuit Home and Community Care Program*, significant gaps remain in the service continuum, particularly with regards to higher levels of care provided in the facilities located in the communities and the under-funding of the cares now delivered. Currently neither DINAC nor Health Canada has the required authorizations to ensure the delivery of services beyond levels 1 and 2. The Assistant Deputy Ministers from both Ministries have agreed on correcting gaps in long-term care provided in the communities by conducting research, establishing costs and developing strategic options. That is when a joint working group on continuing care was created to review the issues related to the delivery of higher levels of care as well as the gaps in the institutional care provided in First Nations and Inuit communities.

In April 2006, this joint working group will be tabling a business case for the development of a national policy on long-term care in First Nations and Inuit communities. The objective of the business case is to convince the Treasury Board to invest in continuing care in First Nations and Inuit communities.

2.1.2 Mandate

Duration: April 1st, 2004, to June 30, 2006

Supervise the activities and provide recommendations with regards to the three components of continuing care for the Quebec First Nations and Inuit. These three components include:

a) This research project entitled *Assessing Continuing Care Requirements in First Nations and Inuit Communities*;
b) Policy development;
c) Integration of quality care.

a) Assessing Continuing Care Requirements in First Nations and Inuit Communities Project

A resolution was adopted in December 2003 by the Assembly of First Nations (AFN), which supported the research project as well as the cost evaluation for continuing care. Following this resolution a national committee, the Joint Working Group, was created to oversee the research at the national level. The three selected regions are Quebec, Manitoba and Nunavik. As previously mentioned, this group is comprised of representatives from the AFN, First Nations organizations working in continuing care, Health Canada and DINAC.

b) Policy development

The Joint Working Group was also mandated to develop a business case, which includes possible options regarding continuing care and long-term care. These options will take into account urgent needs for culturally-adapted and integrated continuing care that will be appropriate, accessible, efficient and comparable to those delivered to other Canadian citizens, while being governed by First Nations and Inuit. In the context of this initiative, long-term care do not include home care and institutional care in a hospital. The deadline to complete the business case is October 2006.

c) Integration of quality care

In order to improve and promote the integration of health and social services programs in First Nations communities, Health Canada, DINAC, the AFN and ITK are working on a conceptual model for the integration of continuing care services.

2.1.3 Quebec Regional Table on Continuing Care

The Indian Affairs' Social Policy and Programs Branch has provided funds for the creation of the Quebec Regional Table on Continuing Care in 2004/2005. The members of the First Nations Child and Family Services Regional Table (FNCFS) were the ones who recommended that a regional table on continuing care be created. The FNQLHSSC approached all the First Nations communities in Quebec to sit on this regional table. In addition to the three (3) communities involved at the beginning of the research project, two communities providing institutional care expressed their interest: Mashteuiatsh and Wendake, the latter also joined the group of participating communities later on.

The Quebec Regional Table on Continuing Care acts as a regional advisory group taking an active part in the planning and implementation of the research project, with the FNQLHSSC's research team.

<u>Roles of the Quebec Regional Table on Continuing Care:</u>

- identify the issues specific to the region or the communities that may have impacts on the development or the implementation of the project;
- provide advice and support on the development and dissemination of the information pertaining to the study;
- provide advice in order to guide the development of the data collection tools (review of the various tools proposed for the data collection and suggestions and comments on their format and content);
- provide advice to the FNQLHSSC research team with regards to issues that could be raised during the study;
- support the research team and the participating communities in the continuing care needs assessment;
- provide information to the First Nations and Inuit communities on the progress of the work related to all three components of continuing care: the research project and the cost establishment, the development of policies and the integration of quality care.

<u>Guidelines:</u>

- all the documents and correspondence must be in both official languages;
- during the process the best interest of the First Nations members will be the main concern of the Regional Table;
- the main task of the Regional Table will be to identify the issues specific to the First Nations communities;
- the national and interdepartmental issues will be redirected to the appropriate Ministry or organization;
- the creation and operation of the Regional Table must in no manner reduce the current funding formulas nor the provincial service funding;
- the parties commit to exchanging best practices and information in order to ensure adequate communication;

- the Regional Table will serve as a forum where all new developments regarding the three components of continuing care will be presented;
- there will have to be consensus for all recommendations of the Regional Table.

Accountability:

The Regional Table representatives shall be accountable of all activities, issues and recommendations before their respective authorities.

Composition:

- one representative from each of the 4 First Nations communities of Quebec participating in the research project (Kahnawake, Kitigan Zibi, Timiskaming and Wendake);
- one representative from FNIHB – Quebec Region;
- one representative from DINAC – Quebec Region;
- two representatives from the FNQLHSSC;
- one representative from Mashteuiatsh.

The members of the Table have the right to invite any other person.

Co-chair:

The representative from DINAC – Quebec Region – and the representative from Mashteuiatsh both co-chair the Table.

First Nations representatives:

Keith Leclaire, Kahnawake Shakotiia' takehnhas (KSCS) Community Services;
Michael Horn, Kahnawake Shakotiia' takehnhas (KSCS) Community Services;
Denise Paul, Mashteuiatsh Band Council;
Arden McBride, Timiskaming First Nations ;
Lionel J. Whiteduck, Kitigan Zibi Band Council;
Lison Picard, Huron-Wendat Nation Council;
Jules Picard, FNQLHSSC;
Sophie Picard, FNQLHSSC (Home Care Coordinator).

Government representatives

Francine Charade, Health Canada (FNIHB);
Alain Léveillée, Indian and Northern Affairs Canada (INAC).

2.1.4 Meetings

The FNQLHSSC has the mandate to:

- draft the meeting agendas in collaboration with both co-chairs;
- distribute the minutes in both official languages;
- coordinate the logistics for the meetings or the conference calls of the Regional Table.

Meeting schedule:

In-person meetings and conference calls will be held when required.

Planned meetings for the Regional Table:

May 26, 2004, Ottawa
September 3, 2004, Montreal
November 11, 2004, Quebec City
March 30, 2005, Quebec City
June 8-9, 2005, Quebec City
November 8, 2005, Montreal
January 31, 2006, Montreal
March 1, 2006, Quebec City

Ad hoc meetings may be convened by the Table when required, within the budget allotted.

Quorum:

One Co-chair and the representatives from all 4 communities participating in the research project must be present for any meeting or conference call to be held.

2.2 Research Objectives

The goals of this research project are to:

- determine the needs in terms of continuing care (such as established by the evaluation of levels of care) of the people living in First Nations and Inuit communities;
- identify which continuing care services are currently provided in First Nations and Inuit communities;
- develop the options and costs of delivering continuing care services in First Nations and Inuit communities.

Achieving these goals will allow for the implementation of the Assembly of First Nations' *First Nations Action Plan on Continuing Care*, a plan premised on the three following key concepts:

- sustainable funding: "Sustainability requires funding matched to the population growth, health needs and real cost drivers as well as effective measures to monitor and track spending";
- flexibility in program design: "Flexibility in designing the continuing care program is necessary to meet the diverse needs of First Nations communities";
- coordination towards a holistic approach: "Coordination of program/service delivery is essential to ensure an effective and efficient program. Existing continuing care services to First Nations are provided by multiple jurisdictions, which negatively impacts on cost effectiveness and quality of care. If achieved under First Nations control, coordination could empower First Nations to create a continuum of continuing care services that is more efficient and effective in addressing their needs"[66].

The main research questions are:

- based on the evaluation, how many people need continuing care (per type of care) in First Nations communities;
- which services do people need at each level of care in facilities and at home, and what is the demand for each of these services;
- what is the contribution of family caregivers (either family members or friends);
- Are there differences in the types of services provided depending on the remoteness of the communities;
- what are the clients' preferences regarding the place where the care is provided;
- what is the clients' satisfaction level regarding the continuing care services received;
- what is their quality of life;
- are the home and institutional care appropriate for the clients who receive them;
- what is the cost of service delivery?

The results of this research project will be the laying foundation for the development of policy options with regards to continuing care in First Nations and Inuit communities.

2.3 Ownership, Control, Access and Possession (OCAP) Principles and Self-Determination Objectives

The Royal Commission Report on Aboriginal Peoples (1996) gives evidence of some frustrations experienced in Aboriginal communities when it comes to research:

> "The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information

---

[66] Assembly of First Nations, 2005, *First Nations Action Plan on Continuing Care,* p. 4.

> should be collected, who should gather that information, who should maintain it, and who should have access to it.
>
> The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters."[67]

Requested for a long time by First Nations in Canada, the principles of Ownership, Control and Access (OCA) were first developed by the *First Nations Regional Longitudinal Health Survey*'s steering committee in 1998. The "Possession" principle was added afterwards, thus forming a set of rules of ethics that are an expression of self-determination in the fields of research, management and creation of information. The OCAP principles underlie the current research project. The following definitions describe these concepts:

"Ownership:

> The notion of ownership refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information. It is distinct from stewardship. Stewardship or management of data or information by an institution which is accountable to the group is a means through which it is possible to achieve ownership.

Control:

> The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research, information and data. The principle of "control" asserts that First Nations members, their communities and representative bodies are within their rights in seeking to control research and information management processes which impact them. This includes all stages of research projects, and more broadly, research policy, resources, review processes, formulation of conceptual frameworks, data management, and so on.

Access:

> First Nations people must have access to information and data about themselves and their communities, regardless of where these are currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. On a practical basis this is possible through standardized and formal protocols.

---

[67] Royal Commission on Aboriginal Peoples, Report of the Royal Commission on Aboriginal Peoples, vol 3 : Gathering Strength (online), Chapter 5, p.4 (1997) http://www.indigenous.c.ca/v3/vol3Ch5s8.2tos9.3asp. Quoted in: Espey, Jennifer, stewardship and OCAP: A Discussion Paper for the First Nations Statistical Institute, May, 2002, First Nations Statistics.

Possession:

> While “ownership” identifies the relationship between people and their data in principle, the idea of “possession” or “stewardship” is more literal. Although not a condition of ownership, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party are in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.”[68]

The OCAP principles are a visionary and proactive concept. They open new paths to self-determination and the exercise of power in the fields of research and information and announce positive changes for the First Nations communities.

In this research project, the OCAP principles were respected and put forward all along the process. Specific criteria for the viability of this project were taken into account:

- the community authorities give their consent to participate in this project;
- the community authorities authorize the collection of information;
- the communities invited to participate are considered as partners;
- the results are published in a regional report presented to Health Canada and DINAC;
- the three regional reports (Manitoba, Quebec and Nunavik) are consolidated into a national report;
- the regional report and the national report are transmitted to the Quebec Regional Table on Continuing Care and the communities involved in the project;
- the results are published and used;
- community reports are produced and transmitted to the communities involved in the project;
- the data collected belongs to the participating communities;
- upon request from the local authorities, the participating communities may obtain a copy of the raw data;
- the community reports are sent to the community authorities before any other organization;
- the raw data is kept at the FNQLHSSC on behalf of the communities;
- the community cultural calendars and events are respected;
- the Quebec Regional Table on Continuing Care is consulted at each step of the research;
- the Quebec Regional Table on Continuing Care must validate all the regional reports;
- the First Nations of Quebec Regional Research Committee is consulted on and informed of this project;
- all the documents coming from this research are available in French and English.

Research Protocol

The elements developed in the previous section find their expression in the *First Nations of Quebec and Labrador Research Protocol*, a reference document for the Assembly of First

---

[68] Schnarch, B., 2004, *Ownership, Control, Access and Possession (PCAP) or Self-Determination applied to Research* , Journal de la santé autochtone, National Aboriginal Health Organization, vo l.1(1), p. 81.

Nations of Quebec and Labrador's various commissions and organizations. This protocol was adopted by the AFN's Assembly of Chiefs in May 2005 and developed in collaboration with the FNQLHSSC, the First Nations of Quebec and Labrador Sustainable Development Institute (FNQLSDI) and the First Nations of Quebec Human Resources Development Commission (FNQHRDC). The protocol aims to promote precise and informed ethical research whose deployment respects the will of the First Nations involved.

The participatory approach, consultation, informed consent, right to information and access to research results are key elements of the protocol. They have been put forward and applied all along the process of this assessment of continuing care needs among First Nations.

Kahnawake Protocol

All research work conducted on the Mohawk territory of Kahnawake must be authorized and approved by the Research Council on Health and Social Services Onkwatakaritahtshera. The research projects that are approved are then subject to a contract. The Kahnawake Shakotiia' takehnhas Community Services (KSCS) was also a partner on this research project.

2.4 Cultural Context of the Research Environment

> « For Aboriginal Peoples, culture is critically important for feelings of self-worth and identity. […] The emotional and mental health problems among Aboriginal Peoples are typical of Indigenous populations worldwide who have been repressed in the expression of their culture or the governance of their institutions »[69].

The National Aboriginal Health Organization (NAHO) defines itself as "an Aboriginal designed and controlled body, [which] will influence and advance the health and well-being of Aboriginal Peoples through carrying out knowledge-based strategies"[70]. In order to give concrete expression to and clarify this statement, NAHO has developed a work frame intended for Aboriginal communities, researchers and research centres in order to foster research work that is culturally appropriate for Aboriginal peoples. Reminders that research is one of many ways to create knowledge, the following principles identified in the work frame are in line with the Research Protocol previously presented:

- the research will target communities' priorities and needs;
- the methods will be culturally appropriate and respectful of diversity;
- the research process will be transparent and inclusive;
- the research design will be credible and of high quality;
- the research will respect the OCAP principles.

---

[69] NAHO, 2003, *Ways of Knowing: A Framework for Health Research,* p. 13. Available at http://www.naho.ca/english/about_naho.php.

[70] NAHO, website, consulted February 13, 2006, http://www.naho.ca/english/about_naho.php.

This document specifies that not only does the First Nations' concept of health differ from the Western and biomedical vision, but that there also exist some differences among the various Aboriginal cultures. However two main basic principles are common to all these peoples: balance and respect.

Health: the Aboriginal perspective

As mentioned earlier, traditionally health is part of a person as a whole and is not limited to his body. The physical, mental, emotional, spiritual, cultural and social aspects interact and influence the health and well-being of a person. Health is also linked to the natural and human environment, from the family to the clan, from the community to the nation. Treating a disease must therefore include this comprehension of how all aspects of a person complete themselves in order to fight the unbalance the disease originates from. Hence the Aboriginal approach reveals to be holistic, global, and sensitive to the different areas of human life.

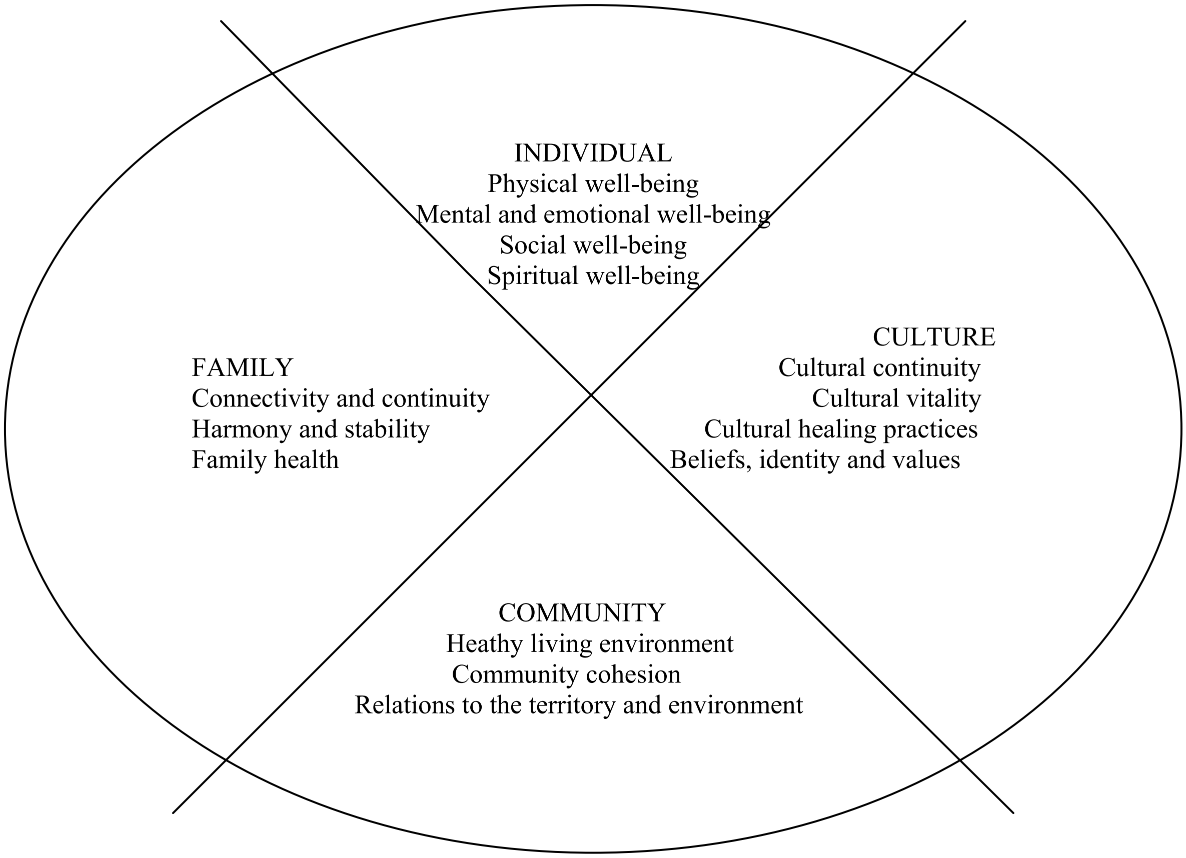
For Aboriginal peoples, colonization, cultural repression, family and community dismemberment, chronic unemployment, poverty, the low level of high school graduates and unhealthy living environments are all health determinants of Aboriginal community members. In order for the strategies aiming the improvement of health to be efficient, they must not only take into consideration these risk factors, but they must also be rooted in the values, principles and knowledge of the members.

Finally, one individual's health and well-being have repercussions and impact the health and well-being of his family and community. "The meaning of Aboriginal health and well-being is understood, in its broadest cultural perception, as: *"The total (Aboriginal) health of the total (Aboriginal) person within the total (Aboriginal) environment""* [71]. The following chart illustrates this.

---

[71] NAHO, 2003, *Indigenous ways of knowing ; Toward building a cultural framework,* p. 11-12.

Chart 2.1: Interaction of the individual, his health and his environment



The Royal Commission Report on Aboriginal Peoples (1996) states that “Many Aboriginal people say they have never had access to enough services that are sensitive to their unique history and needs. At a deeper level, they say the system is incapable of delivering health and well-being to Aboriginal people and that more of the same will not alter this fact. Many who spoke to us argued that strategies for health that originate from within Aboriginal cultures are the key to restoring well-being among Aboriginal people. The critique of existing service systems and the affirmation of the relevance of Aboriginal traditions of health and healing were consistent refrains in our hearings and research”[72].

---

[72] Royal Commission Report on Aboriginal Peoples, 1996, vol.3, chap. 3.

3. Methodology

Four communities in the Quebec Region were invited to participate in the research project because of the home care and institutional care they provide in the community: Kahnawake, Kitigan Zibi, Timiskaming and Wendake. Let it be noted that two other First Nations communities in the Quebec Region provide home care and institutional care for Elders: the Innu community of Mashteuiatsh and the Mohawk community of Kanesatake.

3.1 Community Profile [73]

Kahnawake (Mohawk)

Located ten kilometres south of Montreal, on the southern shore of Lake St-Louis, the Mohawk community of Kahnawá:ke, « On the rapids », has 9,275 residents, of which 7,330 live in the community. Mohawk and English are the two languages most used by the population. The community is considered a large-size community with its 51.2 km^2 surface area. The community has a pre-school (Step-By-Step), two primary schools (Kateri and Karonhianónhnha) and a secondary school (Kahnawake Survival School). The Karonhianónhnha primary school is a Mohawk immersion school in which there are 12 primary-level classes and 4 pre-school-level classes. The community also has an Aboriginal police service, a health centre and a sports centre which includes a skating rink during winter and a lacrosse field during summer.

Through the health services, the Elders' home Turtle Bay Elders Lodge, an independent living centre for the elderly, offers all the everyday living commodities. For a monthly fee, it allows Elders to lead an independent life under the supervision of a nurse. Meals and other commodities are provided. It is an interesting alternative for people who cannot take care of a house. The home has 22 lodging units and four beds are intended for long-term care.

Kahnawake is the only First Nations community in Quebec to have a hospital within the community. The Kateri Memorial Hospital Centre**,** which celebrated its centennial in 2005, is funded by the provincial government and has a total of 43 beds, 33 of which are intended for long-term care (patients whom the physician visits on a weekly basis) and 10 active beds (patients whom the physician visits on a daily basis).

In addition to the Turtle Bay home and the Kateri hospital, the community of Kahnawake has a day centre (19 places), a second centre with a similar vocation (25 places) and a centre for adults with an intellectual disability (approximately 12 places).

In July 2005, there were 24 people at the Turtle Bay Elders Lodge, 173 people were receiving home care (provided by 41 employees) and 32 patients in long-term care at the Kateri Hospital.

---

[73] The data on the population is from DINAC (2004), whereas those concerning the size of the communities are from *2001 Community Profiles,* on Statistics Canada's website http://www12.statcan.ca/english/Profil01/CP01/Index.cfm?Lang=E.

The community of Kahnawake is recognized as a model community with regards to the heath and social services offered on its territory. Despite this, it also has its share of problems. According to the Health Policy Director – Kahnawake Shakotiia' takehnhas Community Services, the lack of services or staff available at all times (24 hours a day, seven days a week), combined to a lack of places in the community facilities forces the people to stay at the community hospital. The Director indicates that when they don't obtain a place in the community, some clients are temporarily taken in by the provincial health network, which he deems to be already saturated for the non-Aboriginals.

Kitigan Zibi (Algonquin)

Located 130 km north of Hull and close to the city of Maniwaki, Kitigan Zibi, "Garden River", is the Algonquin community with the biggest population (2,605, of which 1,491 live in the community). It is considered as a medium-size community with a surface area of 172.1 km^2. Founded in 1851, and borders Eagle River to the west, Desert River to the north and Gatineau River to the east. English, Algonquian and some French are the languages commonly used by its residents. The community has a heath centre, a primary and secondary school (Kitigan Zibi Kikinamadinan), an Early Childhood Centre, a community centre, a community radio, an Aboriginal police service, a youth centre, a centre for victims of family violence and a few grocery stores.

The Home Care Program offers services to non-autonomous Elders, a few disabled persons as well as single parents discharged from the hospital. The program sometimes addresses special requests for home care. The service need is assessed by a nurse, a community health representative and a social worker based on criteria developed by the community nurses and approved by the Health and Social Services Director in the community. When it is established that an Elder needs services on a permanent basis, they are encouraged to ask for a place at the Kiweda group home. The Home Care Program also provides specialized services to individuals who require them, such as spring cleaning, snow shovelling, etc.

The Kiweda « Our house » group home, contribute in maintaining the Elders in the community and helps them keep their autonomy. Its clientele is comprised of independent adults and patients recuperating or recovering from surgery. The home has nine rooms that can accommodate up to twelve clients (double occupancy in certain rooms), and ensures meal preparation, general maintenance and special services to Elders. When the autonomy of a patient diminishes to the point of requiring long-term institutional care, Elders are encouraged to go to the *Foyer Père Guinard* home, in the neighbouring town of Maniwaki, which has the necessary equipment, physicians and nurses.

The Algonquin community also has the Nicholas Stevens Centre for physically- or intellectually-disabled people. The centre offers learning educational activities that aim to achieve a greater autonomy for the clients and an opening up to diversified interests. The centre also offers workshops, outings as well as organized activities to foster and stimulate the integration into the society of individuals living with a disability. In June 2005, the group's main interests were carpentry and artistic productions.

Elders can also count on the Endong centre to gather and take part in recreational activities organized by the centre. Elders usually gather once or twice a week to share a community meal, play bingo, cards or bean bag toss. These activities are an opportunity to use the traditional language and discuss various subjects concerning the community.

In June 2005, there were 12 people at the Kiweda group home and approximately 70 people were receiving home care. Four persons work all year providing institutional care, whereas ten persons provide home care. Finally the health centre is authorized by the Band Council to take demands from other Algonquin communities if some beds are vacant.

Timiskaming (Algonquin)

On the shores of Lake Témiscamingue, adjacent to the municipality of Notre-Dame-du-Nord, the community of Timiskaming, « Head of the Lake », constituted as a reserve in 1851, has a total surface area of 18.8 km^2 and a population of 1,555 persons, of which 544 live in the community. It is a medium-size community. There are three convenience stores, a restaurant, an Aboriginal police service, a primary school and pre-school, an Early Childhood Centre and a health centre.

Providing continuing care services, the Anishnabe Long-Term Care Centre has 27 beds for permanent lodging. It also provides services to the Algonquin communities of Eagle Village/Kipawa (population of 654, 275 of which reside in the community) and Long Point/Winneway (703 members, 355 of which reside in the community).

In July 2005, there were 17 clients receiving home care services provided by 13 social services employees. At the Anishnabe Long-Term Care Centre there are 22 First Nations members and 4 non-Aboriginals. The staff at the Centre is composed of 7 nurses and 11 Personal Support Workers (PSW). The health centre also provides continuing care services and, as of July 2005, 7 clients from the Timiskaming community were receiving the services provided by 2 PSW. There were also 8 recipients from Long Point and 15 recipients from Eagle Village.

Wendake (Huron-Wendat)

Exiled from the Georgian Bay around 1650, the Hurons established themselves definitely in the village of Lorette in 1697. Wendake has a population of 2,988, of which 1,276 live in the community of 1.46 km^2. It is a medium-size community. It has a health centre, an Aboriginal police service, a primary school (Ts8taïe), an Early Childhood Centre and a youth centre. The community also has forty lodging units for independent Elders or people with a low income.

Various services for Elders exist in the community. First there is the *Résidence Marcel Sioui* home, which is a double vocational public facility: accommodation for non-autonomous individuals (long term) and a short-term assistance service. The admission applications are addressed to the *Résidence Marcel Sioui* home, and then reviewed by the facility's multidisciplinary committee comprised of a physician, a nurse and a psychologist, as well as the person responsible from the home. It has twelve beds and provides three meals a day and snacks, bedding services, laundry, janitor, medication surveillance, bathing assistance, television and cable, transportation for medical appointments, pastoral and recreational activities, telephone (payable by the recipient) and a psychosocial consultation service. Home care and assisted living services are provided monthly to approximately 80 people. Finally, two committees organize various social, cultural, recreational, sports or educational (health, nutrition, etc.) activities for the Elders in the community.

3.2 Selection of Community Sample

The four communities participating in the survey were selected among the communities offering continuing care services with a facility providing continuing care in the community. The synthesis of the data collected at the national level will include the data from the Inuit communities of Nunavik and the participating communities in Manitoba.

Regarding the First Nations communities in the Quebec Region, only 6 out of the 29 communities having access to the programs have a facility for Elders. For this reason, **the results of this survey are not representative of the global situation of the First Nations communities in Quebec.**

The sampling at the community level was developed in collaboration with key persons in the health centres and with the help of the lists of continuing care recipients.

Regarding the Timiskaming community specifically, since there was a limited number of potential candidates at home as well as in a facility, all the names in the lists were included in the sampling.

For the three other communities (Kahnawake, Kitigan Zibi and Wendake), home clients were selected randomly given the size of the population. Using a list of all home care recipients, 1 recipient out of 2 was selected.

The three communities' in home as well as in facilities clients were all included. Under the supervision of the training agent, the interviewers divided among themselves the people to interview, favouring the ones they knew, their extended family members or those with whom they had good relationships. At the end of their mandate, the interviewers were to destroy the list of names.

3.3 Consent and participation

A letter explaining the project, what it involved and its spin-offs, was sent to the Band Councils and Health and Social Services Directors of the communities targeted. As mentioned previously the community authorities' written consent to take part in this research project and to collect data on certain members of their community was requested and obtained.

The first contact the continuing care clients had with the research project was different and adapted according to the various communities. Based on the recommendations of the interviewers and Health Directors, the following strategies were adopted:

- Kahnawake: the local coordinator sent a letter to the whole population, with the KSCS (Kahnawake Shakotiia'takehnhas Community Services) letter head, explaining the project, its objectives and wishing for the targeted individuals' participation;
- Kitigan Zibi and Timiskaming: the interviewers phoned or visited the targeted individuals to explain the project, its objectives and the importance of their participation;
- Wendake: the training agent sent a letter to the clients on the list, with the FNQLHSSC letter head, explaining the project, its objectives and announcing the name of the four community interviewers who would be conducting the survey.

Following the first contact with the client, and before the interview would begin, the interviewers were to obtain three consents from the clients:

1) consent to participate in the study;
2) consent to provide the name and phone number of their main family caregiver;
3) consent to allow a paid worker from the local health centre to extract information from the multiple clientele personal autonomy evaluation (based on the functional autonomy measurement system (SMAF)).

Clients were free to provide one, two or the three consents requested.

Following the client's consents, the interview could begin immediately or a meeting could be set based on the client's availability. Once the interview was carried out and following the client's consent, the interviewer contacted the family caregiver identified by the client to explain the project. If the family caregiver agreed to participate, the interviewer set a meeting with him to fill out the appropriate questionnaire. Regarding the SMAF, and always with the client's consent, the interviewer would phone the paid worker from the health centre responsible for filling out the client's functional autonomy measurement system. The interviewer would then gather all the documents concerning the client in an envelop identified with a pre-determined number. It is important to specify that the client could refuse to provide his family caregiver's name and/or to allow that a paid worker from the local health centre extract information. In this case the interview with the client was still carried out if he consented to it.

Contest for the respondents

In order to encourage the participation of the clients and the family caregivers, and to thank them for taking the time to fill out the questionnaires, the individuals who participated in the research project could enter a contest to win $250. An amount of $500 was allotted to each participating communities. This amount was then divided in two separate draws: one for the clients and one for the family caregivers. The draws were held at the FNQLHSSC in November 2005 for the communities of Wendake, Kitigan Zibi and Timiskaming. The community of Kahnawake was responsible for its own draw.

3.4 Development of tools

Developed by the firm Hollander Analytical Services ltd, the proposed methodology and the questionnaires were reviewed by the Quebec Regional Table on Continuing Care. Although each participating region had a common body of questions, each region reviewed and adapted the questionnaires to its own needs.

The questionnaires were designed based on the following work:

Browne, G., Gafni, A., Roberts, J. & Hoxby, H. (1992). *Approach to the measurement of costs (expenditures) when evaluating the efficiency of health and social programmes.* (Working Paper Series. Paper 92-12). Hamilton, Ontario: McMaster University, System-Linked Research Unit on Health and social Service Utilization.

Chapleski, E.E., Sobeck,J., & Fisher, C. (2003). Long-term care preferences and attitudes among Great Lakes American Indian families: Cultural context matters. *Case Management Journals*, *4* (2), 94-100.

First Nations and Inuit Regional Longitudinal Health Survey. (2002). *Adult questionnaire.* disponible au www.ainc-inac.gc.ca.

Hébert, R., Carrier, R., & Bilodeau, A. (1988). The Functional Autonomy Measurement System (SMAF): Description and validation of an instrument for the measurement of handicaps. *Age and Ageing, 17* (5), 293-302.

Hollander, M., Chappell, N., Havens, B., McWilliam, C., & Miller, J.A. (2002). *Substudy 5: Study of the costs and outcomes of home care and residential long term care services.* National Evaluation of the Cost-Effectiveness of Home Care: Victoria.

Penning, M. & Chappell, N.L. (1996). *Home support services in the Capital Regional district: client survey. Final report.* Victoria: Centre on Aging, University of Victoria.

In the Quebec Region, given the target group for the research project comprised mainly of elderly people with limitations due to their health, the Quebec Regional Table on Continuing Care tried to reduce and simplify the client questionnaire. The Table also recommended eliminating the diary, a document where the various workers had to systematically register all the daily actions related to the care provided to the client. This additional task seemed unrealistic for health professionals already overloaded with work. Finally, certain key persons from the communities of Mashteuiatsh and Wendake, in collaboration with the FNQLHSSC, have also reviewed the questionnaires pertaining to phase 2 of the study and have provided their input.

Regional questions

In order to adapt the questionnaires to the needs of the Quebec Region, the Quebec Regional Table on Continuing Care deemed relevant to add a few questions that were not present in the client and family caregiver questionnaires developed at the national level.

First, for the client questionnaire, the interviewer was to indicate at the beginning of the interview the type of care provided to the client (long-term or short-term care). Then the interviewer was to indicate the language in which the interview was to be carried out.

At question 51, the client was asked: "If you had complete choice for your living situation, what kind of housing situation would you prefer?". One of the possible answers, "Living in an assisted living situation", gave a choice of sub-answers to which two answers were added: Hospital in the community and Hospital outside the community. This distinction was important since the residents of Kahnawake have a hospital in the community. Moreover, it is possible that some clients may want to receive care in a hospital outside their community.

A question was added in order to determine if the clients interviewed had people around them who accompanied them or assisted them in activities other than care. The question reads as follows:

"People sometimes look to others for companionship assistance, guidance or other types of support. Could you tell me how often each of the following kinds of support is available to you when you need it?"

	All the time	Most of the time	Some of the time	Almost none of the time	Refused
Someone you can count on to listen to you when you need to talk					
Someone you can count on when you need help					
Someone to take you to the doctor when you need it					
Someone who shows you love and affection					
Someone who can give you help with your daily routine					
Someone to have good time with					
Someone to share your meals with					
Someone to take you to church					

Finally, a note in the client questionnaire instructed the interviewers to take a break halfway through the interview. The note reads as follows:

"Interviewer:
Rest for the client
Please propose to the client to take a small break or to complete the interview at another moment. Schedule another appointment right away."

In the family caregiver questionnaire, the questions regarding the type of care received by the client (long-term or short-term care) and the language in which the interview was to be held were added.

Participant Consent Form (Appendix 2)

In order to ensure an informed consent and to guarantee the confidentiality of respondents, the consent form included a presentation page indicating:

- the research partners;
- the funding sources;
- the objectives of the study;
- the advantages for the respondent and his family;
- privacy;
- the study's procedures and duration and the access to results;
- the right to withdraw from the study at any time;
- a resource-person and his phone number to contact him at any time.

It is important to specify that the participant could choose to consent only to fill out the client questionnaire and not to the two other demands. Even in that case, that client's questionnaire was included in the research project.

A statement of consent then confirmed that the client had read the document and understood its content and implications. A specific box was inserted for the signature of the parent or the tutor in the case of a participant less than 18 years of age. Finally, a reserved space was also inserted in the case of an adult requiring a legal tutor.

An example of the consent form was given to the participant.

Family Caregiver Consent Form (Appendix 3)

Identical to the participant consent form, with the exception of a few sentences, the family caregiver consent form aimed to obtain the informed participation of the main family caregiver identified by the client.

Client Questionnaire (Appendix 4)

Requiring an average of two hours to be completed, the client questionnaire includes the following sections:

A. Demographics: age, gender, language, level of schooling, income and household;
B. Housing (clients at home)[74]: commodities, equipment, renovations, repairs;
C. Housing (clients in a facility): commodities, desired improvements, evaluation of the various departments (nursing, dietary, etc.) and staff;
D. Use of health-related services: family caregiver, assistance received from the family caregiver and the formal caregiver, hours per week, costs;
E. Other health-related services: supplies, aids or devices received or bought, costs ;
F. Satisfaction with health-related services: care and support provided by the family caregivers and the formal care system;

---

[74] The client answered section B or C depending on his place of residence at the time of the survey.

G. Location of services: preferred location to live and receive care;
H. Health, quality of life: elements impacting health, support available;
I. Additional comments.

Family Caregiver Questionnaire (Appendix 5)

Requiring an average of an hour to be completed, the family caregiver questionnaire includes the following sections:

A. Provision of assistance: relationship to the client, distance from his home, other clients;
B. Type of care provided: tasks and time involved (family caregiver and health system);
C. Other health-related services: supplies, aids or devices received or bought, costs ;
D. Satisfaction with health-related services: care and support provided by the formal care system, difficulties encountered in providing care;
E. Location of services: preferred location to live and receive care;
F. Effects of caregiving: impacts of the involvement as family caregiver;
G. Demographic information: age, gender, language, level of schooling, income and household;
H. Additional comments.

Functional Status Questionnaire (Appendix 6)

Completed by a paid worker of the local health centre, the functional status questionnaire allows for information to be extracted from the functional autonomy measurement system (SMAF). Within the context of this study the following sections were used to create the functional status questionnaire:

1. Activities of daily living: eating, washing, dressing, etc. ;
2. Mobility: walking, negotiating stairs, propelling wheelchair, etc. ;
3. Communication: vision, hearing, speech;
4. Mental functions: memory, orientation, comprehension, judgment and behaviour;
5. Instrumental activities of daily living: housekeeping, meal preparation, shopping, budget, etc.;
6. Right to refuse care.

The following is brief description of the Functional Autonomy Measurement System (*Système de mesures de l'autonomie fonctionnelle - SMAF*) used to evaluate the functional status:

"[It is] a tool to measure autonomy developed [at the research centre on geriatrics, the *Centre de recherche en gérontologie et gériatrie,* of the Sherbrooke University] according to the functional concept of health and the World Health Organisation's classification of disabilities, resources and handicaps. It measures 29 functions of the activities of daily living, mobility, communications, mental functions and instrumental activities of daily living. Each function of the SMAF is measured on a scale according to very precise criteria, and based on information obtained through questioning and observation of the subject or through questioning a third party. Translated in seven languages, this tool has been used in several epidemiological and evaluative research surveys. It is also widely used by clinicians to assess and ensure the follow-up of clients receiving home care as well as those living in a facility. This tool was integrated to the multi-clientele tool used at the provincial level.

The SMAF allows one to quickly obtain a portrait of a subject's functional autonomy and identify the resources currently gravitating around him. Three tools were developed based on the SMAF:

- Autonomy Measurement Scale;
- Client Care Record;
- Autonomy Profile"[75].

3.5 Data collection and encryption

The interviews were carried out at the place chosen by the client or the family caregiver, which could be at home, in a facility or in a public place (a restaurant, community hall). During the training interviewers were strongly recommended to hold individual interviews and to avoid having the client interviewed in the presence of his family caregiver, and vice-versa.

The following is the schedule of training and data collection activities:

Table 3.1: Calendar of training and data collection activities

Community	Training	Collection start	Collection end
Kahnawake	August 16 & 17	August 19	October 7
Kitigan Zibi	August 9 & 10	August 11	September 30
Timiskaming	August 2 - 4	August 5	September 30
Wendake	August 22 & 25	August 24	October 7

For each respondent the completed questionnaire was sealed into an envelop with the consent forms and the coupon for the draw. All the envelops were then gathered in prepaid and pre-addressed envelops and posted together to the FNQLHSSC's office.

The data encryption and analysis was done using the SPSS (Statistical Package for Social Sciences) software. A variable data dictionary for all three questionnaires was developed and the data entry was carried out by the research unit at the FNQLHSSC without any noteworthy problems.

3.6 Data Storage and Security

The questionnaires received at the FNQLHSSC were kept in a locked cabinet in the office of the research team members. The data transferred electronically was accessible only to the members

---

[75] Institut universitaire de gériatrie de Sherbrooke, 2005, available at www.iugs.ca/FR/500/formation.asp?Section=500&ForId=8).

of the research team who were linked through a secured and exclusive electronic network. With the exception of the signed consent forms, no name appeared on the various questionnaires and the people interviewed were identified with an arbitrary numerical code.

The completed questionnaires were stored in a locked cabinet at the FNQLHSSC's office on behalf of the communities during the time required to complete the analysis and final report of this research project. They will be destroyed in five years. Finally in compliance with OCAP principles, it will be possible for the communities to put in a request to recover the questionnaires once the final report is tabled. The community of Kahnawake has already expressed its intention of recovering the questionnaires that will then be kept in a locked cabinet in the offices of the health centre and destroyed at a later date.

3.7 Research limitations

In the course of this survey, a number of elements have impacted on the validity of the results presented in this report; they are presented in this section.

First, it is important to specify that this survey was initiated and developed by the partners at the national level, which are Health Canada and DINAC, in collaboration with Hollander Analytical Inc. Thus, a number of this survey's parameters — the size of the sample, the community selection criteria, the number of respondents, the time and funding allotted to the survey — were determined by them and therefore influenced the progress of this research.

With regard to the sampling, because of the size of the sample (4 communities) and the small number of respondents it is made of, **the results presented are not representative of all the First Nations communities of Quebec.** Let it be noted that the goal of the survey was not to provide a portrait of all the communities, but rather to determine the continuing care needs of the people living in the selected communities, to identify what continuing care services are currently provided in those communities and to develop the options and costs associated with the delivery of continuing care services in those communities. In support of this goal, the survey was developed as a pilot project with a non-probability sampling. "A non-probability sampling is a means of selecting population units using a subjective method (i.e. non random). It is not necessary to have a complete survey frame in the case of a non-probability sampling, which makes it a fast, easy and inexpensive way to obtain data"[76]. While a non-probability sampling allows one to collect data quickly and at a low cost, the results however cannot be generalized to the whole population. That is why the results presented in this research report are not representative of all the First Nations communities of Quebec.

The three regional reports – Manitoba, Nunavik and the present report – have been developed to be merged in one national report once they are completed. The results of the three regional reports will therefore complement each other in order to provide a more global portrait of the situation in terms of continuing care among First Nations and Inuit in Canada.

---

[76] Statistics Canada, 2003, Méthodes et pratiques d'enquête, 97.

Moreover, because of the low degree of variability between the participating communities being studied in the Quebec region, the precision of the results is increased, which means the sample is relatively homogenous. This is due to the fact that the four communities share a number of parameters, which are the following:

- Similar size (three medium size and one large size);
- Located in zone 1 (the community is located within 50 km of the nearest service centre with year-round access);
- Have at least one seniors' home in the community.

Consequently, **the four communities may be compared among themselves, but are not representative of all the First Nations communities of Quebec**.

In addition, a few errors occurred in the course of the research: errors in the design of the questionnaires, in the survey, interview, respondent and non-response process and in the processing.

Regarding the translation of the questionnaires, in some cases where the respondent had to answer a multiple-choice question, the categories in English did not correspond to those in French. Both questionnaires in English and in French therefore did not offer the same choices of answers to the people interviewed. This error in the design of the questionnaires also impacted the data encoding.

The multiplication of interviewers — and therefore of ways of conducting the interviews — as well as the presence, in some cases, of a tutor to answer for the client, may also have generated some errors in the answers.

Moreover, the fact that the interviewer might have previously known his client during the interviews also might have impacted the answers. The interviewer might have had a favourable or unfavourable influence on the answers of his/her respondent. The interviewer might also have unconsciously interpreted the answers of the client based on the knowledge he/she had of the client.

Regarding the two latter points however, it is important to note that the cultural context in which the research took place recommended using interviewers from the same community as the respondent. It must be noted that hiring First Nations contractual staff living on the participating community presented two advantages. First, knowing the field and the language may reduce the interpretation problems and misunderstandings of certain notions that are difficult to translate. Second, the respondents' level of trust may be higher towards a member of the same community than when the questionnaire is administered by a Non-Aboriginal stranger. However, hiring such staff may have as downside the concern that one's answers will not remain confidential because of the close relationships between community members and that the answers will be interpreted based on the interviewer's knowledge. That being said, the situation involving less risks was favoured.

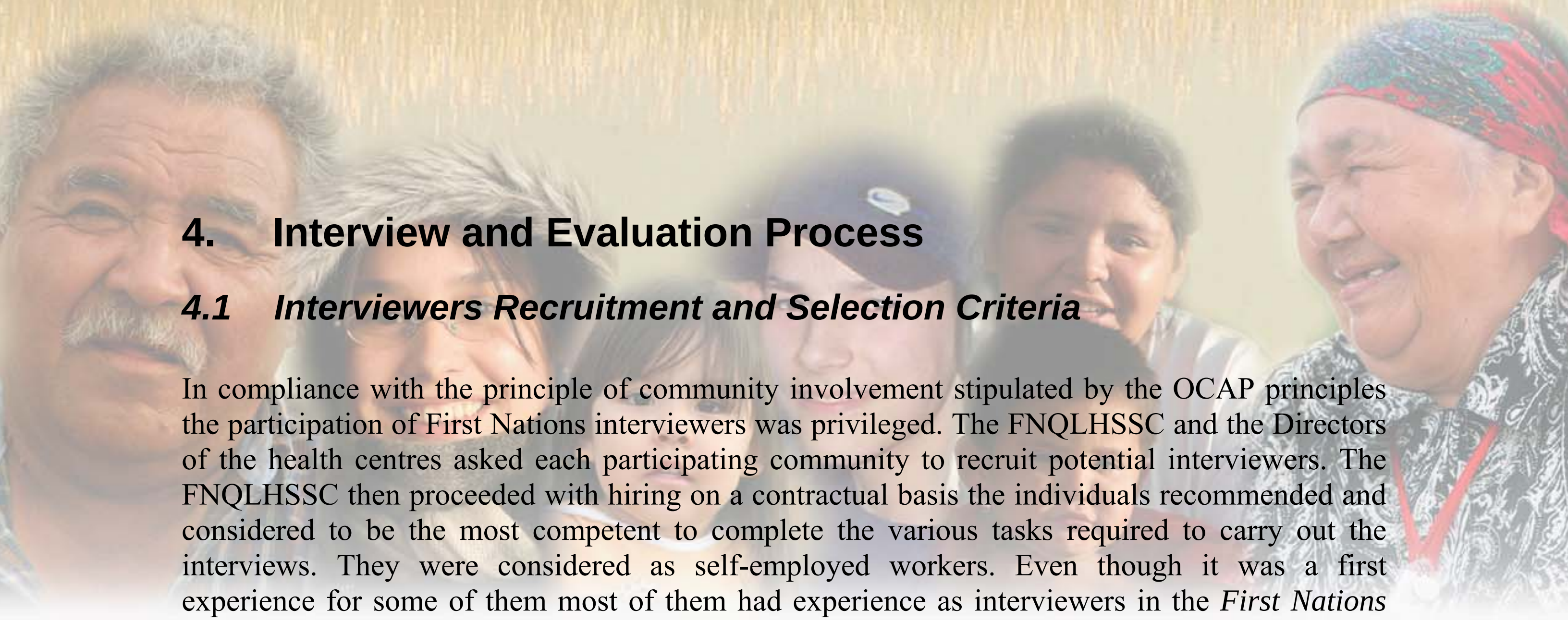
Concerning the respondents' errors, it is possible that respondents might have skewed some answers. Several factors may explain this limitation: the fact that the people interviewed could be sick and therefore in a vulnerable situation, social desirability, which consists of giving answers that one believes to be the "right" ones at the social level (the ones to be socially "expected"), the language or translation into the mother tongue and the distinct cultural context of First Nations, explained in 1.2 and 2.4.

Errors due to non-responses also occurred all along the survey process. In several occasions, the respondents gave incomplete answers or simply did not answer, which unquestionably skews the results. These questions were identified in the report.

Finally, since the survey took place over several years, changes in the staff associated with this research might have generated some limitations to the research, including interpretation limitations, during the preparation, data collection and drafting.

In conclusion, it is important to note that it is a pilot project and that the funding and time allotted to the project limited the scope of the survey and the size of the selected sampling.

With regard to the sampling, because of the size of the sample (4 communities) and the small number of respondents it is made of, the results presented are not representative of all the First Nations communities of Quebec.



4. Interview and Evaluation Process

4.1 Interviewers Recruitment and Selection Criteria

In compliance with the principle of community involvement stipulated by the OCAP principles the participation of First Nations interviewers was privileged. The FNQLHSSC and the Directors of the health centres asked each participating community to recruit potential interviewers. The FNQLHSSC then proceeded with hiring on a contractual basis the individuals recommended and considered to be the most competent to complete the various tasks required to carry out the interviews. They were considered as self-employed workers. Even though it was a first experience for some of them most of them had experience as interviewers in the *First Nations Regional Longitudinal Health Survey* held in Quebec in 2002.

Table 4.1: Number of interviewers per community

Community	Number of interviewers
Kahnawake	**7**
Kitigan Zibi	**3**
Timiskaming	**6**
Wendake	**4**

Hiring on a contractual basis First Nations members living in the community surveyed had the following advantages:

- the knowledge of the field and the language used in the community are invaluable assets for a better quality of the data collected. The interviewers are able to limit the interpretation problems and the misunderstanding that results from concepts hard to translate;
- the level of trust is often higher in the presence of a fellow citizen than when the questionnaire is administered by a non-Aboriginal stranger.

However, hiring First Nations contractual staff living in the community may also present certain disadvantages. For example, it might happen that the respondent fears a confidentiality breach because of the close links existing between community members. Moreover, in a case where the interviewer knows the respondent personally, it might happen that he interprets the answers based on his own knowledge of the respondent's personal situation. Finally, since many interviewers were trained in each community, there is multiplication of the mode of conduct of the interviews. This might increase the number of interpretations of the respondents' answers.

4.2 Interviewers Training

The interviewers received training in each of the communities. Two members of the FNQLHSSC' research unit were mandated to provide the training. The training themes were as follows:

- History of the evaluation of continuing care needs;
- Sampling;
- Consent to disclose information and data protection;
- Interview techniques;
- Means to deal with various situations in the course of an interview;
- Record keeping, shipping material and drafting of short reports;
- Meticulous review of questionnaires, question by question.

An “Interviewers Manual” was handed to each interviewer. The training generally took place over two to three days and included a practical part: paired up in teams, the individuals would simulate an interview, from the first contact on the phone to the conclusion of the interview.

Following this training, one of the two training agents stayed in the communities for a few days as a resource person for the interviewers, to advise them, guide them and solve potential problems.

All the interviewers as well as the trainers signed an oath of silence before a Commissioner of oaths.

4.3 Support Provided to Interviewers

In addition to the training agent staying in the communities a few days longer as a resource-person for the newly-trained interviewers, a toll-free line was installed so the interviewers could contact the FNQLHSSC’s research team members at any time during business hours. The local Health Directors were also available to support the interviewers when required.

The community of Kahnawake, who has a research team at the KSCS, took over the supervision of its interviewers and the responsibilities related to their remuneration and administration. The interviewers and the coordinator in Kahnawake would communicate with a FNQLHSSC research agent every week to report on the progress of the meetings with the clients, to solve potential problems or to provide advice to the interviewers.

Regarding the remuneration, the interviewers were responsible for sending in their time sheets to the FNQLHSSC on the time basis they chose. Thus some of them faxed their time sheet every week whereas some others included it in the envelops they shipped to the FNQLHSSC at the end of their mandate. For the communities of Kitigan Zibi, Timiskaming and Wendake, the wage was based on the number of hours worked and not on the number of questionnaires completed, therefore taking into account the time invested in phone calls, going to and returning from the meeting, explaining the project and administering the questionnaire (which can vary considerably depending on the client’s physical condition). The interviewers could also claim for the mileage involved in meeting the targeted individuals.

The remuneration mode of the interviewers in Kahnawake was at the community’s discretion. The interviewers were remunerated for each questionnaire completed and handed to the local coordinator. No additional cost was allowed. The coordinator's salary was based on an hourly rate and a certain number of hours per week established by the local authorities.

4.4 Management of interview-related difficulties

A significant number of clients refused to disclose the name of their family caregiver to the interviewers, sometimes because they did not have any.

Table 4.2: Consent-related difficulties in each community

	Client's refusal to participate	Refusal to provide name of family caregiver	No family caregiver (family)	Family caregiver not interviewed	Refusal - SMAF
Kahnawake	**5.1%**	**9.0%**	**-**	**39.7%**	**3.8%**
Kitigan Zibi	**16.7%**	**69.8%**	**11.3%**	**1.9%**	**1.9%**
Timiskaming	**14.3%**	**-**	**-**	**-**	**-**
Wendake	**7.4%**	**16.7%**	**7.4%**	**5.6%**	**11.1%**

* The (-) sign indicates a null value.

Finally, some interviewers abandoned: five of them found full-time employment significantly reducing the time they could invest in conducting interviews. Most of them transmitted the name of their clients to their colleagues who, for the most part, took on the clients.

4.5 Interviewers Experience

Following the data collection, interviewers were given an evaluation form on their experience. Four interviewers sent back their evaluation form to the FNQLHSSC, thus limiting the data analysis concerning their experience. The main points are as follows:

1. Training

The training received seems to have been very much appreciated both for its duration and content: it prepared them adequately for the work that was expected of them. The interviewers also appreciated the trainers' flexibility, among other things for giving a specific training to the people who could not attend the training. Generally speaking, the training seems to have been more efficient for people who did not wait too long before starting the interviews.

The interviewers considered the material to have been somewhat useful. In general, the interviewers mostly consulted it to refresh their memory regarding the training or as support for first contacts.

2. Technical support

The assistance provided by the FNQLHSSC during the data collection was very much appreciated. This assistance met the needs of the interviewers when they arose. The assistance was easily accessible, understanding, patient, encouraging and open to suggestions. Generally speaking, the interviewers also considered the administrative elements to be quick and efficient.

3. Consent forms and questionnaires

The interviewers agree to say that the consent forms were clear and culturally adapted. For some of them however they were slightly too long, which was inconvenient.

The interviewers found the questionnaires to be culturally adapted. An interviewer mentioned that it was easy to identify the questions specific to the more isolated communities. Some interviewers however indicated that some questions were less clear or repetitive and there were too many of them. Finally, they indicated it would be preferable if the questionnaires took less time to fill out.

4. Personal experience

Generally speaking, the interviewers are very satisfied and proud to have completed the interviews they were mandated to carry out. They enjoyed listening to the respondents who sometimes confided in them.

They also underlined the respondents’ generosity, openness and availability in doing this in their community’s interest. Some of the interviewers learned to respectful and honest through the contact with the respondents.

5. Participation in the study

In the evaluation form, the interviewers were asked about the reasons that, according to them, justified the refusal to participate of clients and family caregivers. According to them, the reasons explaining the clients’ refusal were either personal or they just did not want to be disturbed. Some clients indicated the services provided were good as they were in order to justify their refusal to participate.

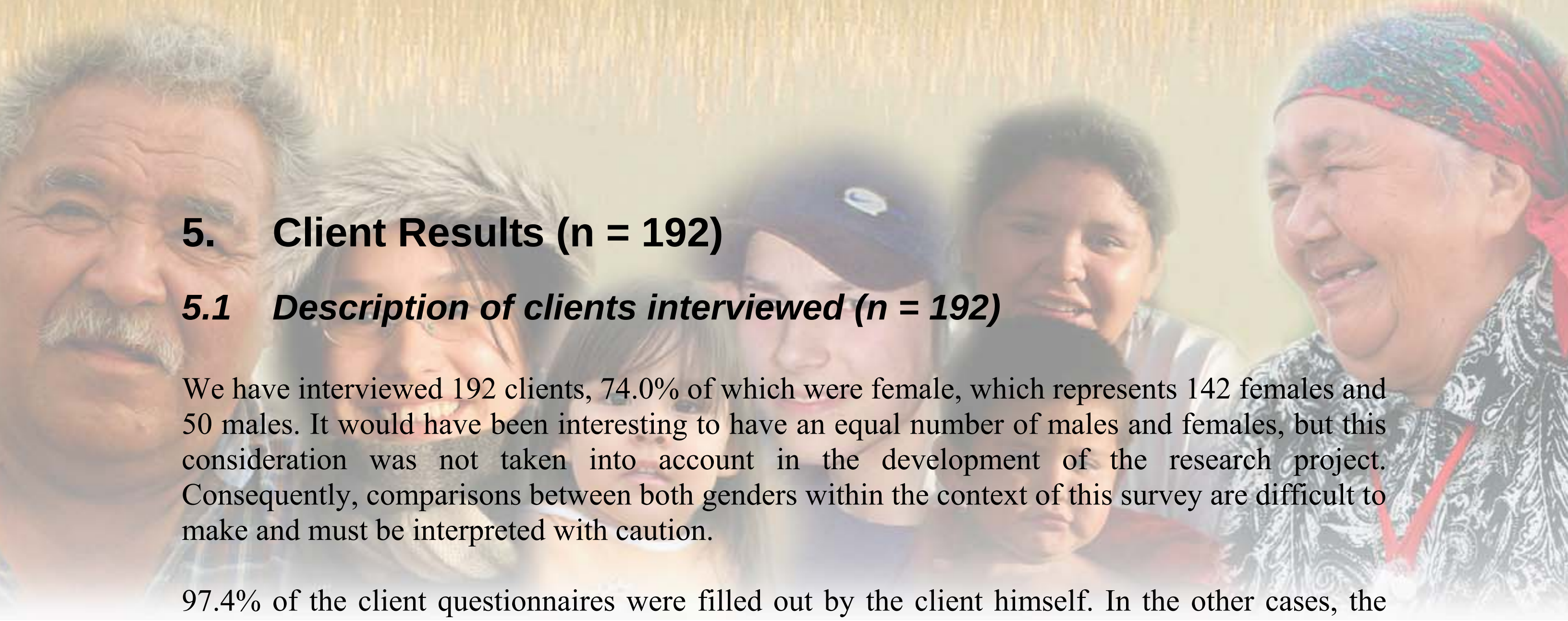
Regarding the reasons explaining the family caregivers’ refusal to participate, the interviewers deem that the main reasons are the clients’ refusal to disclose the name of his family caregiver or not having a family caregiver. Some family caregivers contacted for the study also indicated they did not have the time to answer the questionnaire.

6. Taking stock

Regarding the relevancy of this research project on continuing care, the interviewers indicated that the interview had allowed the respondents to express their needs regarding the care and services they receive. They hope the research project will result in positive changes in the community by meeting the needs for missing care and services and improving the existing ones.

Some interviewers suggested expanding the clientele interviewed since many people without a formal caregiver still receive care and services by professionals from the formal care system. The interviewers would have liked to see these people taken into account more in this research project.

Finally, a majority of interviewers indicated they would accept repeating the experience.



5. Client Results (n = 192)

5.1 Description of clients interviewed (n = 192)

We have interviewed 192 clients, 74.0% of which were female, which represents 142 females and 50 males. It would have been interesting to have an equal number of males and females, but this consideration was not taken into account in the development of the research project. Consequently, comparisons between both genders within the context of this survey are difficult to make and must be interpreted with caution.

97.4% of the client questionnaires were filled out by the client himself. In the other cases, the questionnaires were completed, through proxy, by a professional from the formal care system, the family caregiver or a paid professional.

78.9% of clients receive long-term care, 21.1% of them therefore receive short-term care.

The following table represents the client's place of residence according to the type of care received. One can note that a high percentage of clients requiring continuing care are at home.

Table 5.1: Client's place of residence according to type of care received

Place of residence	Long term (n=151)	Short term (n=41)
At home	**65.2%**	**97.2%**
In a facility or the community hospital	**34.1%**	**2.8%**
Other	**0.7%**	**-**

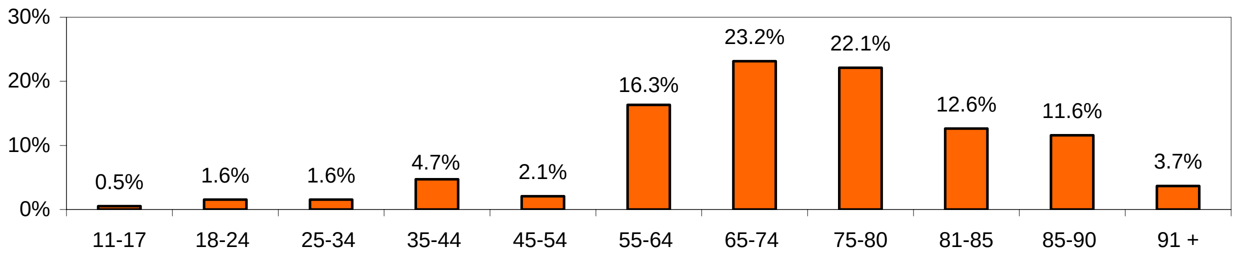
*The (-) sign indicates a null value.

Out of the 192 clients interviewed, 72.4% of them live at home, 27.0% in a facility or the community hospital. 0.6% of clients live elsewhere.

71.2% of interviews were carried out in English, 28.3% in French and 0.5% in Algonquian. However 3.3% of clients asked for assistance from an interpreter.

Half of the clients are 75 years and over, as demonstrated by the following graph.

Chart 5.1: Breakdown of clients according to age group

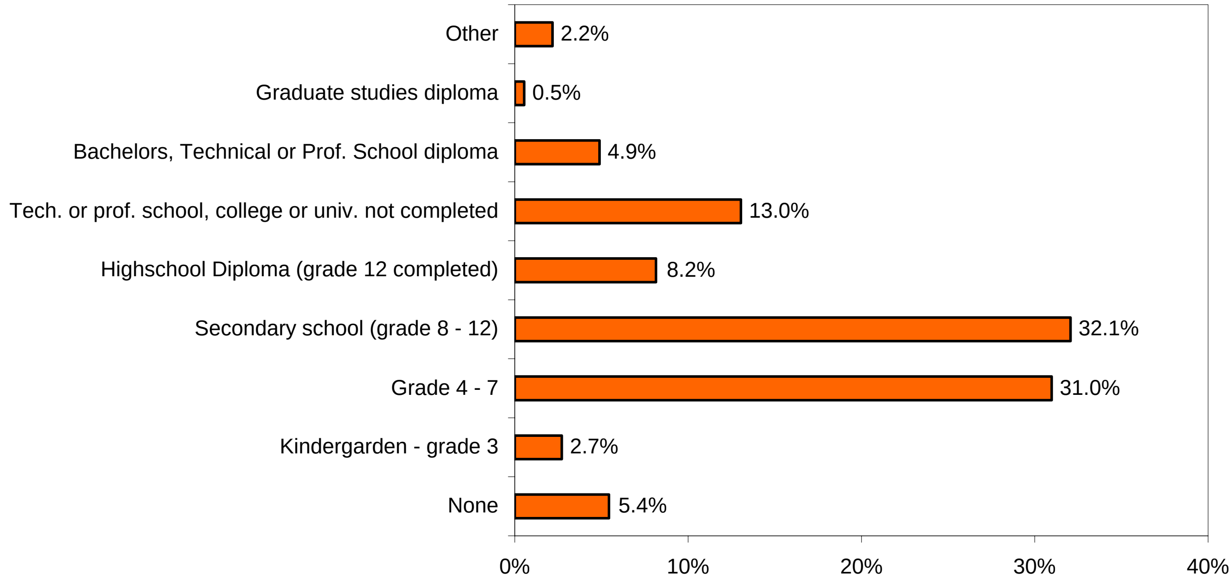


77.7% of client speak English, 54.9% speak French, 18.1% speak Algonquian and 26.9% speak Mohawk (some clients identified more than one language).

79.8% of clients understand English and 62.7% understand French. 17.6% of clients understand Algonquian and 29.0% understand Mohawk (some clients identified more than one language).

Regarding the language used on a daily basis by clients, 64.8% use English, 34.2% use French, 11.9% use Algonquian and 13.5% Mohawk (some clients identified more than one language).

Chart 5.2: Breakdown of clients according to level of schooling



95.7% of clients interviewed do not have a paid job. 61.7% receive basic old age benefits and 24.4% receive Quebec or Canada pension plan benefits. 14.6% receive an income from a retirement program, a pension, a retirement pension or benefits. 9.4% receive income security (social assistance), 8.8% receive an income from another source, 8.3% receive workers compensation and 6.8% receive guaranteed income supplement or spouse's allowance (clients could indicate more than one source of income).

45.4% of clients interviewed live alone. 36.2% live with another person and 18.4% with two to five other persons.

Approximately the same percentage of males and females receive long-term care: 78.6% of males and 79.1% of females. 64.0% of males live at home and 36.0% in a facility whereas 75.4% of females live at home and 19.0% in a facility, 4.9% at the community hospital and 0.7% elsewhere. It should be noted though that the sampling is comprised of 74.0% of females. These results should therefore be interpreted with caution.

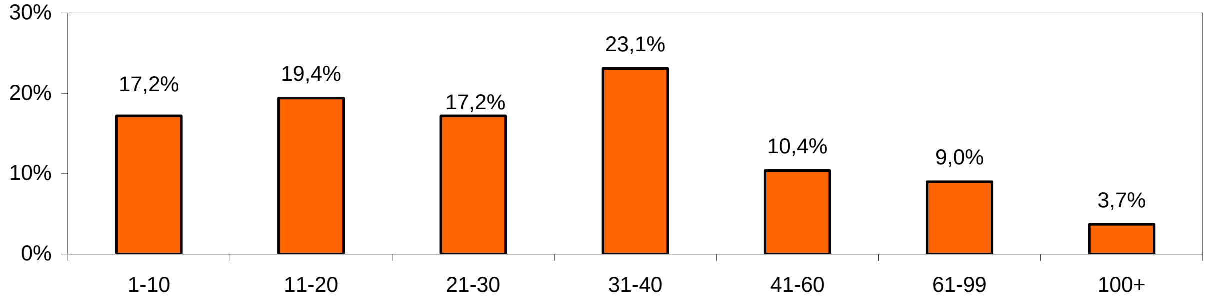
5.1.1 Living situation of clients at home (n = 139)

The results in this section pertain solely to clients living at home, which is 72.4% of individuals interviewed (n = 139).

81.0% of clients living at home are owners, 12.4% are tenants and 6.6% live in a house that belongs to the Band Council. 18.1% of homes have three rooms or less, 42.8% have four or five rooms and 39.1% have six rooms and over.

The clients' homes are all equipped with a fridge, running water (hot and cold), flush toilets, telephone and electrical heating system in 33.3% of cases, oil heating system in 3.6% of cases, others not having specified. 99.3% of clients' homes are equipped with a stove to cook (80.0% of stoves are electrical, others use propane), have garbage collection services and have access to electricity. 92.6% of homes are linked to a sewage system or to a septic tank, 83,1 have a water line and the homes of 31.6% of clients are fringed by a sidewalk.

Chart 5.3: Home age group



According to clients, 40.9% of homes are in need of repairs, mainly those 21 years old and over. Regarding repairs, 27.9% of clients indicate their home needs major repairs, 22.8% minor repairs, whereas others believe regular maintenance is sufficient. Repairs mostly concern the bathroom, the windows and the roof.

The following table demonstrates that homes owned by clients generally require more major or minor repairs than homes owned by someone else.

Table 5.2: Repair needs according to ownership of clients' residence

	Tenant (n = 17)	Owner (n = 109)	Owned by Band Council (n = 9)
Major repairs	**11.8%**	**30.3%**	**22.2%**
Minor repairs	**17.6%**	**24.8%**	**11.1%**
Regular maintenance	**70.6%**	**43.1%**	**66.7%**

51.4% of clients living at home indicate their home requires or has required modifications following their physical condition or health problems. These modifications consisted for 25.0%

of handrails, adapted shower and/or baths in the bathroom, for 13.6% an access ramp and 8.6% handrails in the house (elsewhere than the bathroom). These modifications were done for almost two thirds of clients. The main reason explaining why the required modifications were not done is the cost (20.9%).

Finally, 16.7% of clients at home have indicated the presence of mildew in their home in the twelve months previous to the study and 39.1% consider their running water not to be suitable for consumption. Let it be noted that the perception that running water is not suitable for consumption does not mean it is in fact not suitable for consumption but rather that it is perceived as such by clients who have responded.

5.1.2 Living situation of clients in a facility (n = 52)

The following results pertain solely to the clients living in a facility, which is 27.0% of individuals interviewed (n = 52).

27.5% of clients living in a facility share their room with someone and 9.8% of clients have a spouse or a member of their family in a neighbouring room. 72.5% of clients therefore live by themselves in their room.

11.5% of clients in a facility consider their room in need of minor repairs and 84.3% that regular maintenance is sufficient. No client has mentioned major repairs; the others do not know or refused to answer.

18.4% of clients in a facility consider that improvements are necessary to the air circulation in their room, 18.0% to the size of their room, 12.0% to the floor, 8.0% to the noise level, 6.4% to the temperature control, 6.1% to the lighting and 6.0% to the taps. Almost all of them consider that improvements regarding the mirrors in their room are necessary. The cold floors and insufficient lighting were also mentioned as required improvements.

Furthermore, 24.0% of clients in a facility consider that their room needs modifications to the size of the bathroom, 17.4% to the type, size or location of the bathtub, 12.2% to the size of the room, 10.6% to handrails, 10.0% to the height or location of the toilet and 6.0% to the width of doorways. Refrigerators that are too low or too small were also indicated in the modifications.

98.0% consider their room and facility to be safe.

The following tables present a fairly good overall evaluation by the clients of the facility, the various departments and the staff. One can note that regarding the facility, food and activities have been evaluated lower whereas safety and staff have received a better evaluation.

Table 5.3: Evaluation of the facility by the client

	Poor	Fair	Good	Excellent
Food	3.9%	19.6%	49.0%	27.5%
Facilities	2.0%	7.8%	52.9%	17.6%
Services	2.0%	7.8%	56.9%	19.6%
Activities	-	16.0%	58.0%	14.0%
Safety	2.0%	5.9%	62.7%	29.4%
External sidewalks	2.1%	6.3%	37.5%	12.5%
Staff	-	5.9%	68.6%	23.5%
Visitors	2.2%	8.7%	58.7%	13.0%

*Clients could choose not to answer or not to know.

Regarding the various departments in the facility, dietary and social activities have also been evaluated lower whereas maintenance, nursing and housekeeping receive a better evaluation.

Table 5.4: Evaluation of the facility's various departments by the client

	Poor	Fair	Good	Excellent
Nursing	-	7.8%	66.7%	17.6%
Dietary	7.8%	17.6%	62.7%	9.8%
Housekeeping	2.0%	9.8%	56.9%	25.5%
Laundry	4.1%	8.2%	49.0%	22.4%
Maintenance	-	3.9%	64.7%	23.5%
Administration	2.0%	9.8%	45.1%	9.8%
Social activities	2.0%	18.0%	58.0%	12.0%

* Clients could choose not to answer or not to know.

Finally, concerning the staff, although evaluations seem relatively similar, the staff's friendliness and helpfulness have been evaluated slightly higher whereas courtesy and professionalism have been evaluated slightly lower.

Table 5.5: Evaluation of the staff at the facility by the client

	Poor	Fair	Good	Excellent
Courtesy	-	13.7%	52.9%	29.4%
Friendliness	-	9.8%	51.0%	37.3%
Helpfulness	2.0%	8.0%	50.0%	38.0%
Professionnalism	2.0%	9.8%	43.1%	35.3%

* Clients could choose not to answer or not to know.

Regarding the evaluation of the facility, its departments and staff, it is necessary to provide some balance to the results. During discussions, some continuing care workers indicated that the clients' evaluation could in fact be lower globally; it is possible that client might have feared having their care and services reduced if they gave a bad score to the facility.

30.0% of clients in a facility believe that more services should be offered, such as a recreationist and a massage therapist according to 9.6% of clients and a social worker according to 5.8% of them. Alcoholics Anonymous and taxi services as well as computers were also indicated.

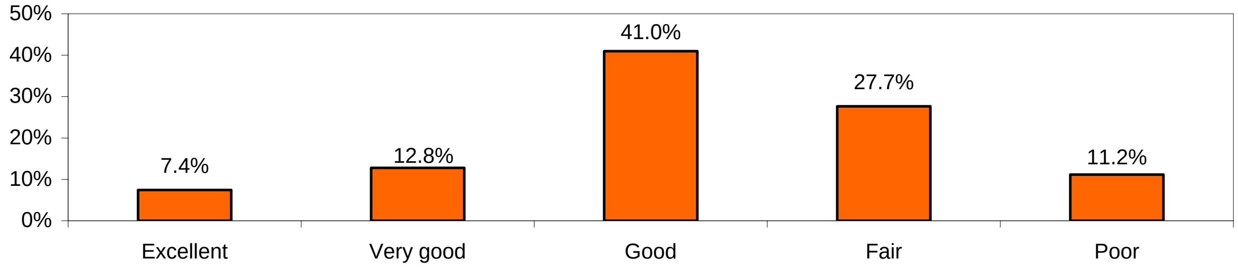
Despite everything, 96.2% of clients would recommend their facility to someone else.

5.1.3 Health and quality of life (n = 192)

This section applies to all the clients interviewed, which is 192 individuals.

As demonstrated by the following graph, 20.2% of clients indicated their health was either excellent or very good, 41.0% good and 38.9% fair or poor.

Chart 5.4: Client's perception of his overall health



93.6% of clients indicate they are happy with their life. Many things make them happy: contact with their family, friends and animals were often mentioned. Health, happiness, life, peace, nature, harmonious relations, activities (bingo, gardening, crochet, cards, knitting, painting, cooking, etc.), food (chocolate, spaghetti, coffee, wine, beer, etc.), music, reading, dancing, cinema, television, travelling and restaurants were also mentioned. Finally, sleeping, sex, memories of the past, their home and their autonomy seem to make clients happy as well.

The clients also listed things that made them unhappy: bad health, misfortune of others, bad news, violence, death, war, conflicts, concerns, stress, solitude, lack of respect, loss of autonomy and lack of money were the most frequent ones.

The following table presents the factors that influence health according to the clients. Sleep, diet and physical activities seem to be the factors that impact health the most whereas politics, bereavement in the community and non-voluntary separation from the spouse to get into institutional/facility setting have the least impacts on health, according to clients. Diseases and medical problems such as arthritis, diabetes and vision problems have also been mentioned as factors influencing health.

Table 5.6: Factors that influence health according to clients

Factors	
Sleep / rest / lack of sleep	33.2%
Good diet	25.9%
Exercise / regular physical activities / lack of exercise	23.8%
Stress / concerns / good stress	20.2%
Physical, emotional, mental and spiritual balance	15.5%
Medication	12.4%
Emotional well-being	10.4%
Personal bereavement	9.8%
Social support	8.3%
Financial	3.1%
Good sex life	2.6%
Politics	1.6%
Community bereavement	1.6%
Non-voluntary separation from spouse to get into institutional/facility setting	0.5%

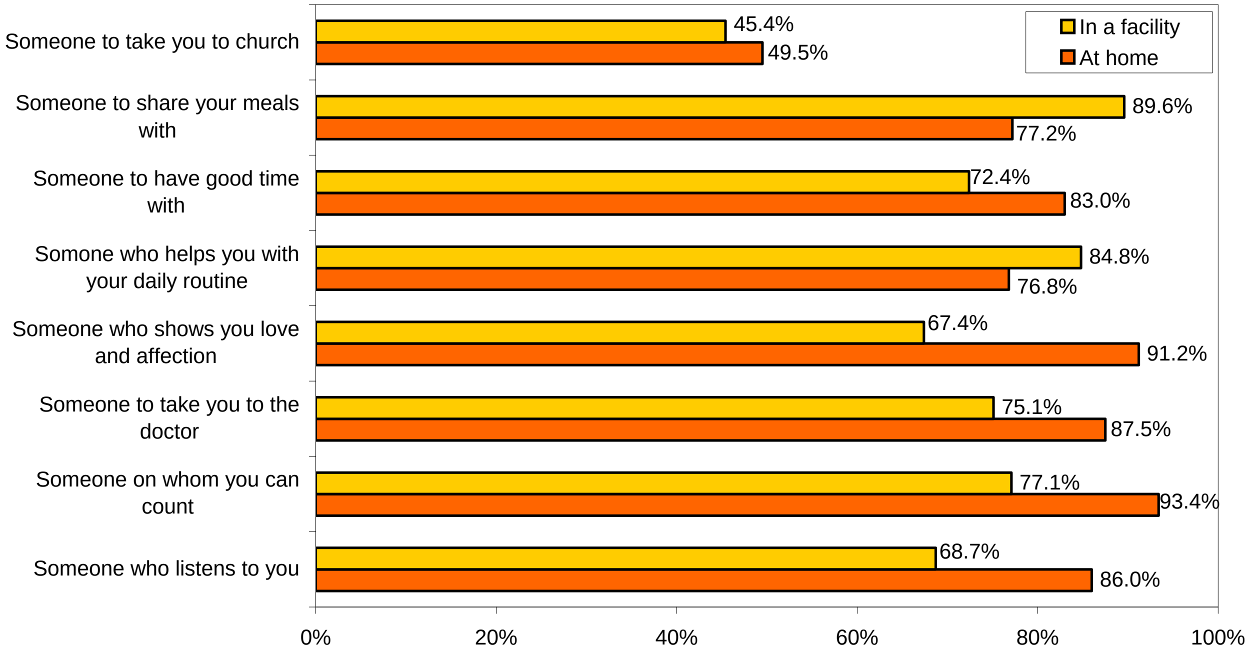
Table 5.7 presents the availability of support according to clients. One can note that a higher level of clients have someone on whom they can count all or most of the time (88.8%) compared to someone who can take them to church (47.9%).

Table 5.7: Availability of support

	All the time	Most of the time	Some of the time	Almost none of the time
Someone who can take you to the doctor	69.1%	15.4%	8.0%	3.7%
Someone who shows you love and affection	68.8%	16.1%	8.6%	4.3%
Someone on whom you can count	67.0%	21.8%	8.0%	2.1%
Someone to share your meals with	64.4%	16.5%	10.1%	8.0%
Someone to have good time with	61.3%	19.4%	12.9%	4.3%
Someone who can give you help with your daily routine	60.3%	19.0%	9.2%	8.2%
Someone who listens when you need to talk	59.9%	20.9%	14.4%	3.7%
Someone to take you to church	39.9%	8.0%	12.9%	11.0%

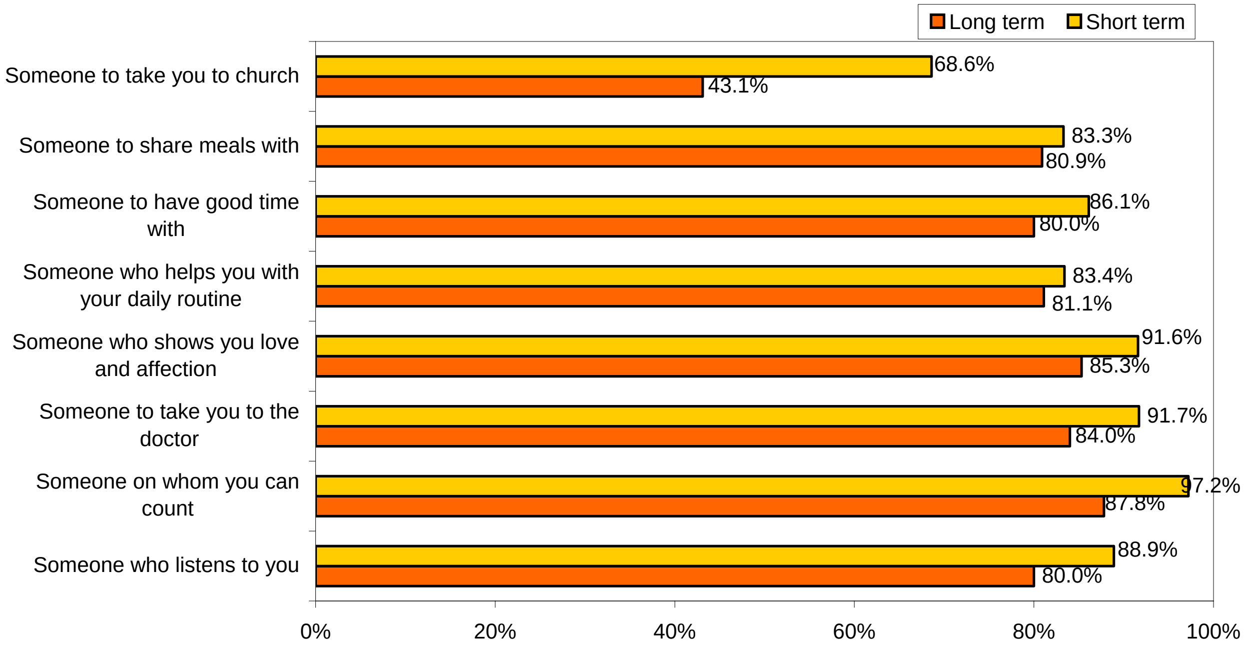
By crossing support available all or most of the time with the location of the client (chart 5.5), one can notice that clients at home access support more often than clients in a facility, with the exception of someone to share meals with and someone who can give you help with your daily routine. Another significant difference is that 91.2% of clients at home indicate they have someone who shows them love and affection all or most of the time whereas that rate falls to 67.4% for clients in a facility.

Chart 5.5: **Support available all or most of the time according to client's location**



Now by crossing support available all or most of the time with the type of care (chart 5.6), one can see that clients requiring short-term care indicate they receive support all or most of the time in a higher percentage than clients requiring long-term care.

Chart 5.6: **Support available all or most of the time according to type of care**



5.1.4 Summary: Description of clients

192 clients interviewed:

- 142 females and 50 males
- 78.9% in long-term care
- 72.4% at home
  27.0% in a facility
- half the clients are 75 years and over

139 clients at home:

- 44.9% live alone
  37.0% live with another person
- 81.0% own their home
  12.4% are tenants
- 40.9% of homes need repairs
- 27.9% of homes need major repairs
  22.8% of homes need minor repairs
  49.3% of homes need regular maintenance
- homes owned by clients generally need more major or minor repairs than homes owned by someone else
- 51.4% of homes have required or require modifications following the clients' physical condition

52 clients in a facility:

- 72.5% are alone in their room
- 11.5% of rooms need minor repairs
  84.3% of rooms need regular maintenance and none need major repairs
- 98.0% consider their room and facility to be safe
- 96.2% would recommend their facility to someone else

out of the 192 clients:

- 20.2% indicated their health as excellent or very good
  41.0% as good
  38.9% as fair or poor
- 93.6% are happy with their life
- sleep, diet and physical activities seem to be the factors that most impact health
- 88.8% have someone on whom they can count all or most of the time
- clients at home receive support more often than those in a facility, with the exception of someone to share meals with and someone who gives help with the daily routine
- 91.2% of clients at home indicate they have someone who shows them love and affection all or most of the time
  67.4% of clients in a facility
- clients in short-term care indicate they receive support all or most of the time in a higher percentage than those in long-term care

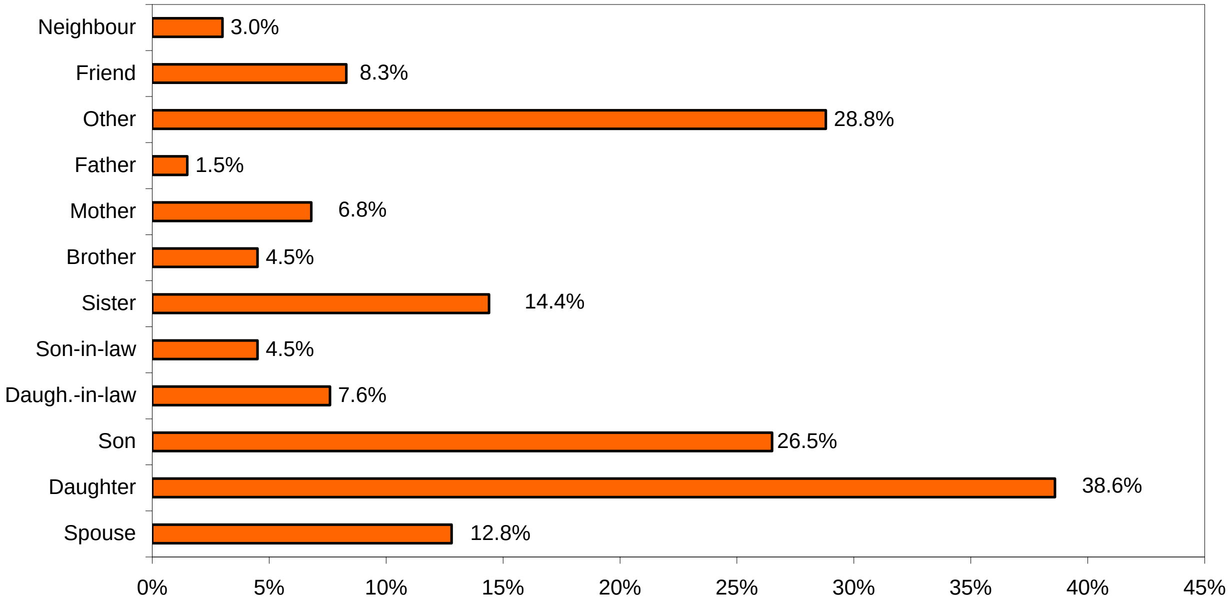
5.2 Use of Continuing Care Services (n = 192)

69.2% of clients interviewed indicated they had a family caregiver, a family member, a friend, a neighbour or any other person who provided them care and/or support outside of the formal care system. 25.1% of clients indicated they did not have anyone and 5.7% of clients indicated they did not know if they had a family caregiver or it did not apply.

At this point it is important to clarify the concept of family caregivers. This terminology refers to a family member, a friend, a neighbour or any other person who provides care and/or support outside of the formal care system. We know there are some paid health professionals among the family caregivers identified by the clients. They are therefore included in the category. Moreover, with the tools used in the data collection, it is impossible to identify the family caregivers who receive remuneration such as provided by DINAC. It is also impossible to know the number of paid and non-paid hours provided by family caregivers. It would be interesting to have future research work cover those issues.

The data presented in chart 5.7 pertains to clients who have indicated they had a family caregiver, which are 132 individuals. The chart shows that in 38.6% of cases the family caregiver is a daughter and in 26.5% of cases a son. The family caregiver is therefore a child of the client in 65.1% of cases.

Chart 5.7: Relationship between family caregiver and client



28.8% of clients however have answered “other”, category which includes niece, nephew, grand-child and paid professional.

60.2% of clients with a family caregiver (n = 132) have been receiving care from that person for over 5 years, 18.1% over 2 years but less than 5, 10.1% 1 to 2 years and 8.7% less than a year. 3.0% do not know or refused to answer.

25.0% of family caregivers (n = 132) live in the same house as their client, 23.5% live very close, 56.1% live in the same community as their client and 2.6% live far. Therefore family caregivers generally live close to their client.

The following table shows the assistance provided to clients by family caregivers. The results presented apply to all the clients, which is 192 individuals. One can see that a higher percentage of family caregivers assist their client with light housekeeping and cleaning, house maintenance and chores outside. A lower percentage of family caregivers assist their client with mobility inside, communication and obtaining a traditional healer.

Table 5.8: Assistance provided by family caregivers

Assistance	
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry	65.1%
House maintenance inside, including minor house repairs, painting, heavier cleaning	60.9%
House maintenance and chores outside, including carrying water or wood, chopping wood, shovelling snow, lawn care	59.8%
Nursing or medical care, including installing prosthesis or orthosis, skin care, foot care, planning or taking medications, any special medical treatments	48.1%
Obtaining medical equipment, medical supplies and medicine	41.7%
Coordinating and arranging medical appointments and medical or nursing services	40.3%
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places	38.7%
Other tasks, such as budgeting, bill payments, completing forms	32.1%
Identifying professionals who could provide services and/or medical equipment	30.4%
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting	28.3%
Eating, including assistance with eating, meal planning, meal preparation	26.7%
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside	15.3%
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services	13.2%
Obtaining traditional healer/traditional medicines	8.3%

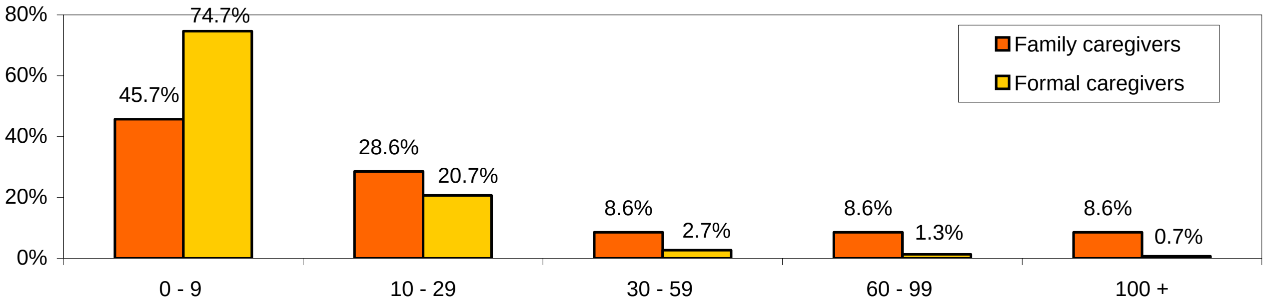
To complete the previous table, the following table presents the individuals assisting the clients with the same activities. It indicates that formal caregivers assist clients in higher percentage with light housekeeping and cleaning as well as with nursing or medical care. When it comes to other tasks, mobility outside the house and house maintenance and chores outside the house, family caregivers provide assistance to the clients. Finally, one can note that in a higher percentage, no one assists clients with communication and mobility inside the house.

Table 5.9: Individuals assisting the clients

	No one	Family caregiver	Formal care system
Eating, including assistance with eating, meal planning, meal preparation	13.5%	15.5%	17.6%
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting	13.0%	9.8%	20.7%
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services	19.7%	5.2%	4.7%
Other tasks, such as budgeting, bill payments, completing forms	11.9%	24.9%	6.2%
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry	2.1%	14.5%	50.3%
House maintenance inside, including minor house repairs, painting, heavier cleaning	7.8%	17.1%	29.0%
House maintenance and chores outside, including carrying water or wood, chopping wood, shovelling snow, lawn care	4.7%	23.8%	24.4%
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside	18.7%	5.7%	8.3%
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places	10.4%	24.9%	19.7%
Nursing or medical care, including installing prosthesis or orthosis, skin care, foot care, planning or taking medications, any special medical treatments	8.3%	6.7%	42.0%
Identifying professionals who could provide services and/or medical equipment	10.9%	7.3%	20.2%
Coordinating and arranging medical appointments and medical or nursing services (including nursing care, physiotherapy, occupational therapy)	11.4%	11.9%	26.4%
Obtaining medical equipment, medical supplies and medicine	8.8%	8.3%	30.6%
Obtaining traditional healer/traditional medicines	13.0%	4.1%	2.1%

The following chart presents the number of hours per week provided by all the family caregivers compared to the number of hours provided by all the formal caregivers. One can see that formal caregivers mostly provide (74.7%) between 0 to 9 hours of care and support per week while a majority of family caregivers, 54.4%, provide 10 hours and over of care and support on a weekly basis. 17.2% of family caregivers provide 60 hours and over of care and support to their client on a weekly basis.

Chart 5.8: Number of hours per week provided by all the family and formal caregivers



5.2.1 Contribution of family caregivers (n = 192)

Family members provide 44.6% of the assistance by family caregivers, other relatives contribute 21.2%, friends 10.4% and volunteers 3.6%. It is therefore in a proportion of 65.8% that family members (close or extended) provide assistance to clients.

The following table shows the number of hours per week provided by the various family caregivers to clients. It is important to note that the non-response rate being very high for this question, the results presented concern only the clients who have answered, which is a small proportion of clients. They must therefore be interpreted with caution. One can see in this table that only the close family members provide 30 hours and more of care and support to their client (28.0%).

Table 5.10: Number of hours per week provided by the various family caregivers

	Family member (n = 86)	Other relative (n = 41)	Friend (n = 20)	Volunteer (n = 7)	Spiritual care (volunteer) (n = o)	Other (n = 9)
0 - 9,9	**48.8%**	**85.4%**	**80.0%**	**71.4%**	**-**	**88.9%**
10 – 29,9	**23.3%**	**14.6%**	**20.0%**	**28.6%**	**-**	**11.1%**
30 – 59,9	**7.0%**	**-**	**-**	**-**	**-**	**-**
60 – 99,9	**10.5%**	**-**	**-**	**-**	**-**	**-**
100 +	**10.5%**	**-**	**-**	**-**	**-**	**-**

The tasks carried out by these family caregivers, such as described by the clients, are presented in the following table. The category "Spiritual care (volunteer)" was deleted since it was not mentioned by anyone. The same caution must be exercised with the results presented in this table.

Table 5.11: Tasks carried out by the various family caregivers

	Family member	Other relative	Friend	Volunteer	Other
Errands, outings	30.0%	6.5%	4.0%	1.0%	1.0%
Socialization	20.0%	5.0%	8.5%	2.6%	0.5%
Housekeeping, laundry	17.0%	3.5%	0.5%	1.0%	1.0%
Meal preparation	16.0%	0.5%	1.6%	-	-
Moral support	9.5%	1.0%	1.0%	-	1.0%
Bath, hygiene	8.5%	-	-	-	0.5%
Budget and paperwork	7.5%	2.1%	-	-	-
House maintenance outside	7.0%	1.0%	-	-	-
Phone calls, getting news	7.0%	1.0%	-	-	1.0%
Accompaniment to medical appointments	5.0%	1.0%	-	-	-
Various tasks as needed	4.5%	2.6%	-	-	-
Repairs	2.6%	-	-	-	-
Assistance with medication	1.6%	0.5%	-	-	1.0%

5.2.2 Contribution of formal caregivers (n = 192)

The home support workers/homemakers provide 50.3% of the assistance by formal caregivers, home care nurses contribute 25.4%, maintenance workers 23.8%, home care aides and foot care nurses 6.7% and physicians 5.2%.

The following table shows the number of hours per week provided by the formal caregivers. As in the previous section, the non-response rate being very high for this question, the results presented concern only the clients who have answered, which is a small proportion of clients. They must therefore be interpreted with caution. One can see that home support workers/homemakers are the caregivers who provide most care with 0 to 9.9 hours per week.

Table 5.12: Number of hours per week provided by the various formal caregivers

	0 – 9.9	10 – 29.9	30 – 59.9	60 – 99.9	100 +
Home support worker/homemaker (n = 97)	76.3%	19.6%	3.1%	1.0%	-
Maintenance (n = 46)	87.0%	13.0%	-	-	-
Home care aide (n = 13)	76.9%	7.7%	-	7.7%	7.7%
Home care nurse (n = 49)	100.0%	-	-	-	-
Foot care (n = 13)	100.0%	-	-	-	-
Public health nurse (n = 8)	100.0%	-	-	-	-
Community worker (n = 7)	100.0%	-	-	-	-
Physician (n = 10)	100.0%	-	-	-	-
Occupational therapist (n = 0)	-	-	-	-	-
Physiotherapist (n = 5)	80.0%	20.0%	-	-	-
Massage therapist (n = 1)	100.0%	-	-	-	-
Social worker (n = 0)	-	-	-	-	-
Traditional healer (n = 0)	-	-	-	-	-
Spiritual care (n = 0)	-	-	-	-	-
Other (n = 8)	87.5%	-	12.5%	-	-

The following table lists the tasks carried out by some of these caregivers, i.e. those mentioned the most by family caregivers. The same caution must be exercised with the results presented in this table.

Table 5.13: Tasks carried out by the various formal caregivers

	Home support worker	Maintenance	Home care aide	Home care nurse
Housekeeping	45.9%	13.1%	2.1%	-
Shopping	7.5%	-	-	-
Meal preparation	5.5%	-	1.6%	-
Bath, hygiene	4.0%	-	5.5%	-
Home maintenance outside	1.6%	12.2%	-	-
Budget	1.6%	-	-	-
Socialize	1.0%	-	-	-
Maintenance	-	4.0%	-	-
Various tasks when needed	-	4.5%	-	-
Vital signs	-	-	-	19.2%
Follow-up and check-up	-	-	-	19.0%
Medication	-	-	-	8.0%
Blood sampling and testing	-	-	-	6.0%
Cutting nails	-	-	-	3.5%
Foot care	-	-	-	-
Blood sugar	-	-	-	3.5%

5.2.3 Other health-related services (n = 192)

22.4% of clients received supplies, devices and other aids (i.e. wheelchair, walker, cane, syringe, dressings, pillows or tissues) in the month preceding to the survey.

Medication was the supply mentioned by the highest number of clients and in over 85.0% of cases they were paid by Health Canada's Non-Insured Health Benefits Program (NIHB). After that come a walker, dressings, vision care, syringes and a cane. The list is completed by a wheelchair, ostomy material (incontinence material) and diabetic foods.

In the month preceding the survey 9.9% of clients have bought (or someone bought it for the client) supplies, devices or aids (for example a walker, cane, syringes, dressings, pillows or tissues) for a value of less than $100. A cane (value between $20 and $37) was the item most often mentioned.

In the twelve months preceding the survey 12.6% of clients have bought (or someone bought it for the client) devices or aids (for example a wheelchair, house renovations, specialized vehicle or special clothing) for a value of more than $100. Items most frequently mentioned by clients were a wheelchair (value of $300), special clothing or shoes (value between $60 and $800) and a walker (value between $300 and $700).

In the month preceding the survey 27.6% of clients were referred to services outside their community. Out of them, 24.5% were referred to a specialist, 18.9% to an eye care specialist, 11.3% for hospitalization, 7.5% to a dentist, 5.7% for foot care and 3.8% to a psychiatrist. The cost of these services varied between $10 and $400. 92.5% of clients who were referred to services outside their community were satisfied with the services received.

5.2.4 Satisfaction with health-related services (n = 192)

Table 5.14 indicates the clients' level of satisfaction with regards to statements pertaining to the care and support provided by family caregivers. The table presents a fairly high level of satisfaction. However, it is important to make a few points concerning these results. Just as with the evaluation of facilities, their departments and their staff, some continuing care workers indicated in the course of discussions that clients' overall satisfaction might, in fact, be lower in reality. It is possible that clients might have feared having their care and services reduced if they expressed their dissatisfaction. Moreover, it is customary for many of these clients to thank the Creator or life for what is provided to them. Finally, many clients might not be aware of all the possibilities in the provincial network, for example. In other words, they do not know what they are missing. Thus indicating they are satisfied does not necessarily mean their needs are met but rather that they are satisfied with what they receive.

In light of these comments, the table indicates that 70.8% of clients always or almost always feel comfortable with the person who provides them care and only 52.3% believe their family feels it's their responsibility to look after them.

Table 5.14: Satisfaction of the clients with regards to statements pertaining to the care and support provided by family caregivers

	Never	Sometimes	Always or almost always
You receive care from someone you feel comfortable with	0.6%	2.8%	70.8%
The people who provide you with care respect, understand and listen to you	0.6%	3.9%	69.1%
The people who provide you with care are sensitive to your needs, beliefs and practices	1.1%	3.4%	68.5%
The care you receive is provided by the right person(s)	0.6%	4.6%	65.3%
The care you need is available at the time you need it	1.7%	11.2%	57.5%
You receive the care/service you need often enough	1.1%	12.3%	57.5%
The length of time that you receive the care is long enough	1.1%	12.0%	56.0%
Your family believes it's their responsibility to look after you	4.0%	7.4%	52.3%

* Clients could choose not to answer or not to know.

Table 5.15 indicates the level of satisfaction of the clients with regards to statements pertaining to the care and support provided by formal caregivers. The level of satisfaction also seems to be high. The points made at the previous table are also valid for this table.

Table 5.15: Satisfaction of the clients with regards to statements pertaining to the care and support provided by formal caregivers

	Never	Sometimes	Always or almost always
You receive care from someone you feel comfortable with	-	6.5%	86.5%
The people who provide you with care respect, understand and listen to you	-	7.1%	85.3%
The people who provide you with care are sensitive to your needs, beliefs and practices	-	6.4%	85.0%
You receive the care/service you need often enough	1.6%	10.2%	81.8%
You are satisfied with the location where the care is provided	1.1%	6.4%	79.7%
You have easy access to the care and services	2.2%	10.2%	78.0%
The care you need is available at the time you need it	2.1%	13.4%	77.0%
The length of time that you receive the care is long enough	3.8%	12.9%	76.3%
You have the means to pay for these care services	12.6%	6.0%	12.6%
You pay for these care services	28.6%	6.0%	10.4%

* Clients could choose not to answer or not to know.

Concerning care from the formal care system, 47.3% of clients indicate they always or almost always have their say on who provides the services whereas 23.4% indicate they never do.

55.1% indicate they always or almost always have their say in what services are provided compared to 13.9% who indicate they never do.

53.5% indicate they always or almost always have their say in when the services are provided, 16.6% indicate they never do.

The following table shows how frequently formal caregivers demonstrate a behaviour that is considered positive by the clients. The latter seem very satisfied with the caregivers' politeness and courtesy whereas they seem more divided concerning the family's involvement in the planning of care.

Table 5.16: Certain behaviours demonstrated by formal caregivers

	Never	Sometimes	Always or almost always
They are polite and courteous	0.5%	4.7%	85.3%
They respect you, understand you and listen to you	0.5%	5.3%	83.7%
They speak the language with which you are most comfortable	0.5%	5.3%	83.6%
They are in a good mood	-	8.9%	81.1%
They do a good job; one that meets your standards	0.5%	11.2%	79.1%
They come when you expect them to	1.1%	10.5%	75.3%
They are willing to help you with things that are not expected, but which you might need	2.1%	10.1%	71.3%
They know when to assist and when to let you do things yourself	1.1%	9.6%	68.6%
The same person comes to provide you with assistance	1.6%	16.6%	65.8%
The helper knows if there are any changes in the kind of care he should be providing	2.7%	10.3%	59.8%
You receive adequate notice of a change in the time or the date the visit was planned	8.7%	12.5%	58.7%
They are skilful in teaching you to look after some of your own needs	4.8%	8.1%	52.7%
The family is involved in the planning of all the care you receive	22.7%	16.0%	34.3%

In the twelve months preceding the survey, 13.4% of clients have experienced difficulties in affording medication, medical supplies and equipment, and 5.4% in affording the direct cost of care and services. Almost none of the clients have had difficulties in obtaining services, being respected, listened to or understood, getting adapted transportation, services in their area and spiritual care/support, arranging transportation and affording its cost, getting traditional care and affording child care costs. Regarding transportation, some continuing care workers seem to say that results do not correspond to reality. While almost all clients have never had any difficulties in getting adapted transportation, arranging transportation and affording its costs, some continuing care workers indicate on the contrary that transportation is a daily challenge for clients.

In the twelve months preceding the survey, 6.3% of clients have refused treatment or service. They have mostly refused treatment or an intervention and to leave their community. The main reasons mentioned are the impossibility to afford the service, the impression of being able to care for oneself, the refusal of medication and not liking the meals provided.

During the same period, 8.4% of clients were refused service or treatment, mainly because of a lack of resources (financial, services or caregivers available), uncertainty regarding the cut of reimbursement of costs and services because of the presence of a family member at home.

5.2.5 Summary: Use of continuing care services

192 clients interviewed:

- 69.2% indicated they had a family caregiver

out of the 132 clients with a family caregiver:

- 38.6% their daughter is the family caregiver
  26.5% their son
  therefore in 65.1% of cases the children are the family caregiver
- 60.2% have been receiving care from that family caregiver for more than 5 years
  18.1% for more than 2 years but less than 5 years
- family caregivers usually live close to their client
- formal caregivers assist clients with light housekeeping, cleaning, nursing or medical care
- family caregivers assist with mobility outside the house and home maintenance and chores outside
- no one assists with communication and mobility inside the house
- 74.7% of formal caregivers contribute 0 to 9 hours per week
  54.4% of family caregivers contribute 10 hours and more per week
  17.2% 60 hours and more per week

out of the 192 clients:

- 44.6% of family caregivers are close family
  21.2% are extended family
- 50.3% of formal caregivers are home care workers/home support aides
  25.4% are home care nurse
  23.8% are maintenance staff
- 22.4% have received supplies, devices and other aids (1 month before the survey)
- medication was mentioned the most
  out of them, 85.0% were paid by Health Canada's NIHB Program
- 27.6% referred to services outside their community (12 months before the survey)
  92.5% were satisfied with the services received

Concerning the care and services provided by the formal care system:

- 47.3% indicate they always or almost always have their say on who will provide the care services
- 55.1% indicate they always or almost always have their say on what services are provided
- 53.5% indicate they always or almost always have their say on when the services are provided
- clients seem very satisfied with the caregivers' politeness and courtesy

- they seem more divided regarding the family's involvement in the planning of the care

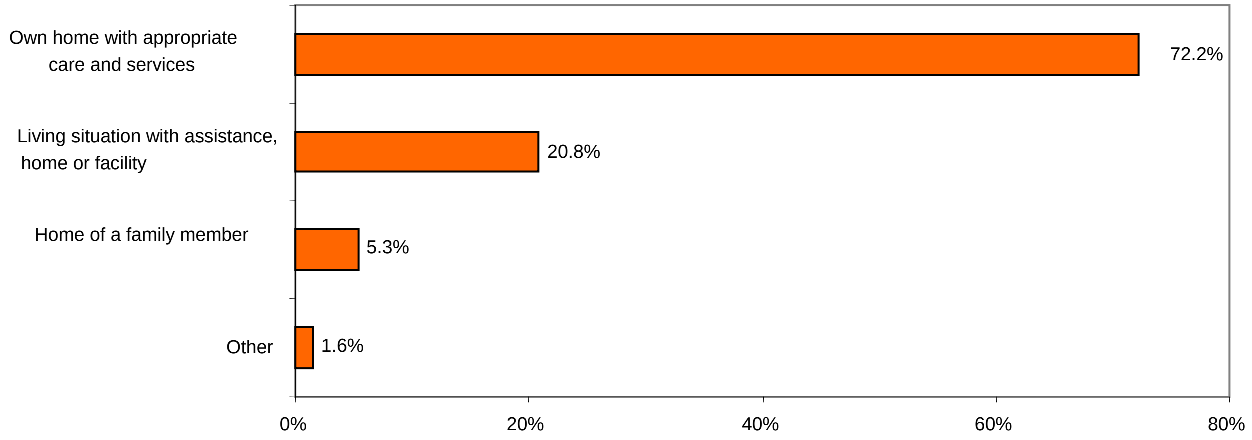
out of the 192 clients:

- 13.4% have experienced difficulties in affording the cost of medication, medical supplies and equipment (12 months before the survey)
- 6.3% have refused services or treatments (12 months before the survey)
  they mainly refused treatments, interventions or to leave the community;
  the causes: not being able to afford the cost, the impression of being able to care for oneself, refusal to take medication or not liking the meals provided (12 months before the survey)
- 8.4% were refused services or treatments;
  the causes: lack of resources, uncertainties regarding the cost being reimbursed or having the services cut because of the presence of a family member at home

5.3 *Perception of Future Needs (n = 192)*

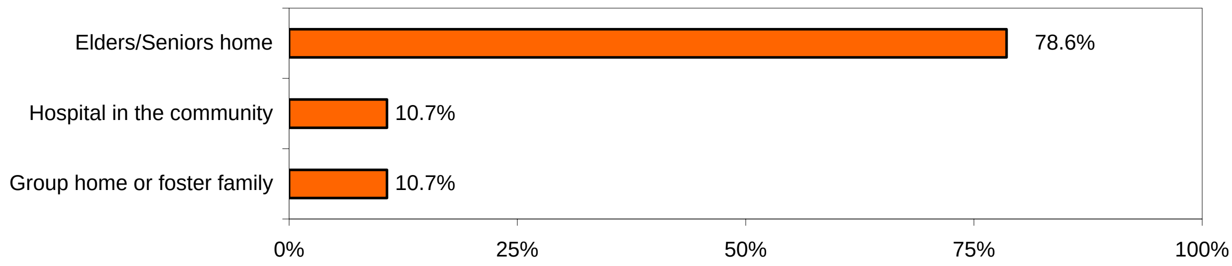
63.2% of clients indicate they know other types of housing than the one in which they live. The following chart shows the place where the client would like to live, if he was given the choice and taking into account his health. The results clearly demonstrate the clients' preference to stay at home with appropriate care and services.

Chart 5.9: Place where the client would like to live, if he was given the choice and taking into account his health



However 20.8% of clients have indicated they would prefer living in an assisted living situation or in a facility. The following chart specifies the nature of these assisted living situations. For information purposes, a personal care home offers some assistance with housekeeping, meals, etc. but essentially the person lives independently. An Elders home/seniors home provides seniors with assistance with activities of daily living, personal care, etc. A group home/foster home generally includes four or fewer people, is part of someone else's home, and that individual provides some assistance with personal care, meals, etc.

Chart 5.10: Preferred type of assisted living situation of clients who have chosen that option



Let it be noted that personal care homes and hospitals outside the community were not selected by clients.

97.3% of clients would prefer to live in their community rather than where services can be easily accessed, (meaning that they would have to live outside their community). Clients therefore prefer by far life in the community to easy access to services.

Table 5.17 shows the clients' preferences regarding the individuals or facilities from whom they would like to receive care and support. Respondents could choose more than one answer.

Table 5.17: Clients' preferences regarding care and support providers

Care and support providers	
Formal care system, community health centre or community hospital	**76.2%**
Family	**63.7%**
Friend	**8.8%**
Neighbour	**4.1%**

67.9% of clients believe there is a need for other types of housing in their community, 20.0% do not and 12.1% do not know or refused to answer. Expanding the existing Elders home, building a home for non-autonomous individuals, housing with easy access for individuals with mobility impairments, apartments for Elders, a respite, support and recovery home, a facility for palliative care and building an Elders care home are the propositions that were made by clients.

If their health were to deteriorate, 36.3% of clients indicated they would wish to stay at home with appropriate care, 22.8% in an Elders home and 22.3% at the hospital (not specified if in or outside the community). 3.1% of clients do not care about the place but would want to stay in the community. 15.5% chose something else.

If they were to need palliative care, 26.9% of clients would want to stay at home, 17.1% in an Elders home, 16.6% at the hospital and 14.0% at the community hospital. 3.6% of clients do not care about the place but would want to stay in the community.

5.3.1 Summary: Perception of future needs

192 clients interviewed:

- 63.2% indicate they know other types of living situations than where they live
- if they were given the choice:
  72.2% of clients would prefer staying at home with appropriate care and services
  20.8% would prefer living in an assisted living situation, in a facility or in a hospital
- 97.3% would want to live in their community rather than where services are easily accessed (involving they would have to leave the community)
- 67.9% believe there is a need for other types of housing in their community
- if their health were to deteriorate:
  36.3% would want to stay at home with appropriate care
  22.8% in an Elders home
  22.3% at the hospital (in or outside the community)
- if they were to need palliative care:
  26.9% would want to stay at home
  17.1% in an Elders home
  16.6% at the hospital
  14.0% at the community hospital

5.4 Clients Aged 0 to 24 Section (n = 4)

In order to maintain the confidentiality of the clients interviewed, respondents aged 0 to 24 are included in this section, which means 4 clients.

5.4.1 Description of clients aged 0 to 24 (n = 4)

Four clients aged 0 to 24 were interviewed, out of which 1 male and 3 females.

Three out of the four questionnaires were completed by the client himself, the other was not specified.

All four clients receive long-term care and live at home.

Three interviews were conducted in English and one in French. One client aged 0 to 24 asked for the assistance of an interpreter.

Three out of the four clients speak, understand and use English most often and one French. Let it be reminded that 3 communities out of the four are English speaking.

At the time of the survey no client aged 0 to 24 had a paid job. At the time of the survey, two clients were receiving a disability pension.

Clients live in households of 3 to 5 persons, including themselves. They all live in a home that they or someone else in the household owns and that is between 15 and 20 years of age. The clients' homes have between 5 and 7 rooms. They all have a refrigerator, a stove (3 propane and 1 electric), electricity, a water line and running water (hot and cold), a flush toilet, garbage collection service, a heating system and telephone. Three out of the four homes have a septic tank or sewage service and two have a sidewalk.

Three out of the four homes need repairs. Two clients aged 0 to 24 indicated that the home where they live needs major repairs, one minor repairs and one that regular maintenance was sufficient. According to them, the bathroom and the floors need repairs.

All those clients' homes required modifications following their physical condition or health problem, such as access ramps, handrails, adapted toilets and showers, secured doors, locks and windows. In the cases where modifications were required but not done, the cost and lack of time are the reasons indicated.

Half of the clients aged 0 to 24 have noticed the presence of mildew in their home. All of them consider their water to be suitable for consumption.

On client aged 0 to 24 described his health as very good, two as good and one as fair.

All four clients indicate that, overall, they are happy with their life. Several things make these clients happy: their family and friends' company, shopping, watching television, playing videogames and the show "Young Adults". Certain things make them unhappy however, such as being with strangers outside of home.

Table 5.18 shows factors that influence health according to clients aged 0 to 24. One can see that sleep and diet are the factors that most influence health according to clients aged 0 to 24. These results are similar to those of clients in general.

Table 5.18: Factors that influence health according to clients aged 0 to 24

Factors	
Sleep / rest / lack of sleep	4/4
Good diet	3/4
Other	2/4
Exercise / regular physical activities / lack of exercise	2/4
Stress / concerns / good stress	1/4
Physical, emotional, mental and spiritual balance	1/4
Médicaments	1/4
Social support	1/4
Emotional well-being	-
Personal bereavement	-
Financial	-
Good sex life	-
Politics	-
Community bereavement	-
Non-voluntary separation from spouse to get into institutional/facility setting	-

Table 5.19 shows the availability of support according to clients aged 0 to 24. It seems good overall, however, one must remember that the sampling is comprised of only 4 persons.

Table 5.19: Availability of support according to clients aged 0 to 24

	All the time	Most of the time	Sometimes	Almost never
Someone who can take you to the doctor	4/4	-	-	-
Someone who shows you love and affection	4/4	-	-	-
Someone on whom you can count	4/4	-	-	-
Someone to share your meals with	4/4	-	-	-
Someone to have good time with	4/4	-	-	-
Someone who can give you help with your daily routine	4/4	-	-	-
Someone who listens when you need to talk	3/3	-	-	-
Someone to take you to church	-	-	1/1	-

* The missing values indicate that one or more clients refused to answer.

5.4.2 Use of continuing care services by clients aged 0 to 24 (n = 4)

All four clients aged 0 to 24 have a family caregiver who has been assisting them for over 5 years. A client identified his mother as his family caregiver, two their parents and one a formal caregiver (present on afternoons).

The following table shows the assistance provided by family caregivers to clients aged 0 to 24. In some cases clients did not answer or answered they did not know.

Table 5.20: Assistance provided by family caregivers to clients aged 0 to 24

Assistance provided	
Nursing or medical care, including installing prosthesis or orthosis, skin care, foot care, planning or taking medications, any special medical treatments	4/4
Obtaining medical equipment, medical supplies and medicine	4/4
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places	4/4
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting	4/4
Eating, including assistance with eating, meal planning, meal preparation	4/4
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services	4/4
House maintenance inside, including minor house repairs, painting, heavier cleaning	2/2
House maintenance and chores outside, including carrying water or wood, chopping wood, shovelling snow, lawn care	2/2
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry	3/4
Other tasks, such as budgeting, bill payments, completing forms	3/4
Identifying professionals who could provide services and/or medical equipment	3/4
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside	3/4
Obtaining traditional healer/traditional medicines	2/4
Coordinating and arranging medical appointments and medical or nursing services	-

To complete the previous table, the following table shows individuals assisting clients aged 0 to 24 with the same activities. Clients could check more than one answer.

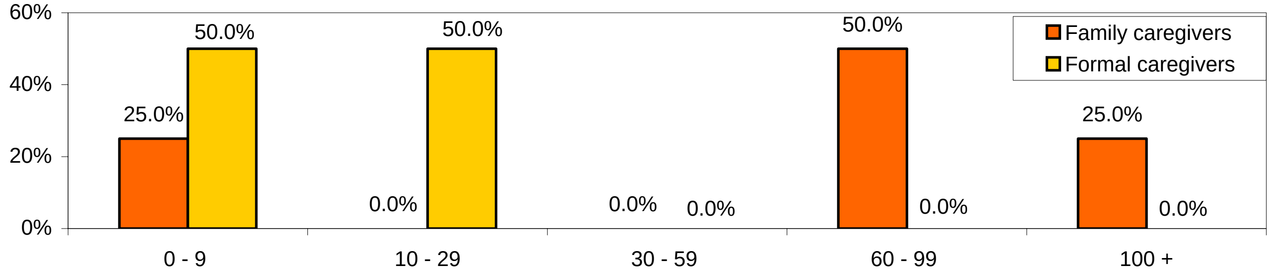
Table 5.21: Individuals assisting clients aged 0 to 24

	No one	Family caregiver	Formal caregiver
Eating, including assistance with eating, meal planning, meal preparation	-	4/4	3/4
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting	-	4/4	3/4
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services	-	3/4	-
Other tasks, such as budgeting, bill payments, completing forms	-	3/4	-
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry	-	3/4	2/4
House maintenance inside, including minor house repairs, painting, heavier cleaning	-	2/4	-
House maintenance and chores outside, including carrying water or wood, chopping wood, shovelling snow, lawn care	-	2/4	-
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside	-	3/4	1/4
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places	-	4/4	-
Nursing or medical care, including installing prosthesis or orthosis, skin care, foot care, planning or taking medications, any special medical treatments	-	4/4	1/4
Identifying professionals who could provide services and/or medical equipment	-	2/4	1/4
Coordinating and arranging medical appointments and medical or nursing services	-	4/4	-
Obtaining medical equipment, medical supplies and medicine	-	4/4	-
Obtaining traditional healer/traditional medicines	-	2/4	-

Compared to clients in general, clients aged 0 to 24 seem to have greater needs in terms of continuing care. In light of the previous tables, family caregivers provide their clients with a fairly wide range of care. Moreover, clients require assistance with each task listed in the tables.

The following chart shows the number of hours per week provided to clients aged 0 to 24 by all the family compared to the number of hours provided by the formal caregivers. One can see that formal caregivers provide 29 hours of care and less per week whereas family caregivers provide three out of the four clients with over 60 hours per week. It is important to remember that the results in this chart apply only to clients aged 0 to 24, which is four individuals. They must therefore be interpreted with caution and cannot be considered representative of all the First Nations.

Chart 5.11: **Number of hours per week provided to clients aged 0 to 24 by all the family and formal caregivers**



Among family caregivers, family members provide most of the care to clients.

The following table shows the number of hours of care and support provided by the various family caregivers to clients aged 0 to 24. It is important to remember that the results in this chart apply only to clients aged 0 to 24, which is four individuals. They must therefore be interpreted with caution and cannot be considered representative of all the First Nations.

Table 5.22: **Number of hours per week provided by the various family caregivers to clients aged 0 to 24**

	Family member	Extended family	Friend	Volunteer	Spiritual care (volunteer)	Other
0 - 9,9	**1/4**	**2/4**	**-**	**-**	**-**	**1/4**
10 – 29,9	**-**	**-**	**-**	**-**	**-**	**-**
30 – 59,9	**-**	**-**	**-**	**-**	**-**	**-**
60 – 99,9	**2/4**	**-**	**-**	**-**	**-**	**-**
100 +	**1/4**	**-**	**-**	**-**	**-**	**-**

The tasks carried out by family members, such as described by clients aged 0 to 24 are, personal care, meal preparation, accompaniment, supervision, assistance with medication and the daily living activities. Regarding the extended family members, they provide assistance when the parents or formal caregivers are not available.

Regarding formal caregivers, home support workers /homemakers provide most of the assistance by the formal care system.

The following table shows the number of hours per week provided by the various formal caregivers to clients aged 0 to 24. Some clients did not answer. The same caution must be applied with this table.

Table 5.23: Number of hours per week provided by the various formal caregivers to clients aged 0 to 24

	0 - 9,9	10 - 29,9	30 - 59,9	60 - 99,9	100 +
Home support workers/homemakers	1/4	2/4	-	-	-
Maintenance	-	-	-	-	-
Home care aide	-	-	-	-	-
Home care nurse	2/4	-	-	-	-
Foot care	-	-	-	-	-
Public health nurse	-	-	-	-	-
Community worker	-	-	-	-	-
Physician	-	-	-	-	-
Occupational therapist	-	-	-	-	-
Physiotherapist	-	-	-	-	-
Massage therapist	-	-	-	-	-
Social worker	-	-	-	-	-
Traditional healer	-	-	-	-	-
Spiritual care	-	-	-	-	-
Other	-	-	-	-	-

The tasks carried out by home support workers/homemakers, such as described by clients aged 0 to 24, are dishwashing, administering medication, personal care, bathing, meal preparation, light housekeeping. Nurses carry out medical tasks and make sure everything goes well for the client.

In the month preceding the survey, 2 clients aged 0 to 24 received supplies, devices or aids (i.e. wheelchair, walker, cane, syringe, dressings, pillows, tissues, etc.). Two did not receive any. Those who did received dressings, syringes, medication and others.

Three clients bought (or someone bought it for them) supplies, devices or aids (walker, cane, syringe, dressings, pillows, tissues, etc.) for a value of less than $100 during the month preceding the survey. One client did not buy any. These purchases also include diapers and specialized clothing for a value of approximately $40.

All of the clients aged 0 to 24 have bought (or someone bought it for them) supplies, devices or aids (walker, cane, syringe, dressings, pillows, tissues, etc.) for a value of more than $100 during the month preceding the survey. These purchases include diapers, specialized clothing and shoes and a wheelchair for a value of approximately $60 to $500.

During the month preceding the survey, two clients were referred to a service outside the community for an appointment in a specialized hospital whereas two were not. Both of them were satisfied with the care received.

Table 5.24 indicates the satisfaction level of clients aged 0 to 24 with regards to certain statements pertaining to the care and support provided by family caregivers. Overall, the table shows a fairly high level of satisfaction, with the exception of respect towards clients and length of care. One must remember though that in the course of discussions, some continuing care workers indicated that the clients' satisfaction might, in fact, be lower in general. It is possible that clients might have feared having their care and services reduced if they expressed their dissatisfaction. Moreover, it is customary for many of these clients to thank the Creator or life for what is provided to them. Finally, many clients might not be aware of all the possibilities in the provincial network, for example. In other words, they do not know what they are missing. Thus indicating they are satisfied does not necessarily mean their needs are met but rather that they are satisfied with what they receive.

Table 5.24: Satisfaction of clients aged 0 to 24 with regards to statements pertaining to the care and support provided by family caregivers

	Never	Sometimes	Always or almost always
You receive care from someone you feel comfortable with	-	-	4/4
The people who provide you with care are sensitive to your needs, beliefs and practices	-	-	4/4
The care you receive is provided by the right person(s)	-	-	4/4
The care you need is available at the time you need it	-	-	4/4
You receive the care/service you need often enough	-	-	4/4
Your family believes it's their responsibility to look after you	-	-	4/4
The people who provide you with care respect, understand and listen to you	-	2/4	2/4
The length of time that you receive the care is long enough	-	2/4	2/4

Table 5.25 indicates the satisfaction level of clients aged 0 to 24 with regards to certain statements pertaining to the care and support provided by formal caregivers. The satisfaction level also seems fairly high.

Table 5.25: Satisfaction of clients aged 0 to 24 with regards to statements pertaining to the care and support provided by formal caregivers

	Never	Sometimes	Always or almost always
You receive care from someone you feel comfortable with	-	-	4/4
The people who provide you with care respect, understand and listen to you	-	-	4/4
The people who provide you with care are sensitive to your needs, beliefs and practices	-	-	4/4
You receive the care/service you need often enough	-	-	4/4
You are satisfied of the place where the care is provided	-	-	3/4
The care and services are easily accessed	-	1/4	3/4
The care you need is available at the time you need it	-	1/4	3/4
The length of time that you receive the care is long enough	-	1/4	3/4
You can afford the care	-	-	2/4
You pay for the care	-	-	2/4

*In some cases, clients did not answer.

Still concerning the care provided by the formal care system, 2 clients aged 0 to 24 indicate they always or almost always have their say on who will provide them with services and what services will be provided, 1 client indicates he never does and 1 does not know. One client indicates he always or almost always has his say on when the services will be provided whereas three indicate they sometimes do.

The following table shows how frequently formal caregivers demonstrate a behaviour that is considered positive by clients aged 0 to 24. Overall, formal caregivers always or almost always demonstrate the behaviours mentioned according to clients, with the exception of adequate notice of a change in the time or date the visit is planned, for which opinions are divided.

Table 5.26: Certain behaviours demonstrated by formal caregivers according to clients aged 0 to 24

	Never	Sometimes	Always or almost always
They are polite and courteous	-	-	4/4
They respect you, understand you and listen to you	-	-	4/4
They speak the language with which you are most comfortable	-	-	4/4
They are in a good mood	-	-	4/4
They do a good job; one that meets your standards	-	-	4/4
The same person comes to provide you with assistance	-	-	4/4
The helper knows if there are any changes in the kind of care he should be providing	-	-	4/4
The family is involved in the planning of all the care you receive	-	-	4/4
They come when you expect them to	-	1/4	3/4
They are willing to help you with things that are not expected, but which you might need	-	-	3/4
They know when to assist and when to let you do things yourself	-	-	3/4
They are skilful in teaching you to look after some of your own needs	-	-	3/4
You receive adequate notice of a change in the time or the date the visit was planned	-	2/4	2/4

In the 12 months preceding the survey, one out of the four clients aged 0 to 24 experienced difficulties in getting adapted transportation, affording the cost of medication, medical supplies and equipment and care services, being respected, listened to and understood and in getting spiritual care and support. Once again, one has to remember that concerning transportation, some continuing care workers indicate that the results might not correspond to reality. Some of them indicate that transportation is a significant challenge for clients.

One client refused services or treatments in the 12 months preceding the survey and three did not refuse any. One client was refused services or treatments in the 12 months preceding the survey, three were not refused any.

5.4.3 Perception of future needs according to clients aged 0 to 24 (n = 4)

Three clients aged 0 to 24 indicate they know other types of housing, one not.

If they were given the choice, two clients would like to live in their own home with appropriate care and services, one client would like to live in a family member's home and one in a home or a facility.

Three clients aged 0 to 24 indicate they prefer living in their community rather than where services are easily accessed, involving they have to live outside the community. One client prefers having easy access to services.

Table 5.27 shows the preferences of clients aged 0 to 24 regarding the individuals or facilities from which they would like to receive care and support. Respondents could check more than one answer. Conversely to client in general, clients aged 0 to 24 seem to indicate they prefer to have their family provide them with care and support. One must however exercise caution in the interpretation of these results considering the difference in the size of the sampling (n = 192 and n = 4).

Table 5.27: Preferences of clients aged 0 to 24 concerning care and support providers

Care and support providers	
Family	**4/4**
Formal care system, community health centre, community hospital	**2/4**
Friend	**1/4**
Neighbour	**1/4**

All of the clients aged 0 to 24 indicated there was a need for other types of housing in their community. The options proposed include a respite or support home and a facility for people with severe illnesses or chronic conditions.

If their health were to deteriorate, one client would like to receive services and care at the community hospital, one client in a house where he could receive adequate care and services and one client would like to remain at home with appropriate care and services. One client did not know.

If they were to need palliative care, one client would like to go to the hospital, two clients would like to remain in their home and one did not know.

One client adds he hopes the show "Young Adults" stays because it helps clients socialize and families get help.

5.4.4 Functional status of clients aged 0 to 24 (n = 4)

Activities of daily living

Concerning activities of daily living, three clients aged 0 to 24 must be fed, washed and dressed by another person, do not participate in their grooming, suffer from total or partial urinary incontinence and require assistance to use the toilet.

Table 5.28: Ability to feed oneself of clients aged 0 to 24

Feeds self independently	-
Feeds self with difficulty	1/4
Feeds self but needs stimulation or supervision or food must be prepared or cut or pureed first	-
Needs some assistance to eat or dishes must be presented one after another	-
Must be fed totally by another person or has a naso-gastric tube or a gastrostomy	3/4

Table 5.29: Ability to wash oneself of clients aged 0 to 24

Washes self independently	-
Washes self with difficulty	-
Washes self but needs cueing or needs supervision or needs preparation or needs help for the complete weekly bath only (including washing feet and hair)	1/4
Needs help for the daily wash but participates actively	-
Must be washed by another person	3/4

Table 5.30: Ability to dress oneself of clients aged 0 to 24

Dresses self independently	-
Dresses self with difficulty	-
Dresses self but needs cueing or needs supervision or clothing must be prepared and presented or needs help for finishing touches only (buttons, laces)	1/4
Needs help dressing	-
Must be dressed by another person	3/4

Table 5.31: Ability to groom oneself of clients aged 0 to 24

Grooms self independently	-
Grooms self with difficulty	-
Needs cueing or needs supervision for grooming	1/4
Needs some assistance for grooming	-
Must be groomed by another person	3/4

Table 5.32: Status of urinary function of clients aged 0 to 24

Normal voiding	1/4
Occasional incontinence or dribbling or needs frequent cueing to avoid incontinence	-
Frequent urinary incontinence	-
Complete and habitual urinary incontinence or wears an incontinence pad or an indwelling catheter or a urinary condom	3/4

Table 5.33: Status of bowel function of clients aged 0 to 24

Normal bowel function	1/4
Occasional incontinence or needs cleansing enema occasionally	1/4
Frequent incontinence or needs cleansing enema regularly	1/4
Always incontinent or wears an incontinence pad or an ostomy	1/4

Table 5.34: Ability to use the toilet of clients aged 0 to 24

Uses toilet independently	1/4
Uses toilet with difficulty	-
Needs supervision for toileting or uses commode, urinal or bedpan	-
Needs help using toilet, commode, bedpan or urinal	3/4
Does not use toilet, uses commode, bedpan or urinal	-

Mobility

Concerning mobility, none of the four clients aged 0 to 24 wears a prosthesis or orthosis. Three out of the four clients require assistance to get up, sit and get in bed, require a simple cane, tripod, quadripod or walker to walk inside and must be transported on a stretcher to get around outside. Three out of the four clients do not negotiate stairs.

Table 5.35: Autonomy in transfers of clients aged 0 to 24

Gets in and out of bed independently	1/4
Gets in and out of bed with difficulty	-
Gets in and out of bed/chair independently, but needs cueing, supervision or guidance	-
Needs help to get in and out of bed/chair	3/4
Bedridden (must be lifted in and out of bed)	-

Table 5.36: Autonomy to walk inside, clients aged 0 to 24

Walks independently (with or without cane, prosthesis, orthosis or walker)	1/4
Walks independently with difficulty	-
Walks independently but needs guidance, cueing or supervision in certain circumstances or has an unsafe gait	-
Needs help of another person to walk	-
Does not walk without a simple cane, tripod, quadripod or walker	3/4

Table 5.37: Ability to install prosthesis or orthosis of clients aged 0 to 24

Does not wear prosthesis or orthosis	4/4
Installs prosthesis or orthosis independently	-
Installs prosthesis or orthosis with difficulty	-
Installing of prosthesis or orthosis needs checking or needs some assistance	-
Prosthesis or orthosis must be installed by another person	-

Table 5.38: Ability to propel oneself in a wheelchair inside, clients aged 0 to 24

Does not need a wheelchair	1/4
Propels wheelchair independently	
Propels wheelchair with difficulty	
Needs to have wheelchair pushed	1/4
Unable to use wheelchair (must be transported on stretcher)	2/4

Table 5.39: Ability to negotiate stairs of clients aged 0 to 24

Goes up and down stairs independently	1/4
Goes up and down stairs with difficulty	-
Requires cueing, supervision or guidance to negotiate stairs or does not safely negotiate stairs	-
Needs help of another person to go up and down stairs	-
Does not negotiate stairs	3/4

Table 5.40: Ability to get around outside, clients aged 0 to 24

Walks independently (with or without cane, prosthesis, orthosis or walker)	1/4
Walks independently with difficulty	-
Uses a wheelchair or three/four-wheeled scooter independently or walks independently but needs guidance, cueing or supervision in certain circumstances or has an unsafe gait	-
Needs help of another person to walk or to use wheelchair	-
Cannot move around outside (must be transported on a stretcher)	3/4

Communication

Concerning communications, all four clients aged 0 to 24 hear adequately with or without a hearing aid. Regarding vision and speech, the results vary.

Table 5.41: Vision of clients aged 0 to 24

Sees adequately with or without corrective lenses	2/4
Vision problems but sees enough for ADLs	2/4
Only sees outlines of objects and needs guidance in ADLs	-
Blind (corrective lenses or magnifying glass)	-

Table 5.42: Hearing of clients aged 0 to 24

Hears adequately with or without hearing aid	4/4
Hears if spoken to in a loud voice or needs hearing aid put in by another person	-
Only hears shouting or certain words or reads lips or understands gestures	-
Completely deaf and unable to understand what is said to him (hearing aid)	-

Table 5.43: Speech of clients aged 0 to 24

Speaks normally	2/4
Has a speech/language problem but is able to express himself	-
Has a major speech/language problem but able to express basic needs or answer simple questions (yes, no) or uses sign language	1/4
Does not communicate (technical aid by computer or communication board)	1/4

Mental functions

Overall, the mental functions of all four clients aged 0 to 24 are normal. Three out of the four clients demonstrate adequate behaviour and two out of three clients have a normal memory and orientation.

Table 5.44: Memory of clients aged 0 to 24

Normal memory	2/3
Minor recent memory deficit (names, appointments, etc.) but remembers important facts	-
Serious memory lapses (shutting off stove, taking medications, putting things away, eating, visitors, etc.)	-
Almost total memory loss or amnesia	1/3

*One value is missing.

Table 5.45: Orientation of clients aged 0 to 24

Well oriented to time, space and persons	2/3
Sometimes disoriented to time, space and persons	-
Only oriented for immediate events (e.g., time of day) and in the usual living environment and with familiar persons	1/3
Complete disorientation	-

*One value is missing.

Table 5.46: Comprehension of clients aged 0 to 24

Understands instructions and requests	2/4
Slow to understand instructions and requests	1/4
Partial understanding even after repeated instructions or is incapable of learning	1/4
Does not understand what goes on around him	-

Table 5.47: Judgment of clients aged 0 to 24

Evaluates situations and makes sound decisions	1/4
Evaluates situations but needs help in making sound decisions	1/4
Poorly evaluates situations and only makes sound decisions with strong suggestions	1/4
Does not evaluate situations and is dependent on others for decision making	1/4

Table 5.48: Behaviour of clients aged 0 to 24

Appropriate behaviour	3/4
Minor behavioural problems (whimpering, emotional lability, stubbornness, apathy) requiring occasional supervision or a reminder or stimulation	-
Major behaviour problems requiring more intensive supervision (aggressive towards self or others, disturbs others, wanders, yells out constantly)	1/4
Dangerous, requires restraint or harmful to others or self-destructive or tries to run away	-

Instrumental activities of daily living

Concerning instrumental activities of daily living, none of the four clients aged 0 to 24 does the housekeeping, meal preparation, shopping, laundry, manage a budget or his medication.

Table 5.49: Ability to do housekeeping of clients aged 0 to 24

Does housekeeping alone (including daily housework and occasional heavy jobs)	-
Does housekeeping with difficulty	-
Does housekeeping (including washing the dishes) but needs cueing or supervision to ensure cleanliness or needs help for occasional heavy jobs (floors, windows, painting, lawn, shoveling snow, etc.)	-
Needs help for daily housework	-
Does not do housework	4/4

Table 5.50: Ability to prepare meals of clients aged 0 to 24

Prepares own meals independently	-
Prepares own meals with difficulty	-
Prepares meals but needs cueing to maintain adequate nutrition	-
Only prepares light meals or reheats pre-prepared meals (including handling the plates)	-
Does not prepare meals	4/4

Table 5.51: Ability to do shopping of clients aged 0 to 24

Plans and does shopping independently (e.g., food, clothes, etc.)	-
Plans and does shopping with difficulty	-
Plans and shops independently but needs a delivery service	-
Needs help to plan or to shop	-
Does not shop	4/4

Table 5.52: Ability to do laundry of clients aged 0 to 24

Does all laundry independently	-
Does laundry independently with difficulty	-
Does laundry but needs cueing or supervision to maintain standards of cleanliness	-
Needs help to do laundry	-
Does not do laundry	4/4

Table 5.53: Ability to use the phone of clients aged 0 to 24

Uses telephone independently (including the use of a directory)	-
Uses telephone and directory with difficulty	-
Answers telephone but only dials a few memorized numbers or emergency numbers	-
Communicates by telephone but does not dial numbers or lift the receiver off the hook	1/4
Does not use the telephone	3/4

Table 5.54: Ability to use transportation of clients aged 0 to 24

Able to use transportation alone (car, adapted vehicle, taxi, bus, etc.)	-
Able to use transportation alone with difficulty	1/4
Must be accompanied to use transportation or uses paratransit independently	-
Uses car or paratransit only if accompanied and has help getting in and out of the vehicle	1/4
Must be transported on a stretcher	2/4

Table 5.55: Ability to take own medication of clients aged 0 to 24

Takes medication unaided according to prescription or does not need medication	-
Takes medication with difficulty	-
Needs supervision (including supervision form afar) to ensure compliance to prescription or uses a medication dispenser aid (prepared by someone else)	-
Takes medication if prepared daily	-
Must be given each dosage of medication, as prescribed (medication dispenser aid)	4/4

Table 5.56: Ability to manage own budget of clients aged 0 to 24

Manages budget independently (including banking)	**-**
Manages budget with difficulty	**-**
Needs help for certain major transactions	**-**
Needs help for some regular transactions (cashing checks, paying bills) but uses pocket money wisely	**-**
Does not manage budget	**4/4**

Level of autonomy

By compiling the data from the questionnaire on the clients' functional status, seven categories were created, based on the functional autonomy measurement system (SMAF), in order to measure the clients' level of autonomy. Category 1 represents clients with the highest level of autonomy and category 7 clients with the lowest level of autonomy. Clients in categories 3 and 4 have an average level of autonomy. Table 5.57 shows the categorization of levels of autonomy of clients aged 0 to 24. One can see that all four clients aged 0 to 24 have a low or very low level of autonomy since they are in categories 5 to 7.

Table 5.57: Categorization of the autonomy level of clients aged 0 to 24

Category 1	**-**
Category 2	**-**
Category 3	**-**
Category 4	**-**
Category 5	**1/4**
Category 6	**2/4**
Category 7	**1/4**

5.4.5 Summary: Clients aged 0 to 24 section

4 clients aged 0 to 24 interviewed:

- 1 male and 3 females
- 4 clients in long-term care
- 4 clients at home

- 3 homes need repairs
- 2 homes need major repairs
  1 minor repairs
  1 regular maintenance
- 4 homes have had modifications following the client's health problem or physical condition

- 1 client aged 0 to 24 described his health as very good
  2 as good
  1 as fair
- 4 clients indicate they are happy with their life
- sleep and diet are the factors that most influence health according to these clients

4 clients aged 0 to 24 have had a family caregiver who assists them for over 5 years:

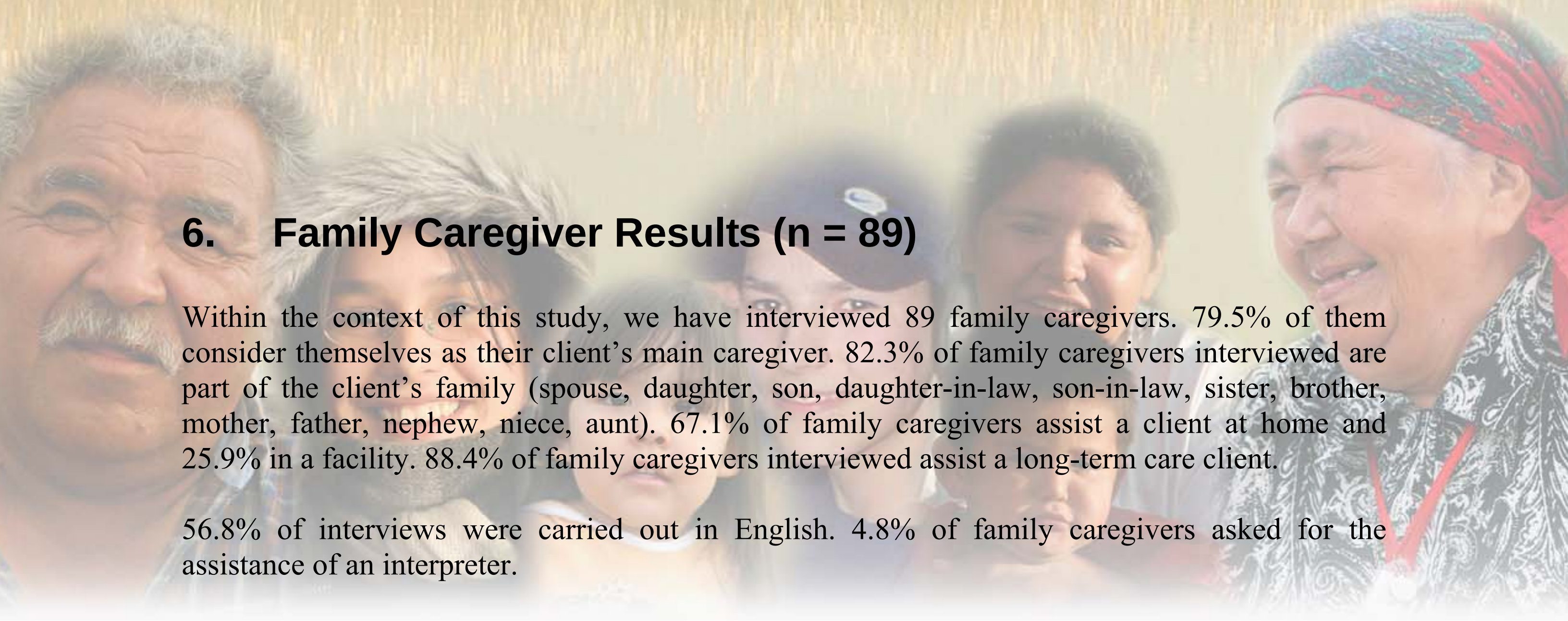
- 1 identified his mother as his family caregiver
  2 their parents
  1 a formal caregiver
- family caregivers provide their clients with a fairly wide range of care
- formal caregivers provide 29 hours of care and less per week
  3 out of the 4 family caregivers provide over 60 hours of care per week
- family members provide most of the assistance by family caregivers
  the tasks carried out are personal care, meal preparation, accompaniment, supervision, assistance with taking medication and assistance in activities of daily living
- home support workers/homemakers provide most of the assistance by formal caregivers
  the tasks carried out are dishwashing, administering medication, personal care, bathing, meal preparation and light housekeeping

- 2 clients aged 0 to 24 were referred to a service outside the community
  (12 months before the survey)
- concerning the care provided by the formal care system:
  2 clients indicate they always or almost always have their say on who will provide services
  2 indicate they always or almost always have their say on what services are provided
  1 indicates he always or almost always has his say on when services are provided
- 1 client refused services or treatments (12 months before the survey)
- 1 was refused services or treatments (12 months before the survey)

- 3 clients aged 0 to 24 indicate they know other types of housing
- if they were given the choice:
  2 would like to live in their own home with appropriate care and services
  1 would like to live at a family member’s home
  1 in a home or a facility
- 3 clients indicated they prefer living in their community rather than where services are easily accessed, involving that they must live outside the community
- 4 clients indicated there was a need for other types of housing in their community
- if their health were to deteriorate:
  1 client would like to receive care and services at the community hospital
  1 in a house where he could receive adequate care and services
  1 would like to remain at home with appropriate care and services
- if they were to need palliative care:
  1 client would like to go to the hospital
  2 would like to remain in their own home

Concerning the functional status of clients aged 0 to 24:

- activities of daily living:
  3 clients must be fed, washed and dressed by another person, do not participate in their grooming, suffer from total or partial urinary incontinence and require assistance to use the toilet
- mobility:
  3 clients require assistance to get up, sit and get in bed, need a simple cane, tripod, quadripod or walker to walk inside and must be transported on a stretcher to get around outside
  3 do not negotiate stairs
- communications:
  4 clients hear adequately with or without a hearing aid
  concerning vision and speech, the results vary
- mental functions:
  4 clients have normal mental functions
  3 have adequate behaviour
  2 have normal memory and orientation
- activities of daily living:
  no client does the housekeeping, meal preparation, shopping, laundry, budget or takes his own medication
- 4 clients have a low or very low level of autonomy: they are in categories 5 to 7



6. Family Caregiver Results (n = 89)

Within the context of this study, we have interviewed 89 family caregivers. 79.5% of them consider themselves as their client's main caregiver. 82.3% of family caregivers interviewed are part of the client's family (spouse, daughter, son, daughter-in-law, son-in-law, sister, brother, mother, father, nephew, niece, aunt). 67.1% of family caregivers assist a client at home and 25.9% in a facility. 88.4% of family caregivers interviewed assist a long-term care client.

56.8% of interviews were carried out in English. 4.8% of family caregivers asked for the assistance of an interpreter.

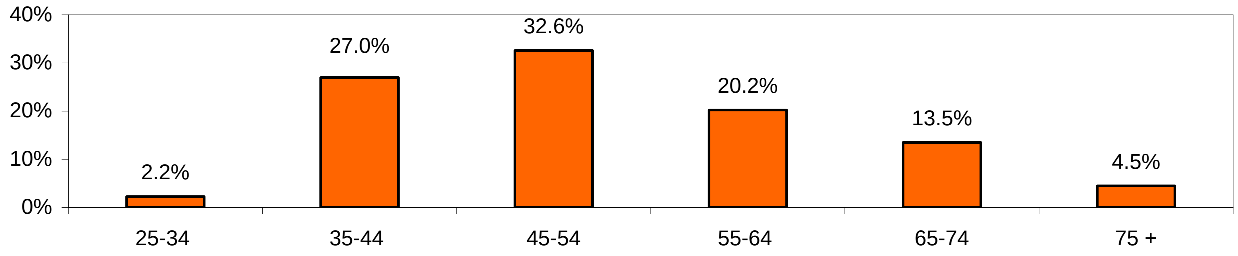
Let it be noted that 27.6% of clients refused to give the name of their family caregiver. Out of all the family caregivers whose names were transmitted, 18.2% could not be interviewed due to a lack of time, availability or contact established.

6.1 Description of Family Caregivers Interviewed (n = 89)

73.0% of family caregivers interviewed are females.

As the following chart shows, 61.8% of family caregivers are less than 55 years old.

Chart 6.1: Breakdown of family caregivers according to age group

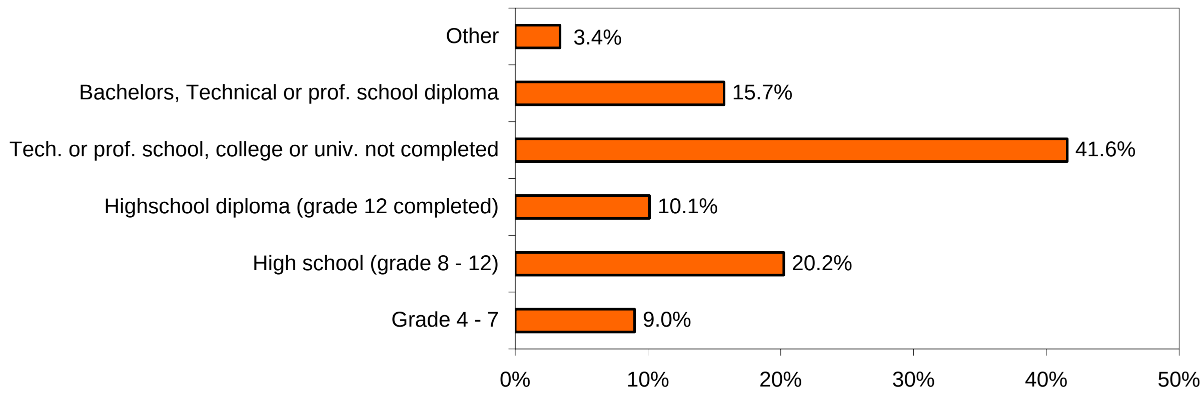


65.2% of family caregivers speak English and 70.1% speak French. 9.0% of family caregivers speak Algonquian and 25.8% Mohawk.

71.9% of family caregivers understand English and 77.5% understand French. 7.9% of family caregivers understand Algonquian and 27.0% Mohawk.

Regarding the language used on a daily basis, 58.4% use English and 44.9% French. 4.5% use Algonquian and 11.2% Mohawk.

Chart 6.2: Breakdown of family caregivers according to level of schooling



64.0% of family caregivers interviewed had a paid job at the time of the survey. 38.2% of them work 35 hours per week and 22.8% work 40 hours per week. 29.1% work less than 35 hours per week and 7.2% work between 45 and 80 hours per week. 2.7% do not know or refused to answer.

In the twelve months preceding the survey, 56.2% of family caregivers received an income from a paid job, 12.4% from a retirement program, pension, retirement pension or benefits, 11.2% from basic old age benefits or child tax benefit, 9.0% from income security (social assistance) and 6.7% from Quebec or Canada pension plan benefits. The other family caregivers received an income from elsewhere or did not receive any.

30.7% of family caregivers interviewed have dependent children. Out of them, 38.5% have one dependent child, 50.0% have two, 3.8% have three and 7.7% have four dependent children.

Table 6.1 shows the impacts of the family caregiver's involvement on his professional life. 23.6% of family caregivers have had to leave their job suddenly to take care of their client and 22.5% have had to take time off work to assist the client with receiving care.

Table 6.1: Impacts of the family caregiver's involvement on his professional life

	Yes	No
Has had to leave job suddenly to take care of the client	23.6%	43.8%
Has had to take time off work to assist client with receiving care	22.5%	46.1%
Performance at work was affected	11.2%	56.2%
Has considered quitting job	8.0%	64.8%
Has lost wages because of helping client	6.7%	59.6%
Has had to change job situation (status, number of hours)	5.6%	68.5%
Has had to change place of residence	5.6%	89.9%
Has had to quit job	1.1%	68.2%
Has had to change jobs or employer	1.1%	73.0%

*Clients could choose not to answer or not to know.

6.1.1 Summary: Description of family caregivers interviewed

89 family caregivers interviewed:

- 79.5% consider themselves as their client's main caregiver
- 82.3% are part of the client's family (spouse, daughter, son, daughter-in-law, son-in-law, sister, brother, mother, father, nephew, niece, aunt)
- 67.1% assist a client at home
- 88.4% of family caregivers interviewed assist a client in long-term care
- 73.0% are females
- 61.8% are less than 55 years old
- 64.0% had a paid job at the time of the survey
- 30.7% have dependent children
- out of them, 38.5% have one dependent child
  50.0% have two dependent children
- 23.6% of family caregivers have had to leave their job suddenly to take care of their client
- 22.5% have had to take time off work to assist their client in receiving care

6.2 Service Delivery (n = 89)

79.5% consider themselves as their client's main family caregiver. 50.0% of family caregivers who indicated they were not their client's main family caregiver indicated the client's children were the main family caregivers, 18.8% that another person was, 12.5% the client's sister and 6.3% the husband, brother or a friend.

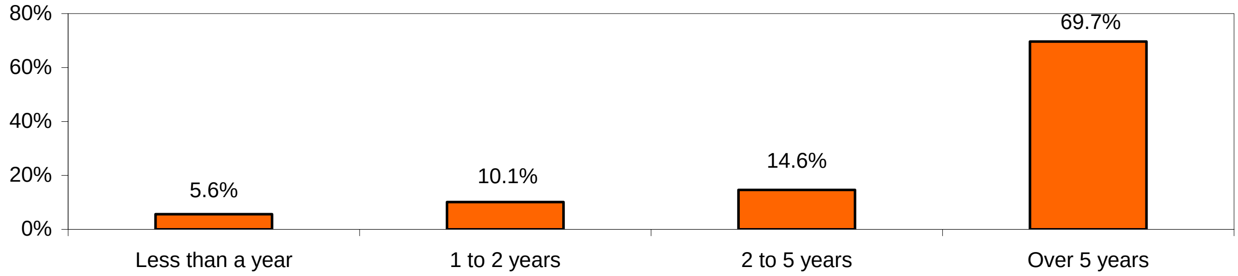
92.1% of family caregivers receive help with the provision of care and support to their client. 31.7% of the latter receive help from the client's son, 28.0% from the sister, 25.6% from a person from the formal care system, 17.1% from the daughter or the brother, 15.9% from another relative and 8.5% from a friend.

37.1% of family caregivers provide care to other people (not including the client targeted in this survey). Out of them, 21.9% provide care to one other person, 18.8% to two other persons, 9.4% three other persons and 6.3% five to six other persons.

30.3% of family caregivers live in the same house as their client, 22.5% live very close and 41.6% live in the same community. Only 5.6% live far away.

Based on the following graph, 69.7% of family caregivers have been providing their client with care for over 5 years.

Chart 6.3: Number of years of care and support provided by the family caregiver to the client



6.2.1 Summary: Service delivery

89 family caregivers interviewed:

- 92.1% receive help with the provision of care and support to their client
- 37.1% provide care to other people (not including the client targeted in this survey)
- 30.3% live in the same house as their client
  22.5% live very close
  41.6% live in the same community
- 69.7% have been providing their client with care for over 5 years

6.3 Type of Care Provided (n = 89)

The following table shows the assistance received by the client according to the family caregiver. One can see that family caregivers provide most of the assistance with light housekeeping or cleaning and least of the assistance with obtaining care from a traditional healer or traditional medicines.

Table 6.2: Assistance received by the client according to the family caregiver

Assistance	
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry	85.2%
House maintenance inside, including minor house repairs, painting, heavier cleaning	71.1%
House maintenance and chores outside, including carrying water or wood, chopping wood, shovelling snow, lawn care	68.4%
Nursing or medical care, including installing prosthesis or orthosis, skin care, foot care, planning or taking medications, any special medical treatments	67.0%
Obtaining medical equipment, medical supplies and medicine	63.5%
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places	62.9%
Coordinating and arranging medical appointments and medical or nursing services	58.0%
Identifying professionals who could provide services and/or medical equipment	56.1%
Other tasks, such as budgeting, bill payments, completing forms	52.3%
Eating, including assistance with eating, meal planning, meal preparation	46.1%
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting	40.9%
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services	27.3%
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside	24.7%
Obtaining traditional healer/traditional medicines	9.7%

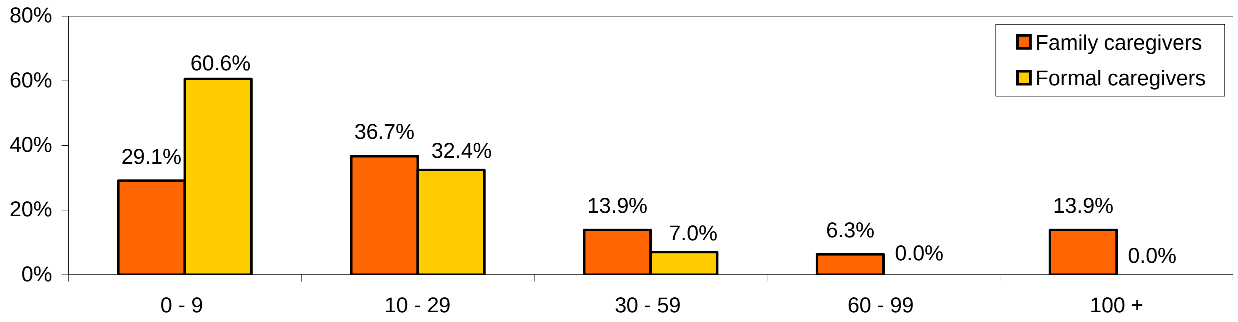
To complete the previous table, the following table presents the individuals assisting the clients with the same activities.

Table 6.3: Individuals assisting the client according to the family caregiver

	No one	Family caregiver	Formal caregiver
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places	5.6%	48.3%	29.2%
Other tasks, such as budgeting, bill payments, completing forms	13.6%	47.7%	6.8%
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry	5.7%	38.6%	63.6%
House maintenance inside, including minor house repairs, painting, heavier cleaning	9.2%	36.8%	23.7%
House maintenance and chores outside, including carrying water or wood, chopping wood, shovelling snow, lawn care	9.2%	36.8%	27.6%
Coordinating and arranging medical appointments and medical or nursing services	13.6%	27.3%	36.4%
Eating, including assistance with eating, meal planning, meal preparation	11.2%	27.0%	28.1%
Obtaining medical equipment, medical supplies and medicine	8.2%	20.0%	48.2%
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services	23.9%	19.3%	11.4%
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting	17.0%	17.0%	26.1%
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside	25.8%	12.4%	11.2%
Nursing or medical care, including installing prosthesis or orthosis, skin care, foot care, planning or taking medications, any special medical treatments	5.7%	11.4%	60.2%
Identifying professionals who could provide services and/or medical equipment	15.9%	11.0%	43.9%
Obtaining traditional healer/traditional medicines	21.0%	8.1%	3.2%

The following chart shows the number of hours per week provided by all the family caregivers compared to the number of hours per week provided by all the formal caregivers, according to the family caregiver interviewed. One can see that 60.6% of formal caregivers provide 0 to 9 hours of care and support per week. Regarding family caregivers, almost three quarters of them, 70.8%, provide 10 hours of care and more per week. 20.2% of family caregivers provide 60 hours of care and more per week, according to the family caregiver respondent.

Chart 6.4: **Number of hours per week provided by all the family and formal caregivers according to the family caregiver interviewed**



6.3.1 Contribution of family caregivers (n = 89)

The family caregiver respondents provide 38.3% of the assistance to clients, other family members provide 22.3% of the assistance, other relatives, 11.9%, and friends 7.3%.

The following table shows the number of hours per week provided by the various family caregivers for the care and support to clients, according to the family caregiver interviewed. It is important to note though that the level of non-response to this question being very high, the results presented can only concern the family caregivers who have answered, which is a small proportion of family caregivers. They must therefore be interpreted with caution.

Table 6.4: **Number of hours per week provided by the various family caregivers according to the family caregiver**

	Family caregiver respondent (n = 74)	Other family member (n = 43)	Other relative (n = 23)	Friend (n = 14)	Volunteer (n = 1)	Spiritual care (volunteer) (n = 2)	Other (n = 3)
0 - 9,9	52.7%	76.7%	91.3%	78.6%	100.0%	100.0%	33.3%
10 – 29,9	20.3%	14.0%	4.3%	21.4%	-	-	33.3%
30 – 59,9	10.8%	4.7%	4.3%	-	-	-	33.3%
60 – 99,9	6.8%	2.3%	-	-	-	-	-
100 +	9.5%	2.3%	-	-	-	-	-

The tasks carried out by family caregivers, such as described by family caregivers, are presented in the following table. The categories “Volunteer” and “Spiritual care (volunteer)” were deleted since they had been mentioned by very few family caregivers. The same caution must be exercised with the results presented in this table.

Table 6.5: Tasks carried out by the various family caregivers according to the family caregiver

	Family caregiver respondent	Other family member	Other relative	Friends
Errands, outings	41.6%	26.9%	14.6%	9.0%
Housekeeping, laundry	30.3%	11.2%	-	1.1%
Meal preparation	29.2%	13.5%	3.4%	3.4%
Socialization	25.8%	24.7%	14.6%	16.9%
Budget and paperwork	19.1%	6.7%	-	-
Bath, hygiene	14.6%	1.1%	1.1%	-
Moral support	12.4%	11.2%	4.5%	1.1%
Accompaniment to medical appointments	12.4%	3.4%	3.4%	-
Various tasks	11.2%	9.0%	6.8%	1.1%
As needed	7.9%	11.2%	-	-
Telephone, getting news	6.7%	7.9%	2.2%	-
Nursing care	6.7%	-	-	-
Repairs	5.6%	7.9%	3.4%	-
Assistance with medication	5.6%	4.5%	-	-

6.3.2 Contribution of formal caregivers (n = 89)

According to the family caregivers interviewed, home support workers/homemakers provide 43.8% of the assistance by formal caregivers, home care nurses provide 36.0% of the assistance, maintenance staff 28.1%, physicians and foot care specialists 14.6% and public health nurses and social workers 5.2%.

The following table shows the number of hours of care and support provided by the various formal caregivers, according to the family caregivers interviewed. As with the previous section, it must be noted that the level of non-response to this question being very high, the results presented concern only those family caregivers who answered, which represents a small proportion of family caregivers. They must therefore be interpreted with caution.

Table 6.6: Number of hours per week provided by the various formal caregivers, according to the family caregivers interviewed

	0 - 9,9	10 - 29,9	30 - 59,9	60 - 99,9	100 +
Home support workers/Homemakers	71.8%	25.6%	2.6%	-	-
Maintenance	88.0%	12.0%	-	-	-
Home care aide	75.0%	25.0%	-	-	-
Home care nurse	93.8%	3.1%	3.1%	-	-
Foot care	100.0%	-	-	-	-
Public health nurse	66.7%	16.7%	16.7%	-	-
Community worker	100.0%	-	-	-	-
Physician	100.0%	-	-	-	-
Occupational therapist	-	-	-	-	-
Physiotherapist	50.0%	50.0%	-	-	-
Massage therapist	-	-	-	-	-
Social worker	100.0%	-	-	-	-
Traditional healer	-	-	-	-	-
Spiritual care	100.0%	-	-	-	-
Other	-	-	-	-	-

The following table lists the tasks carried out by some of these caregivers, i.e. those mentioned most often by family caregivers. The same caution is to be exercised with the results presented in this table.

Table 6.7: Tasks carried out by the various formal caregivers according to the family caregiver

	Home support worker	Maintenance	Home care nurse	Physician
Housekeeping	41.6%	16.9%	-	-
Shopping	11.2%	1.1%	-	-
Meal preparation	11.2%	3.4%	-	-
Bath, hygiene	10.1%	-	-	-
House maintenance outside	-	6.7%	-	-
Budget	-	-	-	-
Socializing	3.4%	-	3.4%	-
Accompaniment to medical appointments	4.5%	-	1.1%	-
Maintenance	-	-	-	-
As needed	-	5.6%	3.4%	4.5%
Vital signs	-	-	29.2%	-
Follow-up and check-up	1.1%	-	25.8%	47.2%
Medication	2.2%	-	11.2%	1.1%
Blood sampling and testing	-	-	7.9%	-
Cutting nails	-	-	1.1%	-
Foot care	2.2%	-	-	-
Blood sugar	-	-	3.4%	-
Changing clothing	-	-	3.4%	-

6.3.3 Other health-related services (n = 89)

According to the family caregivers interviewed, 27.3% of clients have received supplies, devices and other aids (for example, a wheelchair, walker, cane, syringes, dressings, pillows or tissues) during the month preceding the survey.

Medication is the supply mentioned by the most clients and they were paid through Health Canada's Non-Insured Health Benefits (NIHB) Program in over 70.0% of cases. After that come dressings and vision care, a walker, a cane and syringes. A wheelchair, ostomy material (incontinence material) and a pillow complete the list.

According to family caregivers interviewed, in the month preceding the survey, 9.0% of clients bought (or someone bought it for them) supplies, devices or aids (for example, a walker, cane, syringes, dressings, pillows or tissues) for a value of less than $100. Exercise balls for hands, cereal, diapers, a shower, an oxygen tank and clothing were items mentioned.

According to family caregivers interviewed, in the twelve months preceding the survey, 19.3% of clients bought (or someone bought it for them) devices or aids (for example, an wheelchair, home repairs, a specialized vehicle or specialized clothing) for a value of more than $100. Items most frequently mentioned by these family caregivers include a walker (value of $100), repairs or adaptations in the bathroom (value between $65 and $6,000), air-conditioning system (value of $375), headphones (value of $100), tensiometer (value of $110), wheelchair (value of $300), specialized shoes (value of $60), diapers (value of $500) and glasses (value of $200).

Always according to the family caregivers interviewed, in the month preceding the survey, 20.5% of clients were referred to services in their community. Out of them, 50.0% were referred to a specialist (nutritionist, family therapist, physiotherapist, psychologist or psychiatrist) and 27.8% to the hospital or day centre.

In the month preceding the survey, 34.1% of clients were referred to services outside their community. Out of them, 26.7% were referred to consult a specialist, 26.7% to the hospital and 16.7% to meet an eye care specialist. The other clients were referred for chemotherapy, X-rays., a psychiatrist and a massage therapist.

According to the family caregivers interviewed, 77.5% of clients were satisfied with the care received outside their community.

6.3.4 Satisfaction with health-related services (n = 89)

Table 6.8 indicates the satisfaction level of clients with regards to statements pertaining to care and support provided by formal caregivers, according to family caregivers. Overall the table shows a fairly high level of satisfaction. It is important to remember the intervention of some continuing care workers to the effect that family caregivers' satisfaction could, in reality be lower overall.

Table 6.8: **Satisfaction of clients with regards to statements pertaining to the care and support provided by formal caregivers, according to family caregivers**

	Never	Sometimes	Always or almost always
The people who provide the client with care are sensitive to his needs, beliefs and practices	1.2%	13.3%	78.3%
The client is satisfied with the place where services are provided	1.2%	9.8%	78.0%
The people who provide the client with care respect, understand and listen to him	2.4%	14.5%	77.1%
It is easy to find the right person to provide the care and support	7.2%	9.6%	74.7%
The client receives the care/support he needs often enough	3.6%	16.7%	72.6%
The care the client needs is available at the time he needs it	4.8%	25.3%	63.9%
The length of time that the client receives the care is long enough	11.4%	22.8%	57.0%
The family caregiver, the client or another family caregiver pays for the care	31.3%	7.2%	7.2%
If you, the client or another family caregiver pay for the care, the person can afford it	9.8%	3.7%	15.9%

32.6% of family caregivers interviewed indicated they always or almost always had their say on who will provide their client with services, 12.4% sometimes and 44.9% never.

29.2% of family caregivers interviewed indicated they always or almost always had their say on what services their client would receive, 18.0% sometimes and 41.6% never.

24.7% of family caregivers interviewed indicated they always or almost always had their say on when services would be provided to their client, 18.0% sometimes and 46.1% never.

Table 6.9 indicates the satisfaction level of family caregivers with regards to statements pertaining to the care and support provided to the client by the caregivers. One can see that 85.2% of individuals providing care adopt an attitude that is polite and courteous with clients and they use the language he is the most comfortable with, according to family caregivers. Concerning the family's involvement in the care planning, however, according to family caregivers only 41.9% of individuals providing care adopt such an attitude always or almost always whereas 18.6% never do.

Table 6.9: Behaviours demonstrated by individuals providing care according to family caregivers

	Never	Sometimes	Always or almost always
They are polite and courteous	-	5.7%	85.2%
They speak the language with which the client is most comfortable	1.1%	6.8%	85.2%
They are in a good mood	-	8.0%	83.0%
They respect the client, understand and listen to him	-	8.0%	83.0%
They do a good job; one that meets your standards	-	13.6%	78.4%
They are willing to help the client with things they are not expected to, but which the client might need	1.1%	13.6%	73.9%
They know when to assist and when to let the client do things himself	1.1%	10.3%	73.6%
The same person comes to provide the client with assistance	1.1%	12.6%	73.6%
They come when you expect them to	-	14.8%	72.7%
The helper knows if there are any changes in the kind of care he should be providing	8.0%	9.2%	56.3%
The client receives adequate notice of a change in the time or the date the visit was planned	10.3%	12.6%	55.2%
They are skilful in teaching the client to look after some of his own needs	2.3%	11.4%	53.4%
The family is involved in the planning of all the care the client receives	18.6%	16.3%	41.9%

In the twelve months preceding the survey, 17.0% of family caregivers have experienced difficulties in obtaining traditional care to assist their client, 14.8% to afford the cost of medication, medical supplies and equipment and 10.2% in being respected, listened to and understood. Almost none of the family caregivers has experienced difficulties in getting adapted transportation, traditional support and care, services in their region and when needed. It is important to remember the fact that regarding transportation, some continuing care workers seem to say that results do not correspond to reality. While almost all family caregivers and clients indicate they have never had any difficulties regarding transportation, some continuing care workers indicate on the contrary that transportation is a significant challenge.

6.8% of family caregivers have refused services or treatments for their client in the twelve months preceding the survey.

5.7% of caregivers have indicated their client was refused services or treatments.

6.3.5 Summary: Type of care provided

89 family caregivers interviewed:

- 60.6% of formal caregivers provide their client with 0 to 9 hours of care and support per week
  70.8% of family caregivers provide their client with 10 hours and more per week
  20.2% provide their client with 60 hours and more per week
- family caregivers are in 38.3% of cases the respondent
  in 22.3% of cases close family
- formal caregivers are in 43.8% of cases home support workers/homemakers
  in 36.0% home care nurses
  in 28.1% maintenance staff

according to family caregivers:

- 27.3% of clients have received supplies, devices and other aids (1 month before the survey)
- medication was mentioned most often
  out of these, 70.0% were paid through Health Canada's NIHB Program
- 20.5% were referred to services in their community (1 month before the survey)
- 34.1% were referred to services outside their community (1 month before the survey)
  77.5% were satisfied with the care they received outside their community

- 32.6% of family caregivers indicate they always or almost always have their say on who will provide their client with services
  44.9% indicate they never have their say on the person
- 29.2% indicate they always or almost always have their say on what services will be provided to their client
  41.6% indicate they never have their say on the services
- 24.7% indicate they always or almost always have their say on when the services will be provided to their client
  46.1% indicate they never have their say on the moment

according to family caregivers:

- 85.2% of individuals providing care always or almost always demonstrate an attitude that is polite and courteous towards clients and use the language the client is most comfortable with
- 41.9% of individuals providing care always or almost always involve the family in the planning of care

- 17.0% of family caregivers have experienced difficulties in obtaining traditional care in order to help their client (12 months before the survey)
- 14.8% have experienced difficulties in affording the cost of medication, medical supplies and equipment (12 months before the survey)
- 6.8% have refused services or treatments for their client (12 months before the survey)
- 5.7% indicated their client was refused services or treatments

6.4 Perception of Future Needs (n = 89)

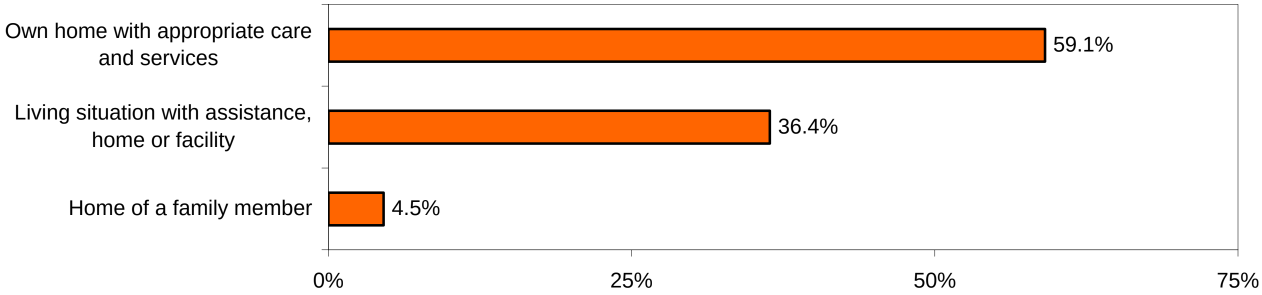
61.4% of family caregivers indicate they know other types of housing for their client. The following table shows the types of housing that were mentioned.

Table 6.10: Types of housing identified by family caregivers

Housing	
Elders home	12.4%
Private apartments	9.0%
At home with services	5.6%
Independent Living Center (Kahnawake)	5.6%
Family member	4.5%
Hospital	2.2%

The following chart illustrates the place where the family caregiver would like his client to live if he were given the choice and taking into account his health. Compared to the results presented in the « Clients » section, where they clearly indicated the clients' preference to remain in their own home with appropriate care and services, family caregivers produced more mixed results. 59.1% chose the client's home and 36.4% a living situation with assistance, a home or a facility.

Chart 6.5: Place where the family caregiver would like to see his client live given the choice and taking into account his health



98.9% of family caregivers prefer that their client's home be located in his community rather than where services are easily accessed, involving that the client would live outside his community.

9.3% of family caregivers prefer that their client receives care and support only from the family, a friend or neighbour and 10.5% from the formal care system only. However 80.2% prefer that their client receives assistance from his family in addition to the formal care system.

80.7% of family caregivers believe there is a need for other housing options in their community. Expanding what already exists, building a facility for non-autonomous persons, houses or apartments for Elders, housing for people with mobility impairment, foster homes and a facility for palliative care are the propositions made by family caregivers.

If their health were to deteriorate, 42.7% of family caregivers would want their client to receive care and services at home, 37.3% would choose an Elders home and 28.0% a hospital.

If their client were to need palliative care, 36.6% of family caregivers would want their client to remain at home, 35.4% to go to the hospital, 14.6% to the Elders home and 11.0% to stay in the community.

6.4.1 Summary: Perception of future needs

89 of family caregivers interviewed:

- 61.4% of family caregivers indicate they know other types of housing situations for their client
- if the client were given the choice:
  59.1% of family caregivers would want their client to remain at home
  36.4% in a living situation with assistance, a home or a facility
- 98.9% would want their client's home to be in his community rather than where services are easily accessed (involving he would leave the community)
- 80.7% of family caregivers believe there is a need for other housing options in their community
- if their client's health were to deteriorate:
  42.7% of family caregivers would want him to receive care and services at home
  37.3% would choose an Elders home
  28.0% a hospital (in or outside the community)
- if their client were to need palliative care:
  36.6% of family caregivers would want him to stay at home
  35.4% to go to a hospital (in or outside the community)

6.5 Impacts of Providing Care (n = 89)

The following table shows the impacts of the family caregiver's involvement. Overall comments are fairly positive. However family caregivers' opinions are divided concerning the future of their client and access to respite care for both the client and the family caregiver.

Table 6.11: Impacts of the family caregiver's involvement on his personal life

	Never or rarely	Sometimes	Often, always or almost always
You get satisfaction about caring for the client	-	9.1%	89.8%
You have support in caring for the client	14.9%	10.3%	66.7%
You believe the client seems to expect you to take care of him/her as if you were the only one he could depend on	25.0%	15.9%	55.6%
You believe the client is dependent on you	22.7%	20.5%	52.3%
You are afraid of what the future holds for the client	36.4%	27.3%	31.8%
You are pulled between caring for the client and trying to meet other responsibilities for your family or work	56.8%	15.9%	26.2%
You believe you should be doing more for the client	54.0%	24.1%	20.7%
You believe that because of the time you spend with the client you don't have enough time for yourself	67.1%	15.9%	13.7%
You believe you can do a better job in caring for the client	62.1%	19.5%	13.7%
You believe the client has access to respite care	23.3%	9.3%	12.8%
You believe the client asks for more help than he needs	77.3%	10.2%	12.5%
You have access to respite care	30.3%	10.5%	10.4%
You believe you don't have enough money to care for the client in addition to the rest of your expenses	56.8%	6.8%	9.1%
You feel strained when you are around the client	64.7%	26.1%	7.9%
You believe you do not have as much privacy as you would like because you are caring for the client	72.7%	6.8%	7.9%
You believe that your social life has suffered because you are caring for the client	78.4%	6.8%	5.7%
You believe your health has suffered because of your involvement with the client	80.5%	12.6%	4.5%
You believe that the client currently affects your relationship with other family members or friends in a negative way	81.9%	12.5%	3.4%
You are uncertain about what to do about the client	73.5%	18.4%	3.4%
You believe you are burdened in caring for the client	81.8%	14.8%	3.4%
You are angry when you are around the client	82.9%	13.6%	3.4%
You are embarrassed over the client's behaviour	84.1%	11.4%	3.4%
You would like to leave the care of the client to someone else	76.1%	18.2%	3.4%
You believe you have lost control of your life since you've become a caregiver	86.3%	5.7%	3.4%
You have lost paid work time in order to care for the client	62.5%	6.8%	2.3%
You believe that caring for the client is a financial burden	71.6%	4.5%	2.2%
You believe that you will be unable to take care of the client much longer	78.4%	10.2%	1.1%
You are uncomfortable about having friends over because of the client	75.0%	2.3%	-
The caring for the client has negatively affected your paid job	62.5%	6.8%	-

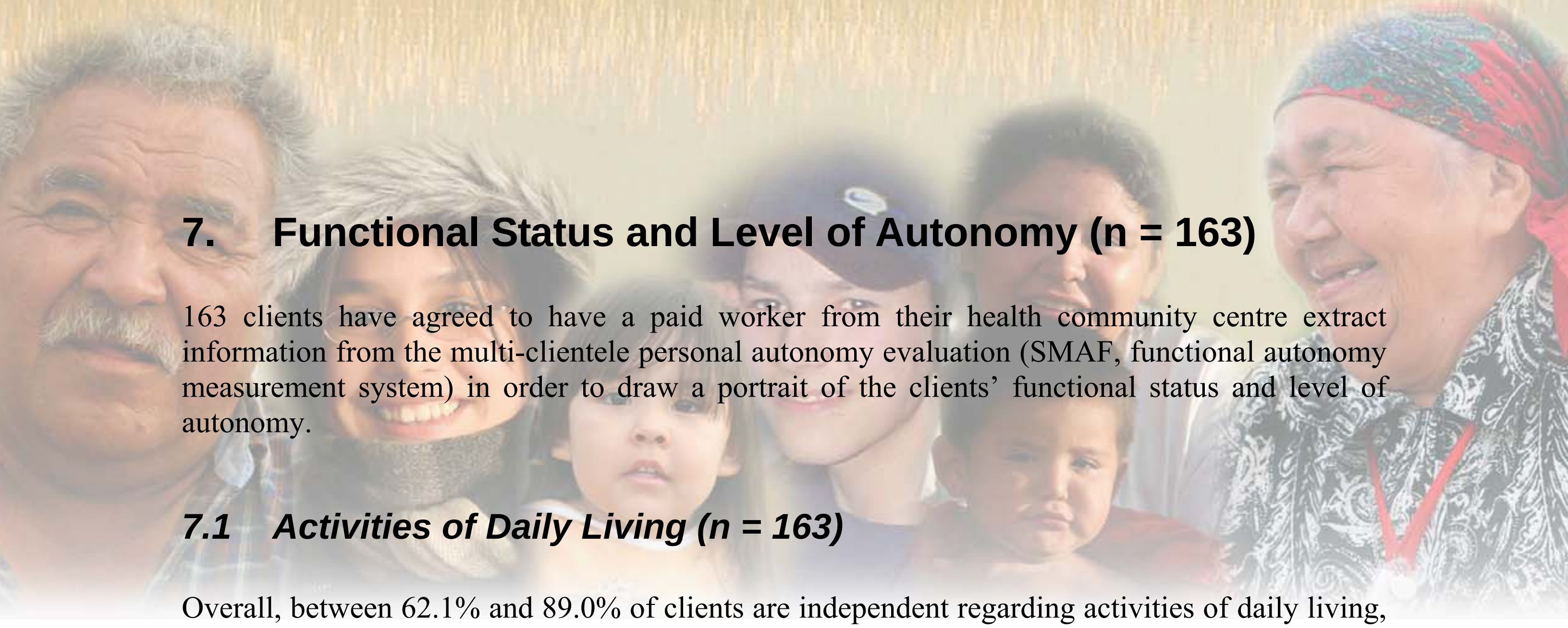
*Family caregivers could choose not to answer or not to know.

Some family caregivers suggested some elements to improve the care and quality of life of their client. Foster socialization, set up activities, diversify care and services, increase the number of hours provided, increase the family's involvement, repair or improve the home/room, set up diets or "meals on wheels" services, maintain the services currently provided, improve communication between the various types of workers, caregivers as well as with the program management, and facilitate access to respite care for family caregivers are some of the suggestions that were made. Building a facility for people with disabilities and a palliative care service were also mentioned.

6.5.1 Summary: Impacts of providing care

89 family caregivers interviewed:

- 89.8% get satisfaction from caring for their client
- opinions are rather mixed concerning the future of the client and access to respite care for both the client and the family caregiver
- suggestions to improve the care and their client's quality of life:
  foster socialization
  set up activities
  diversify care and services
  increase the number of hours provided
  increase the family's involvement
  repair or improve the home/room
  set up diets or "meals on wheels" services
  maintain the services currently provided
  improve communication between the various types of workers, caregivers as well as with the program management
  facilitate access to respite care for family caregivers
  build a facility for people with disabilities
  build a palliative care service



7. Functional Status and Level of Autonomy (n = 163)

163 clients have agreed to have a paid worker from their health community centre extract information from the multi-clientele personal autonomy evaluation (SMAF, functional autonomy measurement system) in order to draw a portrait of the clients' functional status and level of autonomy.

7.1 Activities of Daily Living (n = 163)

Overall, between 62.1% and 89.0% of clients are independent regarding activities of daily living, which means they feed themselves, wash, dress and groom themselves, use the toilet alone and their urinary and bowel functions are normal.

Table 7.1: Ability to feed oneself

Feeds self independently	**87.4%**
Feeds self with difficulty	**4.9%**
Feeds self but needs stimulation or supervision or food must be prepared or cut or pureed first	**4.9%**
Needs some assistance to eat or dishes must be presented one after another	**0.5%**
Must be fed totally by another person or has a naso-gastric tube or a gastrostomy	**2.2%**

Table 7.2: Ability to wash oneself

Washes self independently	**62.1%**
Washes self with difficulty	**7.1%**
Washes self but needs cueing or needs supervision or needs preparation or needs help for the complete weekly bath only (including washing feet and hair)	**9.9%**
Needs help for the daily wash but participates actively	**13.7%**
Must be washed by another person	**7.1%**

Table 7.3: Ability to dress oneself

Dresses self independently	**74.7%**
Dresses self with difficulty	**7.7%**
Dresses self but needs cueing or needs supervision or clothing must be prepared and presented or needs help for finishing touches only (buttons, laces)	**4.9%**
Needs help dressing	**6.0%**
Must be dressed by another person	**6.6%**

Table 7.4: Ability to groom oneself

Grooms self independently	**63.7%**
Grooms self with difficulty	**7.7%**
Needs cueing or needs supervision for grooming	**7.7%**
Needs some assistance for grooming	**14.8%**
Must be groomed by another person	**6.0%**

Table 7.5: Status of urinary function

Normal voiding	79.1%
Occasional incontinence or dribbling or needs frequent cueing to avoid incontinence	12.1%
Frequent urinary incontinence	2.2%
Complete and habitual urinary incontinence or wears an incontinence pad or an indwelling catheter or a urinary condom	6.6%

Table 7.6: Status of bowel function

Normal bowel function	89.0%
Occasional incontinence or needs cleansing enema occasionally	7.1%
Frequent incontinence or needs cleansing enema regularly	0.5%
Always incontinent or wears an incontinence pad or an ostomy	3.3%

Table 7.7: Ability to use the toilet

Uses toilet independently	81.8%
Uses toilet with difficulty	8.3%
Needs supervision for toileting or uses commode, urinal or bedpan	1.7%
Needs help using toilet, commode, bedpan or urinal	8.3%
Does not use toilet, uses commode, bedpan or urinal	-

7.2 Mobility (n = 163)

Concerning mobility, between 52.8% and 91.7% of clients are independent, which means they get in and out of bed, walk inside and outside, negotiate stairs alone, wear no prosthesis or orthosis and do not need a wheelchair to get around. However, 25.0% of clients have difficulties going up and down stairs, 17.6% get in and out of bed with difficulty, 13.2% get around outside with difficulty, 12.8% inside and 13.2% of clients must be transported on a stretcher.

Table 7.8: Autonomy in transfers

Gets in and out of bed independently	75.3%
Gets in and out of bed with difficulty	17.6%
Gets in and out of bed/chair independently, but needs cueing, supervision or guidance	3.8%
Needs help to get in and out of bed/chair	3.3%
Bedridden (must be lifted in and out of bed)	-

Table 7.9: Autonomy to walk inside

Walks independently (with or without cane, prosthesis, orthosis or walker)	69.4%
Walks independently with difficulty	12.8%
Walks independently but needs guidance, cueing or supervision in certain circumstances or has an unsafe gait	5.0%
Needs help of another person to walk	3.9%
Does not walk without a simple cane, tripod, quadripod or walker	8.9%

Table 7.10: Ability to install prosthesis or orthosis

Does not wear prosthesis or orthosis	**91.7%**
Installs prosthesis or orthosis independently	**5.0%**
Installs prosthesis or orthosis with difficulty	**1.7%**
Installing of prosthesis or orthosis needs checking or needs some assistance	**1.1%**
Prosthesis or orthosis must be installed by another person	**0.6%**

Table 7.11: Ability to propel oneself in a wheelchair

Does not need a wheelchair	**85.2%**
Propels wheelchair independently	**5.5%**
Propels wheelchair with difficulty	**1.1%**
Needs to have wheelchair pushed	**5.5%**
Unable to use wheelchair (must be transported on stretcher)	**2.7%**

Table 7.12: Ability to negotiate stairs

Goes up and down stairs independently	**52.8%**
Goes up and down stairs with difficulty	**25.0%**
Requires cueing, supervision or guidance to negotiate stairs or does not safely negotiate stairs	**2.8%**
Needs help of another person to go up and down stairs	**8.9%**
Does not negotiate stairs	**10.6%**

Table 7.13: Ability to get around outside

Walks independently (with or without cane, prosthesis, orthosis or walker)	**64.8%**
Walks independently with difficulty	**13.2%**
Uses a wheelchair or three/four-wheeled scooter independently or walks independently but needs guidance, cueing or supervision in certain circumstances or has an unsafe gait	**8.8%**
Needs help of another person to walk or to use wheelchair	**-**
Cannot move around outside (must be transported on a stretcher)	**13.2%**

7.3 Communication (n = 163)

Overall, between 84.1% and 90.1% of clients are independent in terms of communications, which means their vision, hearing and speech are normal.

Table 7.14: Vision

Sees adequately with or without corrective lenses	**84.1%**
Vision problems but sees enough for ADLs	**13.2%**
Only sees outlines of objects and needs guidance in ADLs	**1.6%**
Blind (corrective lenses or magnifying glass)	**1.1%**

Table 7.15: Hearing

Hears adequately with or without hearing aid	86.3%
Hears if spoken to in a loud voice or needs hearing aid put in by another person	13.2%
Only hears shouting or certain words or reads lips or understands gestures	-
Completely deaf and unable to understand what is said to him (hearing aid)	0.5%

Table 7.16: Speech

Speaks normally	90.1%
Has a speech/language problem but is able to express himself	7.1%
Has a major speech/language problem but able to express basic needs or answer simple questions (yes, no) or uses sign language	1.6%
Does not communicate (technical aid by computer or communication board)	1.1%

7.4 Mental Functions (n = 163)

Between 69.1% and 83.0% of clients have normal mental functions, which means their memory, orientation, comprehension, judgment and behaviour are normal. However, 22.1% of clients have recent memory deficit but remember important facts and 16.6% are slow to understand instructions and requests.

Table 7.17: Memory

Normal memory	69.1%
Minor recent memory deficit (names, appointments, etc.) but remembers important facts	22.1%
Serious memory lapses (shutting off stove, taking medications, putting things away, eating, visitors, etc.)	7.2%
Almost total memory loss or amnesia	1.7%

Table 7.18: Orientation

Well oriented to time, space and persons	82.3%
Sometimes disoriented to time, space and persons	11.6%
Only oriented for immediate events (e.g., time of day) and in the usual living environment and with familiar persons	5.0%
Complete disorientation	1.1%

Table 7.19: Comprehension

Understands instructions and requests	77.9%
Slow to understand instructions and requests	16.6%
Partial understanding even after repeated instructions or is incapable of learning	5.5%
Does not understand what goes on around him	-

Table 7.20: Judgment

Evaluates situations and makes sound decisions	**71.4%**
Evaluates situations but needs help in making sound decisions	**14.3%**
Poorly evaluates situations and only makes sound decisions with strong suggestions	**6.6%**
Does not evaluate situations and is dependent on others for decision making	**7.7%**

Table 7.21: Behaviour

Appropriate behaviour	**83.0%**
Minor behavioural problems (whimpering, emotional lability, stubbornness, apathy) requiring occasional supervision or a reminder or stimulation	**14.3%**
Major behaviour problems requiring more intensive supervision (aggressive towards self or others, disturbs others, wanders, yells out constantly)	**2.7%**
Dangerous, requires restraint or harmful to others or self-destructive or tries to run away	**-**

7.5 Instrumental Activities of Daily Living (n = 163)

Concerning instrumental activities of daily living, results vary. Between 50.3% and 74.4% of clients do the laundry, use the phone and transportation, take their medication and manage their budget alone. However, only 48.4% of clients prepare their meals alone and 36.3% do not. 37.4% of clients plan and do their shopping alone and 28.0% do not shop. 33.1% do not do the laundry and 29.7% do not do housework. Finally, only 7.7% of clients do the housekeeping alone.

Table 7.22: Ability to do housekeeping

Does housekeeping alone (including daily housework and occasional heavy jobs)	**7.7%**
Does housekeeping with difficulty	**4.9%**
Does housekeeping (including washing the dishes) but needs cueing or supervision to ensure cleanliness or needs help for occasional heavy jobs (floors, windows, painting, lawn, shoveling snow, etc.)	**29.1%**
Needs help for daily housework	**28.6%**
Does not do housework	**29.7%**

Table 7.23: Ability to prepare meals

Prepares own meals independently	**48.4%**
Prepares own meals with difficulty	**4.4%**
Prepares meals but needs cueing to maintain adequate nutrition	**2.2%**
Only prepares light meals or reheats pre-prepared meals (including handling the plates)	**8.8%**
Does not prepare meals	**36.3%**

Table 7.24: Ability to do shopping

Plans and does shopping independently (e.g., food, clothes, etc.)	37.4%
Plans and does shopping with difficulty	5.5%
Plans and shops independently but needs a delivery service	8.2%
Needs help to plan or to shop	20.9%
Does not shop	28.0%

Table 7.25: Ability to do laundry

Does all laundry independently	50.3%
Does laundry independently with difficulty	5.5%
Does laundry but needs cueing or supervision to maintain standards of cleanliness	1.7%
Needs help to do laundry	9.4%
Does not do laundry	33.1%

Table 7.26: Ability to use the phone

Uses telephone independently (including the use of a directory)	74.4%
Uses telephone and directory with difficulty	6.1%
Answers telephone but only dials a few memorized numbers or emergency numbers	9.4%
Communicates by telephone but does not dial numbers or lift the receiver off the hook	3.3%
Does not use the telephone	6.7%

Table 7.27: Ability to use transportation

Able to use transportation alone (car, adapted vehicle, taxi, bus, etc.)	56.4%
Able to use transportation alone with difficulty	6.1%
Must be accompanied to use transportation or uses paratransit independently	16.0%
Uses car or paratransit only if accompanied and has help getting in and out of the vehicle	19.3%
Must be transported on a stretcher	2.2%

Table 7.28: Ability to take own medication

Takes medication unaided according to prescription or does not need medication	60.8%
Takes medication with difficulty	-
Needs supervision (including supervision form afar) to ensure compliance to prescription or uses a medication dispenser aid (prepared by someone else)	10.5%
Takes medication if prepared daily	5.5%
Must be given each dosage of medication, as prescribed (medication dispenser aid)	23.2%

Table 7.29: Ability to manage own budget

Manages budget independently (including banking)	**62.4%**
Manages budget with difficulty	**0.6%**
Needs help for certain major transactions	**6.1%**
Needs help for some regular transactions (cashing checks, paying bills) but uses pocket money wisely	**11.0%**
Does not manage budget	**19.9%**

7.6 Level of Autonomy (n = 163)

By compiling the data from the questionnaire on the clients' functional status, seven categories were created, based on the functional autonomy measurement system (SMAF), in order to measure the clients' level of autonomy. Category 1 represents clients with the highest level of autonomy and category 7 clients with the lowest level of autonomy. Clients in categories 3 and 4 have an average level of autonomy. Chart 7.1 draws a portrait of the functional status of individuals in each category. One can see that, generally, instrumental activities of daily living are the autonomy individuals lose first whereas communication is the autonomy they maintain the longest.

Chart 7.1: Average number of independent individuals in each category according to clients' functional status

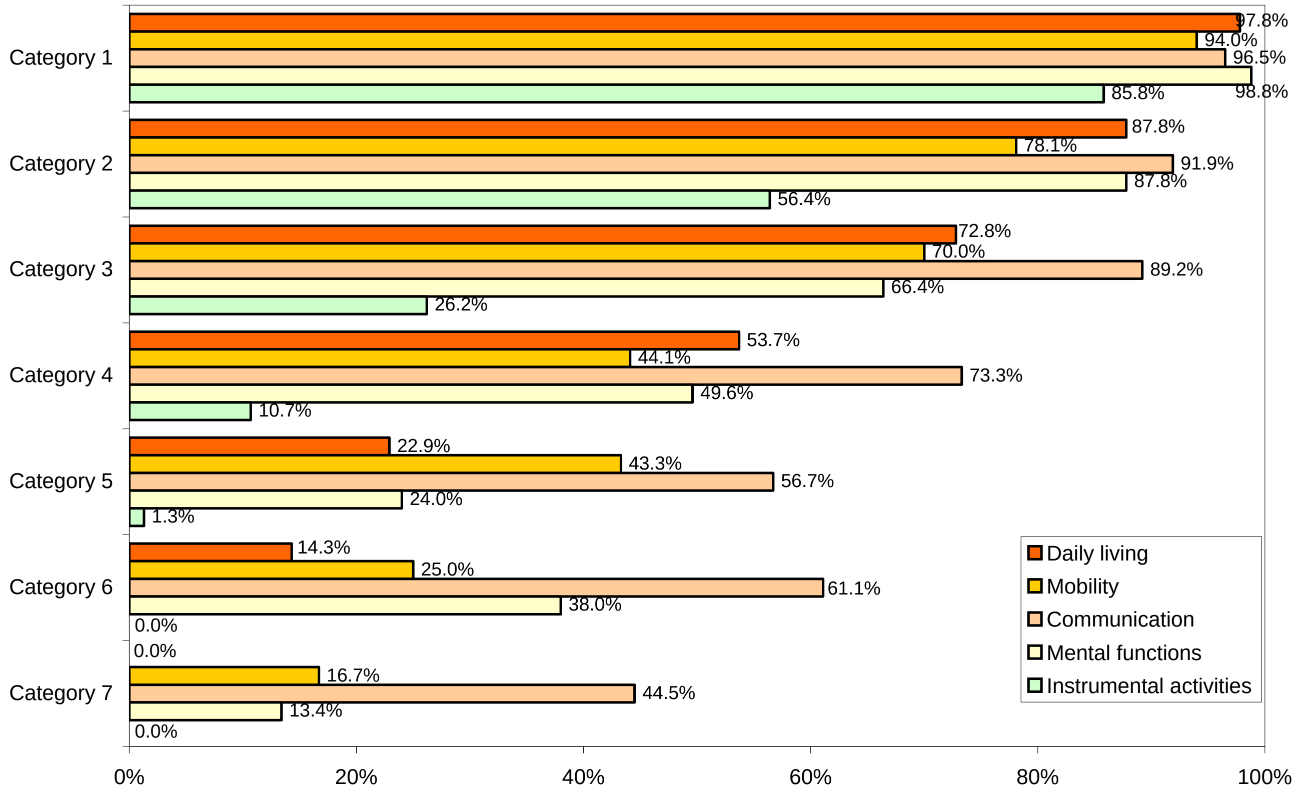


Table 7.30 presents the categorization of autonomy levels. Over half the clients are in categories 1 and 2, one fifth in categories 5, 6 and 7. Table 7.31 presents the categorization of autonomy levels according to the gender. It is important to keep in mind though that close to three quarters of the clients are female.

Table 7.30: Categorization of the autonomy level

Category	
Category 1	36.3%
Category 2	22.5%
Category 3	17.0%
Category 4	13.7%
Category 5	5.5%
Category 6	3.3%
Category 7	1.6%

Table 7.31: Categorization of autonomy levels according to gender

	Male (n = 49)	Female (n = 132)
Category 1	32.7%	37.1%
Category 2	20.4%	23.5%
Category 3	24.5%	14.4%
Category 4	16.3%	12.9%
Category 5	4.1%	6.1%
Category 6	2.0%	3.8%
Category 7	-	2.3%

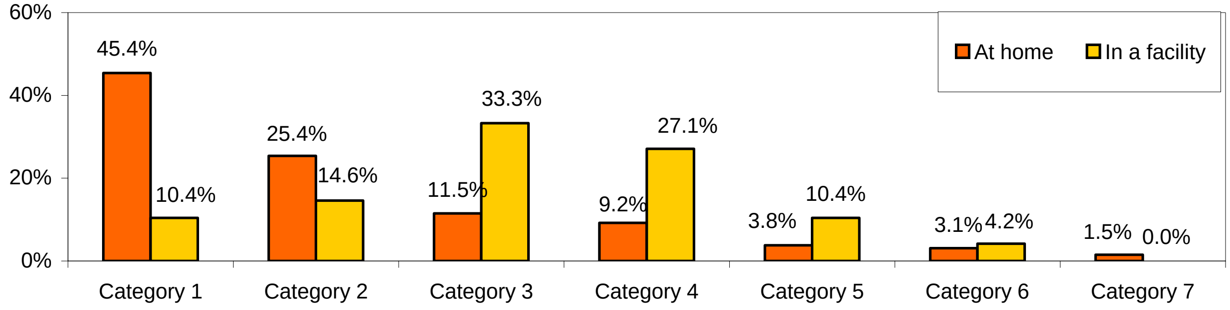
Table 7.32 illustrates the categorization of autonomy levels according to the age group. One can see that clients aged 18 to 54 and 75 and over are mostly in the categories 6 and 7, which are the lowest levels of autonomy.

Table 7.32: Categorization of autonomy levels according to age group

	0-17 (n = 1)	18-54 (n = 19)	55-64 (n = 29)	65-74 (n = 41)	75+ (n = 90)
Category 1	-	26.3%	41.4%	51.2%	30.0%
Category 2	-	21.1%	20.7%	19.5%	25.6%
Category 3	-	21.1%	13.8%	19.5%	16.7%
Category 4	-	5.3%	24.1%	7.3%	14.4%
Category 5	100.0%	5.3%	-	2.4%	7.8%
Category 6	-	15.8%	-	-	3.3%
Category 7	-	5.3%	-	-	2.2%

Looking at the following graph, one can see that a higher percentage of clients in categories 1 and 2 receive care at home whereas clients in categories 3, 4 and 5 are mostly in a facility.

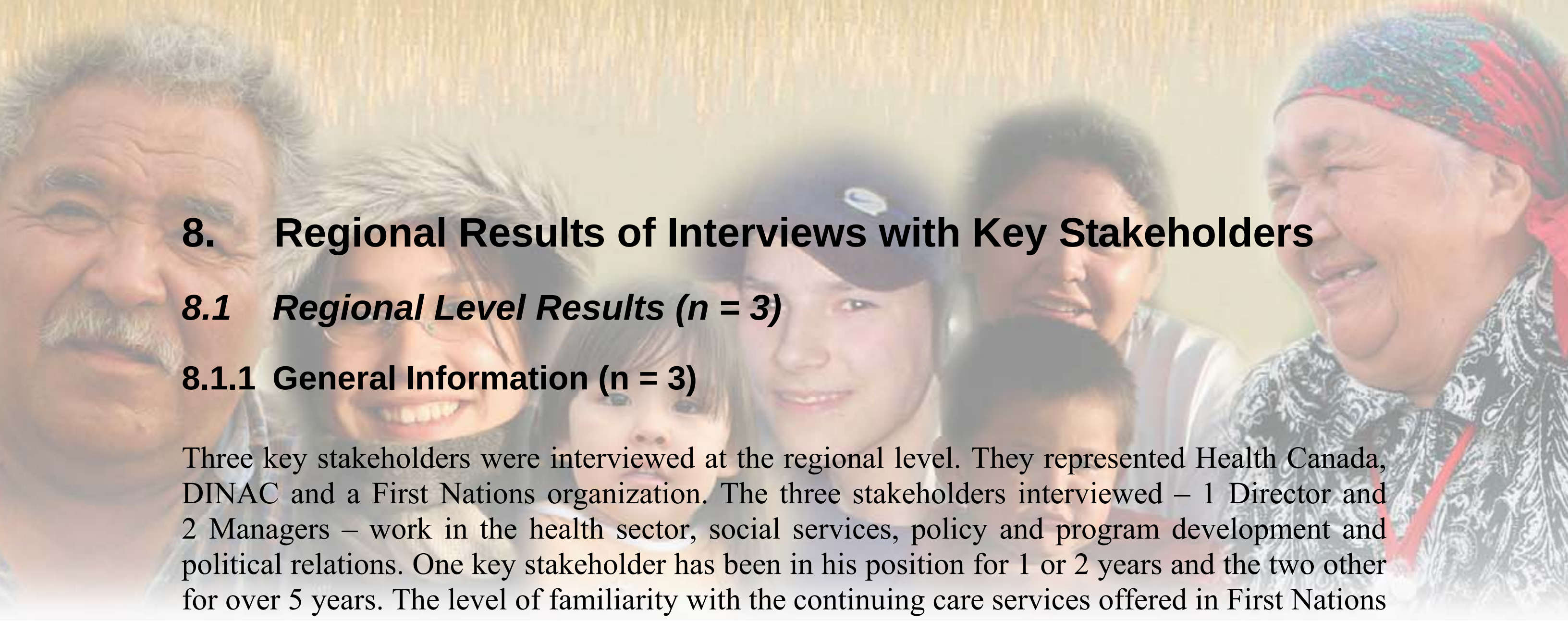
Chart 7.2: Categorization of autonomy levels according to location of client



7.7 Summary: Functional status and level of autonomy

163 clients:

- activities of daily living:
  between 62.1% and 89.0% of clients feed, wash, dress and groom themselves and use the toilet alone and their urinary and bowel functions are normal
- mobility:
  between 52.8% and 91.7% of clients get in and out of bed, walk inside and outside, and negotiate stairs alone, do not wear prosthesis or orthosis and do not need a wheelchair to get around
  25.0% go up and down stairs with difficulty
  17.6% get in and out of bed with difficulty
  13.2% get around outside with difficulty
  12.8% walk inside with difficulty
  13.2% must be transported on a stretcher
- communication:
  between 84.1% and 90.1% of clients have a normal vision, hearing and speech
- mental functions:
  between 69.1% and 83.0%, have a normal memory, orientation, comprehension, judgment and behaviour
  22.1% have minor recent memory deficits but remember important facts
  16.6% are slow to understand instructions and requests
- instrumental activities of daily living:
  between 50.3% and 74.4% do the laundry, use the phone and transportation,
  take their own medication and manage their budget alone
  48.4% prepare their meals alone
  36.3% do not prepare them
  37.4% of clients plan and shop alone
  28.0% do not shop
  33.1% do not do the laundry
  29.7% do no housework
  7.7% of clients do their housekeeping alone
- instrumental activities of daily living are the autonomy clients lose first, communication, the autonomy clients maintain the longest
- 58.8% of clients are in categories 1 and 2 (high level of autonomy)
  10.4% in categories 5, 6 and 7 (low level of autonomy)
- clients aged 18 to 54 and those aged 75 and over are mostly in categories 6 and 7
- clients in categories 1 and 2 mostly receive care at home
  clients in categories 3, 4 and 5 are mostly in a facility



8. Regional Results of Interviews with Key Stakeholders

8.1 Regional Level Results (n = 3)

8.1.1 General Information (n = 3)

Three key stakeholders were interviewed at the regional level. They represented Health Canada, DINAC and a First Nations organization. The three stakeholders interviewed – 1 Director and 2 Managers – work in the health sector, social services, policy and program development and political relations. One key stakeholder has been in his position for 1 or 2 years and the two other for over 5 years. The level of familiarity with the continuing care services offered in First Nations and/or Inuit communities varies from slightly familiar, to somewhat familiar to very familiar. No stakeholder was interviewed at the national level.

8.1.2 Continuing care services in First Nations and/or Inuit communities (n = 3)

Continuing care services funded through Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program*.

The following tables pertain to continuing care services funded through Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program*. For the purposes of this survey, small communities are considered to be those with 500 people or less, medium communities are those with 501 to 1,000 people and large communities are those with 1,001 people or more.

According to two out of the three stakeholders interviewed, in-home nursing care and home support services are often or always offered in small, medium and large communities, generally in an efficient manner. Regarding home maintenance services, day programs, foster care for adults/elderly and institutional services/facility care, two out of the three stakeholders indicate they are never or rarely offered in small, medium and large communities.

In small communities, two out of the three stakeholders also indicate that home respite care is never or rarely offered. Concerning small communities, training and staff turnover were also mentioned as major difficulties. Small communities are often remote and access to provincial services is more limited.

Table 8.1: Service offer in medium and large communities

	How often service is present			How often service is provided in an effective manner		
	Never or rarely	Sometimes	Often or always	Never or rarely	Sometimes	Often or always
Case management (assessment, program management)	-	1/3	1/3	-	1/3	1/3
Information/referral services	-	1/3	1/3	-	1/3	1/3
Training and teaching of personal care staff	1/3	-	1/3	1/3	-	1/3
Meal programs	-	1/3	1/3	-	1/3	1/3
Attendant care	1/3	-	-	1/3	-	-
In-home nursing care	-	-	2/3	-	-	2/3
Home support services (personal care, housekeeping, meal preparation)	-	-	2/3	-	1/3	1/3
Home maintenance (water, wood, minors repairs)	2/3	-	-	2/3	-	-
Day program (including activity program)	2/3	-	-	2/3	-	-
Home respite care	1/3	-	1/3	1/3	1/3	-
Technical aids, equipment and supplies	1/3	-	1/3	1/3	-	1/3
Non-medical transportation services	-	1/3	1/3	1/3	-	1/3
Foster care (adults/elderly)	2/3	-	-	1/3	-	1/3
Institutional services/Facility care	2/3	-	-	1/3	1/3	-

*One respondent did not answer in some cases.

Table 8.2: Service offer in small communities

	How often service is present			How often service is provided in an effective manner		
	Never or rarely	Sometimes	Often or always	Never or rarely	Sometimes	Often or always
Case management (assessment, program management)	-	1/3	1/3	-	2/3	-
Information/referral services	1/3	-	1/3	-	2/3	-
Training and teaching of personal care staff	1/3	1/3	-	1/3	1/3	-
Meal programs	1/3	-	1/3	1/3	-	1/3
Attendant care	-	1/3	-	-	1/3	-
In-home nursing care	-	-	2/3	-	1/3	1/3
Home support services (personal care, housekeeping, meal preparation)	-	-	2/3	-	2/3	-
Home maintenance (water, wood, minors repairs)	2/3	-	-	1/3	1/3	-
Day program (including activity program)	2/3	-	-	2/3	-	-
Home respite care	2/3	-	-	2/3	-	-
Technical aids, equipment and supplies	1/3	1/3	-	2/3	-	-
Non-medical transportation services	1/3	-	1/3	1/3	1/3	-
Foster care (adults/elderly)	2/3	-	-	1/3	1/3	-
Institutional services/Facility care	2/3	-	-	1/3	1/3	-

* One respondent did not answer in some cases.

According to key stakeholders, continuing care services funded through Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program* are sometimes, always or almost always adapted to the First Nations and/or Inuit culture, notwithstanding the size of the community. They also indicate that the staff is Aboriginal, the institutional care program takes into account the characteristics of First Nations and that work has been undertaken to integrate home care (DINAC and Health Canada) and allow First Nations to develop their own service plan.

They also specified that, concerning the program funded through Health Canada, each community had to develop its own service delivery plan. Regarding the part funded through DINAC, a regional policy governs service delivery in a majority of communities.

Opinions are divided when time comes to evaluate if First Nations and Inuit communities have the human, material and financial resources to culturally adapt their home and community care services. One key stakeholder interviewed claims that no, one is not certain – some communities yes and others no, depending on various factors (number of residents, remoteness, access or not to human and material resources…) — and the third one claims that yes — the cultural adaptation does not have a major impact on the financial level, capacity building is an important component for several communities, financial resources are not sufficient to cover the needs of First Nations.

Two out of the three key stakeholders indicated that the facility continuing care services funded through DINAC's *Assisted Living Program* are always or almost always culturally adapted to First Nations and Inuit, notwithstanding the size of the community. According to them, the cultural aspect (Aboriginal staff, activities respecting the Aboriginal context) was taken into account when the facilities were set up and there is a certain flexibility even though a regional frame must be applied. Some stakeholders indicate that communities do not have sufficient financial resources for all of the program whereas others consider cultural adaptation does not have a major impact on the financial level.

The following table presents the needs of the communities with respect to continuing care services funded through Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program* according to the size of the community. Two out of the three stakeholders indicated that small, medium and large communities had higher needs for attendant care, in-home nursing care, day programs, technical and material aids, and institutional services or care. They add that small communities also have higher needs in terms of case management, training and teaching to personal care staff, and in medical transportation services. However key stakeholders indicated that needs vary from one community to another.

Table 8.3: Continuing care services needs according to size of community

	Medium and large communities			**Small communities**		
	Low	**Moderate**	**High**	**Low**	**Moderate**	**High**
Case management (assessment, program management)	-	1/3	1/3	-	-	2/3
Information/referral services	1/3	-	1/3	-	1/3	-
Training and teaching of personal care staff	-	1/3	1/3	-	-	2/3
Meal programs	1/3	-	1/3	1/3	-	1/3
Attendant care	-	-	2/3	-	-	2/3
In-home nursing care	-	-	2/3	-	-	2/3
Home support services (personal care, housekeeping, meal preparation)	-	1/3	1/3	-	1/3	1/3
Home maintenance (water, wood, minors repairs)	-	1/3	1/3	1/3	-	1/3
Day program (including activity program)	-	-	2/3	-	-	2/3
Home respite care	1/3	-	1/3	-	1/3	-
Technical aids, equipment and supplies	-	-	2/3	-	-	2/3
Non-medical transportation services	-	1/3	1/3	-	-	2/3
Foster care (adults/elderly)	1/3	-	1/3	1/3	-	1/3
Institutional services/Facility care	-	-	2/3	-	-	2/3

*Stakeholders did not answer in some cases.

The key stakeholders interviewed indicated that, according to traditional customs, family is often the resource privileged to care for those in need of continuing care. However, the lack of financial resources puts pressure on caregivers who tend to go beyond their own limits, thus jeopardizing their own health. According to the stakeholders, close ones participate often enough or often in the delivery of continuing care services to members of their own family. For this reason many of them would like to be paid for the time they provide their close ones with care. That way, they could provide the service to their client without worrying about their financial situation.

Tables 8.4 and 8.5 present services offered in small, medium and large communities. One can notice that, according to two out of the three stakeholders, medium and large communities often or always have medical transportation in the community and specialty hospital services, supportive housing, and respite care at home and in facilities outside the community. Conversely, in-home mental health services for adults and children, hospital services and palliative care in facilities are never or rarely provided in medium and large communities, according to two out of the three key stakeholders.

Overall, small communities seem to have less services than medium and large communities. Home or community rehabilitation services, specialty hospital services, services of a hospital liaison worker, long-term care and extended care facilities, facility respite care and home and facility palliative care are not offered in small communities according to two out of the three key stakeholders. Outside the community, however, it seems that specialty hospital services, long-term care and extended care facilities and home respite care are often or always available according to two out of the three stakeholders. The questionnaire did not however specify the distance to access the services provided outside the community.

Table 8.4: Services provided in medium and large communities

	Service provided in the communities			Service provided outside the communities		
	Never or rarely	Sometimes	Often or always	Never or rarely	Sometimes	Often or always
Home/community rehabilitation (physiotherapy, occupational therapy, respiratory therapy)	1/3	1/3	-	-	1/3	-
Alternative therapies (massage)	1/3	1/3	-	-	1/3	-
Foot care	1/3	-	1/3	-	1/3	-
Mental health services for adults – in home	1/3	-	-	1/3	-	1/3
Mental health services for adults – in foster care	1/3	-	-	-	1/3	-
Mental health services for adults – in institution/facility	1/3	-	-	-	-	1/3
Mental health services for children – in home	1/3	-	-	1/3	1/3	-
Mental health services for children – in foster care	1/3	-	-	-	1/3	-
Mental health services for children – in institution/facility	1/3	-	-	-	-	1/3
Day hospitals	1/3	-	-	-	-	1/3
Specialty hospital services (pediatrics, geriatrics)	1/3	-	-	-	-	1/3
Hospital liaison worker/discharge planner	-	1/3	-	-	-	1/3
Foster care (children)	1/3	-	-	-	-	1/3
Supportive housing	1/3	-	1/3	-	-	2/3
Group homes	1/3	-	-	-	-	1/3
Long term care facilities (nursing homes) that cover all care levels	1/3	-	-	-	1/3	1/3
Respite care – in home	-	1/3	1/3	-	-	2/3
Respite care – in institution	1/3	1/3	-	-	-	2/3
Palliative care – in home	1/3	-	1/3	-	-	1/3
Palliative care – in institution	2/3	-	-	-	1/3	1/3
Palliative care – in hospital	1/3	-	-	-	-	1/3
Palliative care support	1/3	-	-	-	-	1/3
Technical aids, equipment and supplies	-	1/3	1/3	1/3	-	1/3
Medical transportation	-	-	2/3	-	-	1/3
Adapted vehicle for medical transportation	1/3	-	1/3	-	-	1/3
Special needs/education programs for children	-	1/3	-	-	-	1/3
Health promotion, wellness and fitness programs	1/3	-	1/3	-	2/3	-
Traditional healer/counselling	1/3	1/3	-	1/3	-	-

* Stakeholders did not answer in some cases.

Table 8.5: Services provided in small communities

	Service provided in the communities			Service provided outside the communities		
	Never or rarely	Sometimes	Often or always	Never or rarely	Sometimes	Often or always
Home/community rehabilitation (physiotherapy, occupational therapy, respiratory therapy)	2/3	-	-	-	1/3	1/3
Alternative therapies (massage)	1/3	-	-	-	-	1/3
Foot care	1/3	1/3	-	-	1/3	1/3
Mental health services for adults – in home	1/3	-	-	-	-	1/3
Mental health services for adults – in foster care	1/3	-	-	-	-	1/3
Mental health services for adults – in institution/facility	1/3	-	-	-	-	1/3
Mental health services for children – in home	1/3	-	-	-	1/3	-
Mental health services for children – in foster care	1/3	-	-	-	-	1/3
Day hospitals	1/3	-	-	-	-	1/3
Specialty hospital services (pediatrics, geriatrics)	2/3	-	-	-	-	2/3
Hospital liaison worker/discharge planner	2/3	-	-	-	1/3	1/3
Foster care (children)	-	-	1/3	-	-	1/3
Supportive housing	1/3	-	-	-	-	1/3
Group homes	1/3	-	-	-	-	1/3
Long term care facilities (nursing homes) that cover all care levels	2/3	-	-	-	-	2/3
Respite care – in home	2/3	-	-	-	-	2/3
Respite care – in institution	1/3	-	1/3	-	-	2/3
Palliative care – in home	2/3	-	-	-	1/3	1/3
Palliative care – in institution	2/3	-	-	-	1/3	1/3
Palliative care – in hospital	2/3	-	-	-	1/3	1/3
Palliative care support	1/3	-	-	-	-	1/3
Technical aids, equipment and supplies	1/3	--	-	-	-	1/3
Medical transportation	1/3	-	1/3	1/3	-	1/3
Adapted vehicle for medical transportation	-	1/3	1/3	-	-	1/3
Special needs/education programs for children	1/3	-	1/3	-	-	1/3
Health promotion, wellness and fitness programs	-	1/3	-	-	1/3	-
Traditional healer/counselling	-	1/3	1/3	-	1/3	1/3
Long term care facilities (nursing homes) that cover all care levels	1/3	1/3	-	1/3	-	-

* Stakeholders did not answer in some cases.

To complete the previous tables, the following table shows the effectiveness of the services provided as well as the funding sources according to the size of the community. One can see that according to two out of the three stakeholders, the services of a hospital liaison worker, in-home respite care, medical transportation and vehicle adapted to medical transportation are often or always provided in an effective manner in medium and large communities. Based on the table it is the same with medical transportation, vehicle adapted to medical transportation and health promotion, wellness and fitness programs in small communities. However, according to two out of the three stakeholders, home and community rehabilitation services are never or rarely provided in an effective manner in small communities. The key stakeholders added that specialized health services are rarely available in Aboriginal settings, particularly in remote communities.

Table 8.6: Effectiveness of services provided and funding sources according to size of community

	Medium and large communities			Small communities		
	Never, rarely	Sometimes	Often, always	Never, rarely	Sometimes	Often, always
	Funding sources			Funding sources		
Home/community rehabilitation	1/3	1/3	-	2/3	-	-
	Health Canada			Health Canada		
Alternative therapies	1/3	1/3	-	-	1/3	-
	Community global funding					
Foot care	1/3	-	1/3	-	66.6%	-
	Health Canada			Health Canada		
Mental health services for adults – in home	-	1/3	-	1/3	-	-
	Community overall budget and Health Canada					
Mental health services for adults – in foster care	-	1/3	-	-	1/3	-
Mental health services for adults – in institution/facility	-	1/3	-	-	1/3	-
Mental health services for children – in home	-	1/3	-	-	1/3	-
	Community overall budget and Health Canada					
Mental health services for children – in foster care	-	1/3	-	-	1/3	-
Mental health services for children – in institution/facility	-	1/3	-	-	1/3	-
Day hospitals	-	-	1/3	-	-	1/3
Specialty hospital services	-	2/3	-	1/3	-	1/3
	MSSS*			MSSS		
Hospital liaison worker/discharge planner	-	-	2/3	-	1/3	1/3
	MSSS or community budget			MSSS and Health Canada		
Foster care (children)	-	-	1/3	-	-	1/3
Supportive housing	-	-	1/3	-	-	1/3
Group homes	-	-	1/3	-	-	1/3

Suite	Medium and large communities			Small communities		
	Never, rarely	Sometimes	Often, always	Never, rarely	Sometimes	Often, always
	Funding sources			Funding sources		
Long term care facilities that cover all care levels	-	1/3	1/3	1/3	1/3	-
	MSSS			MSSS		
Extended or chronic care facilities	-	1/3	1/3	1/3	-	1/3
	DINAC or MSSS			MSSS or in another community		
Respite care – in home	-	-	66.6%	-	1/3	1/3
	Health Canada			Health Canada		
Respite care – in institution	-	1/3	1/3	-	2/3	-
	DINAC or MSSS			DINAC or MSSS		
Palliative care – in home	-	1/3	1/3	1/3	1/3	-
	Community budget			Health Canada		
Palliative care – in institution	1/3	-	1/3	1/3	1/3	-
	DINAC or MSSS			DINAC or MSSS		
Palliative care – in hospital	-	-	1/3	-	1/3	-
Palliative care support			1/3		1/3	-
Technical aids, equipment and supplies	-	1/3	1/3	-	2/3	-
	Health Canada			Health Canada		
Medical transportation	-	-	2/3	-	-	2/3
	Health Canada			Health Canada		
Adapted vehicle for medical transportation	-	-	2/3	-	-	2/3
	Health Canada			Health Canada		
Special needs /education programs for children	-	1/3	1/3	-	1/3	-
Health promotion, wellness and fitness programs	-	1/3	1/3	-	-	2/3
	Health Canada			Health Canada		
Traditional healer/counselling	1/3	-	-	1/3	-	1/3
	Communities			Communities		

*MSSS = *Ministère de la santé et des services sociaux*, Ministry of health and social services
**Stakeholders did not answer in some cases.

Continuing care services provided by federal, provincial, regional and municipal programs

According to stakeholders, home and community continuing care services provided by federal, provincial, regional and municipal programs are often or always culturally adapted to First Nations and Inuit, notwithstanding the size of the community and/or the location where people can access these services.

Outside the communities however, stakeholders agree that the services offered are rarely culturally adapted to First Nations and Inuit (notwithstanding the size of the community and/or the location where people can access these services) since they use the same services as the rest of the population.

Institution continuing care services provided by federal, provincial, regional and municipal programs are often or always culturally adapted to First Nations and Inuit, notwithstanding the size of the community and/or the location where people can access these services.

Outside the communities however, stakeholders agree that the services offered are rarely culturally adapted to First Nations and Inuit (notwithstanding the size of the community and/or the location where people can access these services) since they use the same services as the rest of the population. It seems that employees in facilities outside the communities do not know First Nations characteristics.

The key stakeholders did add though that communities located near urban centres had more chances to have their characteristics taken into account.

Table 8.7 shows the needs of communities in terms of access to continuing care services provided by federal, provincial, regional and municipal programs. According to two out of the three key stakeholders, communities have higher needs in terms of in-home mental health services for adults, foster care for children, supportive housing, and home and institution palliative care. However, the needs seem to vary depending on the size of the community (small, medium and large).

Table 8.7: Needs in terms of access to continuing care services provided by federal, provincial, regional and municipal programs in small communities

	Needs within communities			Needs outside communities		
	Low	Moderate	High	Low	Moderate	High
Home/Community Rehabilitation (Physiotherapy / Occupational Therapy /Respiratory Therapy)	-	1/3	1/3	-	2/3	-
Alternative Therapies (massage)	-	2/3	-	-	1/3	1/3
Foot Care	1/3	-	1/3	1/3	1/3	-
Mental Health Services for Adults – in home	-	-	2/3	-	2/3	-
Mental Health Services for Adults – in foster care	-	-	1/3	-	2/3	-
Mental Health Services for Adults – in institution/facility	-	-	1/3	-	2/3	-
Mental Health Services for Children – in home	-	-	1/3	-	2/3	-
Mental Health Services for Children – in foster care	-	-	1/3	-	2/3	-
Mental Health Services for Children – in institution/facility	-	-	1/3	-	2/3	-
Day Hospitals	-	-	1/3	-	1/3	1/3
Specialty Hospital Services (e.g., pediatrics, geriatrics)	-	1/3	-	-	1/3	1/3
Hospital Liaison Worker/Discharge Planner	-	2/3	-	1/3	1/3	-
Foster Care (Children)	-	-	2/3	-	1/3	-
Supportive Housing	-	-	2/3	-	1/3	-
Group Homes	-	1/3	1/3	-	1/3	-
Extended or chronic care facilities	-	1/3	1/3	1/3	-	1/3
Respite Care – in home	1/3	1/3	-	-	1/3	-
Respite Care – in institution	-	1/3	1/3	1/3	1/3	-
Palliative Care – in home	-	-	2/3	1/3	1/3	-
Palliative Care – in institution	-	-	2/3	1/3	-	1/3
Palliative Care – in hospital	-	1/3	1/3	1/3		1/3
Palliative Care Support	-	1/3	-	-	1/3	-
Technical Aids, Equipment and Supplies	-	1/3	1/3	1/3	-	1/3
Medical Transportation	1/3	1/3	-	1/3	1/3	-
Adapted Vehicle for Medical Transportation	1/3	1/3	-	1/3	1/3	-
Special needs/education programs for children	-	-	1/3	-	-	-
Health Promotion, Wellness and Fitness Programs	-	1/3	1/3	1/3	1/3	-
Traditional healer/counselling	-	2/3	-	-	1/3	-

The key stakeholders interviewed agree that the continuing care services currently provided in First Nations and/or Inuit communities often meet the needs of the population. To summarize, they claim that services are adapted but not sufficient.

According to key stakeholders, the additional continuing care services needed are long-term care housing in communities, additional funding in order to provide adequate palliative care and for the clientele requiring a higher number of hours of services, type 3, 4 and 5 levels of institutional care, day centres and health professional care in communities (physiotherapy, occupational therapy, speech therapy, etc.).

Still according to them, no continuing care service provided at the time of the survey was not necessary or, in other words, all the continuing care services were necessary.

At the time of the survey, certain measures had been implemented in order to improve the delivery of continuing care services in communities. According to the stakeholders, discussions with Health Canada and DINAC were in progress to integrate their home and community care programs in First Nations and/or Inuit communities, as well as to develop a national policy on continuing care. These discussions and research seemed to be carried out jointly with First Nations and the various stakeholders wished that new budgets be allotted by the Treasury Board in the upcoming months.

Concerning the coordination[77] of health and/or social services in communities, some stakeholders indicated there were some discussions to develop a strategic frame for social programs for the next ten years, with the participation of First Nations and/or Inuit. The assurance of the continuity of care throughout the various stages of life is sought in the course of these discussions.

Several times the key stakeholders stressed the lack of funding allotted to the delivery of continuing care services in First Nations and/or Inuit communities. There seems to be consensus on this condition in light of the increasing needs of the home and facility clientele. With respect to the type of funding, renewable and recurrent funds are most suited for communities since this allows them to provide viable and sustainable services.

Moreover, the stakeholders described the funding formula used for the delivery of continuing care services in communities as poor. According to them, the funding formula should be updated following the assessment of the home care program. They are against the fact that is it based on the population rather than actual needs and suggest it be weighed against the clientele requiring this type of services.

At the time of the survey, fund transfers from one type of continuing care service to another were prohibited. Some stakeholders propose that First Nations receive block funding, such as with Child and Family Services, for example.

Overall, continuing care services in communities seem somewhat coordinated. It is mentioned that at the time of the survey, each program had its own requirements and their design did not

---

[77] The term “coordination” refers to the possibility for individuals requiring continuing care services to progress easily in a continuum of care.

link the various programs. Some stakeholders hope that the development of a strategic plan for all the programs will help improve the service coordination and the continuity of care between generations. They also explain that in communities with housing facilities, everything functions rather well provided the patient requires type 1 or 2 levels of care (i.e. relatively independent). The clientele requiring higher levels of services must be referred to the provincial system, which has a specific process and where the delays are very long.

With respect to the level of coordination between home and community continuing care services and other health and social services offered in communities, it seems to vary from one community to another. Some stakeholders pinpointed the bureaucracy associated to the fact that the programs are linked to two Ministries. It seems to result in a difficulty to ensure a good coordination.

It is the same situation for the level of coordination between continuing care services in facilities and other health and social services offered in communities, provided that the facilities are located in the communities and the needs of the clientele are not too high.

Opinions are divided regarding the level of coordination between home and community continuing care services offered in communities and health and social services offered outside communities. Some claim there are some links between both whereas others claim the opposite.

Regarding the level of coordination between continuing care services in facilities offered in communities and health and social services offered outside communities, the stakeholders identified the lack of knowledge of facilities located outside communities concerning the reality, culture and characteristics of First Nations.

Finally, the level of coordination between health and social services and the education system in the case of children with special needs seems somewhat good, with the exception of financial responsibility issues. According to the key stakeholders, it seems the programs are protecting their budget.

The stakeholders identified factors that influence the coordination of continuing care services within communities and outside communities. Within communities, the aging population, increase of disabling disease prevalence, inadequacy of funding, significant staff turnover as well as bureaucracy were identified. Outside communities, increase of users in the provincial network, underfunding as well as lack of knowledge of the provincial network regarding the services provided in communities were mentioned.

The following table indicates to what extent some continuing care components are met in communities. According to two out of the three key stakeholders, the access to continuing care services within the community, quality of care provided by care staff and accountability to the local leadership are satisfying or very satisfying. However, the facilitation of care outside of the community, fair treatment of individuals and allocation of resources to continuing care are very poor or adequate according to two out of the three stakeholders. They also indicated that continuing care services meet very poorly or adequately the needs of the people receiving care.

Table 8.8: Satisfaction towards certain continuing care services provided in communities

	Very poor or poor	Adequate	Good or very good
Access to continuing care services within the community (e.g., able to obtain home care services)	-	-	2/3
Facilitation of care outside of the community (e.g., able to obtain long term care)	1/3	1/3	-
Coordination of continuing care services across types of services (e.g., moving from home care to facility care)	1/3	-	1/3
Quality of care provided by care staff	-	-	2/3
Fairness in how people are treated (e.g., equal access to care)	1/3	1/3	-
Fairness in how resources are allocated for continuing care (e.g., funding responds directly to community needs)	1/3	1/3	-
Continuing care services meet the needs of the people receiving care	1/3	1/3	-
Continuing care services meet the needs of family members/close friends of people in care	-	1/3	-
Accountability to the leadership (e.g. Chief and Council)	-	1/3	1/3
Accountability to Health Canada and/or INAC from First Nations/Inuit communities	-	-	2/3
Accountability from Health Canada and/or INAC to First Nations/Inuit communities	-	1/3	1/3

*Stakeholders did not answer in some cases.

According to the key stakeholders, the strengths of the continuing care system for First Nations members, such as it was at the time of the survey, are the adaptability of the program based on the needs of each community, the existence of 7 facilities funded by DINAC for type 1 and 2 clients, the involvement of the close ones to provide services, the access to the provincial network for type 3, 4 and 5 clients and for hospital care. Among the strengths identified is also Health Canada's home care that enables each community to develop its own service plan and thus prioritize needs, the presence of Aboriginal staff and the adaptation of services to First Nations reality.

The weaknesses that came out of this exercise are the fact that the provincial network cannot adapt itself to the First Nations and Inuit cultural component even though long-term care facilities are described as living environments, the lack of funding and type 1 and 2 institutional resources as well as the absence of type 3, 4 and 5 levels of care in communities despite the high level of needs.

In light of the weaknesses previously mentioned, the key stakeholders proposed some measures in order to improve the continuing care system offered to First Nations and/or Inuit. They suggest the funding be more flexible and more appropriate to existing services and programs, that responsibilities be expanded to level 3, 4 and 5 of institutional care and that services be offered to the First Nations clientele living in communities.

To this effect, the key stakeholders interviewed took position on the communities' capacity to manage their own continuing care services and according to them, most communities have the capacity. Some communities could manage continuing care services in a very independent manner, while others could do it with some supervision and a few could not for various reasons. They also indicated that if more specialized services were to be offered in communities, professional training could be provided.

8.1.3 Additional resources (n = 3)

One of the three stakeholders indicated that, based on his skills, he was aware of indicators and/or benchmarks regarding continuing care services offered in communities. Those are the assessment of the recipient's loss of autonomy (Medical assessment form: CTMSP), provincial and federal standards for the construction of seniors homes and the Quebec policies: *seniors and the strategy for the continuity of care for the population of Quebec.*

With respect to indicators and/or benchmarks that would be necessary, one stakeholder out of three suggested establishing performance indicators, adapted training programs and promoting health and prevention services as well as health and social services positions in Aboriginal settings.

Finally, a key stakeholder knows of exemplary programs among First Nations and/or Inuit that include a full range of continuing care services and one stakeholder is aware of unpublished literature on continuing care services for First Nations.

8.1.4 Summary: Regional level results

3 key stakeholders interviewed at the regional level:
In medium and large communities

- services offered in general:
  home nursing care and attendant care, medical transportation in the community, specialty hospital services, supportive housing, home and respite care and institution respite care outside the community
- services usually missing:
  home maintenance services, day programs, foster care for adults or seniors, institutional care, in-home mental health services for adults and children, hospital services and institution palliative care
- higher needs:
  attendant care, home nursing care, day programs, technical aids and equipment, institutional care or services, in-home mental health services for adults, foster care for children, supportive housing and home and institutional palliative care

In small communities

- services offered in general:
  home nursing care and attendant care
- services usually missing:
  home maintenance services, day programs, foster care for adults or seniors, institutional care, home respite care, home and community rehabilitation, specialty hospital services, hospital liaison worker, long-term and extended care facilities, institutional respite care and home and institutional palliative care
- higher needs:
  attendant care, home nursing care, day programs, technical aids and equipment, institutional care and services, case management, training and teaching support staff, medical transportation services, in-home mental health services for adults, foster care for children, supportive housing and home and institutional palliative care

according to the regional key stakeholders

- the needs and services offered vary significantly from one community to another, depending on the size and the remoteness:
  small communities seem to have less services than medium and large ones
  specialized health services are rarely available in Aboriginal settings, particularly in remote communities
- outside communities:
  specialty hospital services, long-term and extended care facilities and home respite care are always or almost always available

concerning cultural adaptation

- home and community continuing care services are often adapted to the First Nations and Inuit culture (notwithstanding the size of the community) outside the community they are less adapted
- communities located near urban centres have more chances of seeing their characteristics taken into account
- opinions are divided when it comes to establishing whether communities have the human, material and financial resources to achieve the cultural adaptation of their home and community care services
- services are adapted but insufficient
- all the continuing care services provided were necessary at the time of the survey

according to the regional key stakeholders

- additional continuing care services required:
  long-term care facilities in communities
  additional funding to provide adequate palliative care and for the clientele requiring several hours of service
  type 3, 4 and 5 institutional care
  day centres
  health professional care in communities

according to the regional key stakeholders

- family is often the resource privileged to care for people requiring continuing care
- the lack of financial resources puts significant pressure on caregivers, who then tend to go beyond their limits, thus jeopardizing their own health. For this reason, several family caregivers wish to be paid for the time they care for their close ones. That way, they could give the services to their client without worrying about their financial situation

concerning coordination

- overall continuing care services in communities are somewhat well coordinated
- bureaucracy was mentioned as it is associated to the fact that the program is linked to two Ministries and facilities outside communities do not know the First Nations reality and characteristics
- coordination seems better in facilities located in communities and for a clientele whose needs are not too high
- factors that influence the coordination of continuing care services within and outside communities:

  within communities

    aging population, increase of the prevalence of disabling diseases, inadequacy of funding, significant staff turnover and bureaucracy

  outside communities

    increase in the number of users in the provincial network, underfunding as well as provincial network's lack of knowledge regarding services offered in communities

according to the regional key stakeholders

- good or very good:

  access to continuing care services within the community, quality of care provided by care staff and accountability to local leadership
- very poor or adequate:

  facilitation of care outside the community, fair treatment of individuals and allocation of resources to continuing care
- continuing care services meet very poorly or adequately the needs of people receiving care

according to the regional key stakeholders

- strengths of the continuing care system for First Nations and Inuit (at the time of the survey): adaptability of the program based on the needs of each community, existence of 7 facilities funded by DINAC for type 1 and 2 clients, involvement of the close ones to provide services, access to the provincial network for type 3, 4 and 5 clients for hospital care, Health Canada's home care, which allows each community to develop its own service plan and prioritize its needs, the presence of Aboriginal staff and the adaptation of services to First Nations reality

- weaknesses of the continuing care system for First Nations and Inuit (at the time of the survey):
  the fact that the provincial network cannot adapt itself to the cultural component of First Nations and Inuit (even though long-term care facilities are described as living environments), the lack of funding and type 1 and 2 institutional resources and the absence of type 3, 4 and 5 levels of care in communities

concerning funding

- renewable and recurrent funds are the most indicated for communities
- poor appreciation of the funding formula used for the provision of continuing care services in communities,
  are against the fact it is based on population rather than on actual needs
  suggest it be weighed against the clientele requiring this type of services
- suggestions:
  allocate more flexible and appropriate funding for existing services and programs
  clarify and expand responsibilities regarding type 3, 4 and 5 institutional care and services offered to First Nations clientele living in communities
  establish performance indicators and adapted training programs
  promote health and prevention services as well as positions in the health and social services sectors in Aboriginal settings

8.2 Community Level Results (n = 5)

8.2.1 General information (n = 5)

As mentioned previously, four communities took part in this survey: Kahnawake, Kitigan Zibi, Timiskaming and Wendake. Out of the four, 3 are medium communities and 1 is a large community.

At the community level, 5 key stakeholders were interviewed (which means two key stakeholders completed the questionnaire in one community): two Health Directors, one Home and Community Care Director, one Long-Term Care Facility Director and one Group Home Coordinator. One key stakeholder has been in his position for less than twelve months, two for more than 2 years but less than 5 years and two for more than 5 years. Their level of familiarity with the continuing care services offered in their community varies from familiar to very familiar.

8.2.2 Continuing Care Services in First Nations Communities (n = 5)

According to the key stakeholders interviewed, in two out of the three communities in the survey, only community registered members are eligible to continuing care services whereas one community accepts any person residing in the community (i.e. First Nations member, Metis, Inuit or non-Aboriginal). One stakeholder did not answer.

According to the key stakeholders, communities all offer continuing care services to seniors, adults with chronic diseases or conditions, adults with mental health needs and children with special needs. One community also offers follow-up at home after hospitalization.

The following table indicates the positions in the community responsible for determining whether people eligible to receive continuing care services actually receive them. The respondents could designate more than one person. One stakeholder did not answer. One can see that, according to the five key stakeholders, home and community care managers and multidisciplinary teams are in charge of verifying the continuing care services provided. However three out of the five stakeholders identified the Health and/or Social Services Director and the Facility Manager.

Table 8.9: People in the communities in charge of verifying the continuing care services provided

People	
Manager of Home/Community Care	**4/4**
Multidisciplinary Team	**4/4**
Health Director	**3/4**
Social Services Director	**3/4**
Manager of Facility	**3/4**
Chief or Council	**2/4**
Community Health Nurse	**2/4**
Nurse in Charge	**1/4**
Other	**1/4**
Public Health Nurse	**-**
Joint Multiple Agencies	**-**

According to the key stakeholders, the process to determine whether a person may or may not receive continuing care services consists in completing an assessment with the multiclientele tool, following a request from an individual or his family, in order to determine his needs.

Continuing care services funded by Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program*

The following table presents the continuing care services funded by Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program*. In some cases, stakeholders did not answer or indicated they did not know the answer. One can see in this table that, according to the majority of five community key stakeholders, management case services, information and referral services, attendant care, home nursing and support care, home respite care, technical aids and equipment, non-medical transportation and facility are offered in communities. Conversely, home maintenance services, day programs and foster care for adults and seniors are either not offered at all or not offered adequately, according to the majority of five community key stakeholders.

Table 8.10: Continuing care services funded by Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program*

Service is present	Offered in an appropriate setting			Offered at an appropriate time			Offered for an appropriate length of time			Offered by an appropriate provider		
	Never, rarely	Sometimes	Often, always	Never, rarely	Sometimes	Often, always	Never, rarely	Sometimes	Often, always	Never, rarely	Sometimes	Often, always
Case Management (assessment, program management)												
4/4			3/3		1/4	3/4			4/4			3/3
Information / Referral Services												
3/3			3/3			3/3			3/3			3/3
Education and Teaching of Personal Care Staff												
3/4			3/3			3/3			3/3			3/3
Meal Program												
3/4		1/2	1/2			3/3	1/2		1/2		1/2	1/2
Attendant Care												
4/4		1/3	2/3		1/3	2/3		1/3	2/3		1/3	2/3
In-Home Nursing Care												
4/4			3/3			3/3			3/3			3/3
Home Support Services (personal care, housekeeping, meal preparation)												
4/4		1/4	3/4		1/4	3/4		1/4	3/4		1/4	3/4
Home Maintenance (water, wood, minor repairs)												
3/4		1/3	2/3	2/3	1/3		1/3	2/3		1/3	2/3	
Day Program (includes activity programs)												
2/4			2/2			2/2			2/2		1/2	1/2
Respite Care – in home												
4/4		1/4	3/4		1/4	3/4		1/4	3/4		1/4	3/4
Technical Aids, Equipment & Supplies												
3/3			3/3			3/3			3/3			3/3
Non-Medical Transportation Services												
4/4			3/3		2/3	1/3		1/3	2/3			3/3
Foster Care (Adults/Elderly)												
-												
Institutional services/Facility Care												
4/4			4/4		1/4	3/4		2/4	2/4			4/4

* The stakeholders did not answer in some cases.

According to the key stakeholders interviewed, the continuing care services funded by Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program* are rarely (1/4) or often, always (3/4) culturally adapted to the people in their community. One stakeholder did not answer.

With respect to facility continuing care services funded by DINAC, two out of the four stakeholders who answered indicated they are never or rarely culturally adapted. The two others indicated they were often culturally adapted. One stakeholder did not answer.

Three out of the four key stakeholders are of the opinion that their community does not have the human, material and financial resources to culturally adapt its home and community care services as well as those in a facility, whereas one stakeholder believes his community does. One stakeholder did not answer.

The following table shows the needs in the communities for continuing care services funded by Health Canada's *First Nations and Inuit Home and Community Care Program* and/or DINAC's *Assisted Living Program*. One stakeholder did not answer. From the table, it can be seen the needs in terms of meal programs are high according to three out of the four key stakeholders who answered and moderate in terms of home maintenance. The relatively fragmented results seem to indicate that the needs vary depending on the communities.

Table 8.11: Needs in terms of continuing care services according to community level key stakeholders

	Low	Moderate	High
Case Management (assessment, program management)	-	2/4	2/4
Information / Referral Services	2/4	2/4	-
Education and Teaching of Personal Care Staff	2/4	2/4	-
Meal Programs	1/4	-	3/4
Attendant Care	2/4	-	2/4
In-Home Nursing Care	2/4	-	2/4
Home Support Services (personal care, housekeeping, meal preparation)	2/4	-	2/4
Home Maintenance (water, wood, minor repairs)	1/4	3/4	-
Day Programs (includes activity programs)	1/4	2/4	1/4
Respite Care – in home	2/4	1/4	1/4
Technical Aids, Equipment & Supplies	1/4	2/4	1/4
Non-Medical Transportation Services	2/4	2/4	-
Foster Care (Adults/Elderly)	1/4	2/4	1/4
Institutional Services/Facility Care	1/4	2/4	1/4

The community level key stakeholders listed means used to care for people requiring continuing care services. Among them are respecting the lifestyle, maintaining dignity, the possibility of addressing individuals in their mother tongue, the feeling that the recipient remains a useful member of his community and gathering the different generations.

Two out of the five stakeholders indicated the close ones often participate in the delivery of continuing care services to members of their own family, regardless of if the person receives care at home, in the community or in a facility. The three others indicate they sometimes participate. One stakeholder indicated his answer varied depending on if the person received care at home or in a facility.

The community level key stakeholders agree to say that, generally, the immediate family members are not paid when they provide their family members with continuing care services.

According to the key stakeholders, the difficulties most frequently encountered by family caregivers are non-existent or limited funds and social issues. Family caregivers must often pursue their personal life (work, family, etc.) and therefore have very little or no respite, which eventually leads them to exhaustion. Thus the limit of 40 hours of service per week offered by

DINAC's program is not sufficient to assist families with persons requiring significant continuing care services. One stakeholder also indicated drug addiction and violence towards Elders.

Table 8.12 shows the services offered in the community of the community level key stakeholders. One stakeholder did not answer or indicated he did not know the answer. No funding source was indicated. Generally, according to the four key stakeholders who answered, foot care, respite care, medical transportation services and health promotion, wellness and fitness programs are offered in the community. The home and community rehabilitation services, in-institution/facility mental health services for children, specialty hospital services, hospital liaison worker and foster care for children are offered outside the community. The distance from the community was not specified. Alternative therapies, supportive housing, facility respite care and traditional healer services seem not to be offered or rarely offered within and outside communities, according to the community level key stakeholders.

Table 8.12: Services provided in the community according to community level key stakeholders

	Present in community	Available outside community	Provided in an effective manner		
			Never, rarely	Sometimes	Often, always
Home/Community Rehabilitation	-	4/4	-	4/4	-
Alternative Therapies	1/4	1/1		1/1	-
Foot Care	4/4	4/4	2/4	1/4	1/4
Mental Health Services for Adults – in home	3/4	3/4	1/3	1/3	1/3
Mental Health Services for Adults – in foster care	1/4	3/3	1/2	1/2	-
Mental Health Services for Adults – in institution/facility	2/3	3/3	1/3	1/3	1/3
Mental Health Services for children – in home	3/4	3/3	-	2/3	1/3
Mental Health Services for Children – in foster care	1/4	3/3	1/3	2/3	-
Mental Health Services for Children – in institution/facility	-	4/4	2/4	2/4	-
Day hospitals	1/4	3/4	1/4	2/4	1/4
Specialty hospital services	2/4	4/4	-	4/4	-
Hospital Liaison Worker/Discharge Planner	3/4	4/4	-	2/3	1/3
Supportive housing	1/4	1/3	-	1/1	-
Group homes	3/4	3/4	-	3/4	1/4
Long Term Care Facilities that cover all care levels	-	3/4	-	2/3	1/3
Extended or chronic care facilities	2/4	3/4	-	1/4	3/4
Respite care – in home	4/4	1/4	-	1/4	3/4
Respite care – in institution	2/4	2/3	-	-	3/3
Palliative care – in home	3/4	1/4	-	-	3/3
Palliative care – in institution	1/4	3/3	1/4	-	3/4
Palliative care support	3/4	2/3	1/4	1/4	2/4
Technical aids, equipment and supplies	3/4	-	-	-	3/3
Medical transportation	4/4	2/4	1/4	-	3/4
Adapted vehicle for medical transportation	3/4	3/3	1/4	1/4	2/4
Special needs/education programs for children	2/4	1/3	1/3	-	2/3
Health promotion, wellness and fitness programs	4/4	2/4	-	1/2	1/2
Traditional healer/counselling	2/4	2/4	-	2/2	-

Home and community as well as facility continuing care services provided by federal, provincial, regional and municipal programs

According to the stakeholders, the home and community as well as facility continuing care services provided by federal, provincial, regional and municipal programs are rarely or sometimes culturally adapted for the people in their community. One stakeholder indicated they were always or almost always because they were managed by First Nations members.

The following table shows the needs of people in their communities, according to the community level key stakeholders, in terms of access to continuing care services provided by federal, provincial, regional and municipal programs. One stakeholder did not answer or indicated he did not know the answer. By reading this table, one can see that, according to community level key stakeholders, the needs in terms of continuing care are high for all the services offered, particularly with respect to foot care, specialty hospital services, hospital liaison workers, extended care facilities and palliative care support.

Table 8.13: Needs in communities in terms of access to continuing care services provided by federal, provincial, regional and municipal programs according to key stakeholders

	Needs in the community			Needs outside the community		
	Low	Moderate	High	Low	Moderate	High
Home/Community Rehabilitation	-	1/4	3/4	-	1/3	2/3
Alternative Therapies	-	1/2	1/2	-	1/2	1/2
Foot Care	-	-	4/4	-	1/3	2/3
Mental Health Services for Adults – in home	-	1/4	3/4	-	2/3	1/3
Mental Health Services for Adults – in foster care	-	1/4	3/4	-	1/3	2/3
Mental Health Services for Adults – in institution/facility	-	1/4	3/4	-	1/3	2/3
Mental Health Services for Children – in home	-	1/4	3/4	-	1/3	2/3
Mental Health Services for Children – in foster care	-	1/4	3/4	-	1/3	2/3
Mental Health Services for Children – in institution/facility	-	1/4	3/4	-	1/3	2/3
Day Hospitals	1/4	1/4	2/4	1/3	1/3	1/3
Specialty Hospital Services	-	-	4/4	-	-	3/3
Hospital Liaison Worker/Discharge Planner	-	-	4/4	-	-	3/3
Foster Care (Children)	1/4	1/4	2/4	1/3	1/3	1/3
Supportive Housing	-	2/4	2/4	-	2/3	1/3
Group Home	-	2/4	2/4	-	2/3	1/3
Long Term Care Facility	-	-	3/4	-	-	3/3
Extended or Chronic Care Facility	-	-	4/4	-	-	3/3
Respite Care – in home	-	1/4	3/4	-	2/3	2/3
Respite Care – in institution	-	1/3	2/3	1/4	2/4	1/4
Palliative Care – in home	-	1/4	3/4	-	2/3	1/3
Palliative Care – in institution	-	1/4	3/4	-	2/3	1/3
Palliative Care – in hospital	-	1/4	3/4	-	2/3	1/3
Palliative Care Support	-	-	4/4	-	1/3	2/3
Technical Aids, Equipment and Supplies	-	1/4	3/4	-	2/3	1/3
Medical Transportation	-	1/4	3/4	-	1/3	2/3
Adapted Vehicle for Medical Transportation	-	1/3	2/3	-	1/3	2/3
Special needs/education programs for children	-	-	3/4	-		2/2
Traditional Counselling/Healing	1/4	1/4	2/4	2/4	1/4	1/4

According to the community level key stakeholders, continuing care services provided by federal, provincial, regional and municipal programs should be managed by First Nations communities.

Generally, the continuing care services that were offered at the time of the survey sometimes or often met the needs of the population. One stakeholder answered rarely. However the key stakeholders indicated that additional services were required in their community, such as institutional long-term care, family caregiver support, institutional palliative care and a group home for children and that therefore more funding was needed. Moreover, no continuing care service provided at the time of the survey was not necessary or, in other words, all services were necessary.

The community level key stakeholders mentioned more than once how the funding allocated was insufficient for the delivery of continuing care services in their community. Institutional care as well as adult care are underfunded by DINAC and home care seems to be underfunded by Health Canada. They also mentioned the lack of qualified staff.

The stakeholders described their appreciation of the funding formula used for the delivery of continuing care services in their community as poor. According to one stakeholder, they are particularly poor with respect to people requiring mental health services. According to all stakeholders, renewable and recurrent funds are the most indicated for their community. Moreover, transferring funds from one type of continuing care service to another was prohibited at the time of the survey.

Overall, continuing care services in communities seem well coordinated, as well as the coordination between home and community continuing care services and other health and social services in the community (one stakeholder did however indicate it was poorly coordinated).

The coordination between facility continuing care and other health and social services in the community also seems good. One stakeholder did however indicate that people have to stop having conflicts and start developing better working relations.

It is the same with the coordination between home and community continuing care services and health and social services outside the community. One stakeholder did however indicate these two services were poorly coordinated.

Concerning the coordination between facility continuing care services in the community and health and social services outside the community, some stakeholders mentioned the fact that the provincial health system does not seem to understand the reality of the situation. They also condemned the lack of communication sometimes between both parties.

Finally, the level of coordination between health and social services and the education system in the case of children with special needs seems somewhat good in general, according to the five community level key stakeholders.

The stakeholders identified factors that influence the coordination of continuing care services within and outside communities. Within their community, the main factor seems to be the lack of financial resources. The stakeholders also pinpointed the lack of communication and cumbersome protocols. Finally, outside communities, they raised the lack of comprehension of First Nations reality and the lack of collaboration between the various organizations and the recipients’ families.

The following table indicates the level of satisfaction towards certain continuing care provided in the community according to the community level key stakeholders. One stakeholder did not answer. Certain continuing care seem to be satisfying or very satisfying according to key stakeholders: access to continuing care services within the community, the quality of care provided by care staff, the fairness in how people are treated and the accountability of communities to local leadership and Health Canada and/or DINAC. However, the fragmented results seem once more to indicate how variable are the needs and services offered in communities. Opinions are divided when it comes to the facilitation of care outside the community, the fairness in how resources are allocated for continuing care, the adequacy of continuing care services for people who receive care and for their family members and friends as well as the accountability of Health Canada and/or DINAC to communities.

Table 8.14: Satisfaction towards certain continuing care services provided in the community according to community level key stakeholders

	Very poor or poor	Adequate	Good or very good
Access to continuing care services within your community (e.g., able to obtain home care services)	-	-	4/4
Facilitation of care outside of your community (e.g., able to obtain long term care)	2/4	1/4	1/4
Coordination of continuing care services between types of services (e.g., moving from home care to facility care)	-	2/4	2/4
Quality of care provided by care staff	1/4	-	3/4
Fairness in how people are treated (e.g., equal access to care)	1/4	-	3/4
Fairness in how resources are allocated (e.g., funding responds directly to community needs)	2/4	1/4	1/4
Continuing care services meet the needs of the people receiving care	1/4	2/4	1/4
Continuing care services meet the needs of family members/close friends of people in care	1/4	2/4	1/4
Accountability to the leadership (e.g. Chief and Council)	-	-	4/4
Accountability to Health Canada and/or INAC	-	-	4/4
Accountability from Health Canada and/or INAC	1/4	1/4	2/4

8.2.3 Additional resources (n = 5)

At the time of the survey, no stakeholder was aware of indicators and/or benchmarks for continuing care services in communities. They did not know of any exemplary First Nations and/or Inuit programs that include a full range of continuing care services nor of any unpublished literature regarding continuing care services for First Nations individuals.

8.2.4 Supplemental questionnaire (n = 5)

As mentioned previously, four communities took part in this survey: Kahnawake, Kitigan Zibi, Timiskaming and Wendake. Three are medium communities and 1 is a large community.

For this supplemental questionnaire, 5 key stakeholders were interviewed (which means two key stakeholders completed the questionnaire for one community).

During data collection, a supplemental questionnaire was administered to community level key stakeholders in order to get more details on specific subjects. This questionnaire was comprised of 5 sections:

A. Estimated number of community members
B. Estimated number of people requiring formal continuing care services in the community
C. General information on formal continuing care services in the community
D. General information on continuing care services provided by family caregivers in the community
E. Additional comments

In completing the questionnaire, the key stakeholders were to include children with special needs, adults with chronic diseases or conditions, adults with mental health needs as well as seniors.

For the purposes of this survey, the key stakeholders were to answer the questions with the following understanding of each definition:

- Continuing care: refers to a range of holistic medical and social services for individuals who do not have, or who have lost, some capacity to care for themselves.
- Facility: refers to a range of housing options, outside of a private home, where continuing care services may be provided.
- Need: refers to a formal care service that is considered to be required by an individual and by a health professional if a health care assessment were to be conducted.
- Formal care service: refers to a service that is provided by a paid health care provider.
- Family caregiver: refers to a family member, close friend, or other individual who provides assistance to an individual requiring continuing care services.

A. Estimated number of community members

Medium and large communities were part of the survey. The following tables show the number of community members by age group and gender based on the example of a medium community and a large community. In the example of a medium community, it can be seen that 147 individuals out of 1298 required continuing care services at the time of the survey, which is more than 11.0% of members who lived in the community at least 6 out of the 12 months preceding the survey. Out of these 147 individuals, 35 are less than 55 years old, which means that there continuing care needs could be long-term needs. In the example of a large community, it can be seen that 263 individuals out of 7313 required continuing care services at the time of the survey, which is more than 3.0% of members who lived in the community at least 6 out of the 12 months preceding the survey. Out of the 263 individuals, 36 are less than 55 years old.

Table 8.15: Portrait of a medium community by age group and gender

Combined Age and Gender Groups	TOTAL number of community members who lived within the community for at least 6 months in the 12 months preceding the survey	Number of community members who lived within the community for at least 6 months in the 12 months preceding the survey AND required continuing care services	Number of community members who did not live within the community for at least 6 months in the 12 months preceding the survey BECAUSE they had to access continuing care services elsewhere
0-17	303	12	-
18-44	473	20	-
45-54	190	3	-
55-64	169	17	-
65-74	88	33	-
75 +	75	62	3
Total	1298	147	3
Male	636	N/A	N/A
Female	662	N/A	N/A
Total	1298	N/A	N/A

Table 8.16: Portrait of a large community by age group and gender

Combined Age and Gender Groups	TOTAL number of community members who lived within the community for at least 6 months in the 12 months preceding the survey	Number of community members who lived within the community for at least 6 months in the 12 months preceding the survey AND required continuing care services	Number of community members who did not live within the community for at least 6 months in the 12 months preceding the survey BECAUSE they had to access continuing care services elsewhere
0-17	1615	1	N/A
18-44	2787	17	N/A
45-54	1189	18	N/A
55-64	698	43	N/A
65-74	486	59	N/A
75 +	538	125	N/A
Total	7313	263	N/A
Male	3515	83	N/A
Female	3798	180	N/A
Total	7313	263	N/A

The following table presents the number of individuals with a chronic condition who did not require continuing care services at the time of the study but who may require services in the future, based on the example of a medium community. Information regarding a large community is not available. This table therefore indicates that, in the case of a medium community, 479 individuals will potentially need continuing care services in the future. As mentioned previously, if a medium community has 1298 members who lived within the community for at least 6 months in the 12 months preceding the survey; these 479 individuals represent more than 36.0% of this sample. To summarize, it is more than 11.0% of the population who lived within the community for at least 6 months in the 12 months preceding the survey who, at the time of the study, needed continuing care and more than 36.0% who may need some in the future.

Table 8.17: Individuals with a chronic condition who did not need continuing care services at the time of the survey but who could need some in the future based on the example of a medium community

Chronic condition	
Diabetes	84
Heart conditions (ex. cardiovascular disease)	123
Respiratory conditions (ex. asthma)	53
Other physical conditions (ex. arthritis)	87
Mental health disorder	34
HIV/Aids, cancer	76
Other condition (kidney disease)	22
Total	479

B. Estimated number of people requiring formal continuing care in the community

In this section, the key stakeholders had to estimate the number of people who need formal home and /or community care and institutional care services, regardless of the availability of the services at the time of the study. Moreover, they had to base their estimations only on the needs of the clients and not on the eligibility criteria, the availability of care staff and/or existing health services.

Finally, their estimations had to include community members who received continuing care services (home, community or institutional care) in the 12 months preceding the survey and the community members who did not receive continuing care services in the 12 months preceding the study but who should have received some according to the key stakeholder.

The following tables present the estimated number of people requiring home and/or community care and institutional care by need level and based on the example of a medium community. The estimations for a large community are not available. Based on the estimations provided by the community level key stakeholders, a total of 194 persons need formal home and/or community care services and 128 need institutional care services. These numbers add up to a total of 322 persons who would have needed formal home care services based on the actual needs in the 12 months preceding the survey, which is twice as much as the 150 who actually received some. These results are based on the example of a medium community and therefore cannot be considered representative of all First Nations. They do however have the advantage of offering a good overview of the situation.

Table 8.18: Estimated number of people requiring home and/or community care by need level and based on the example of a medium community

	Estimated number of people who lived within the community for at least 6 months in the 12 months preceding the survey AND who needed home and/or community care	Estimated number of people who did not live in the community for at least 6 months in the 12 months preceding the survey BECAUSE they had to access home and/or community care elsewhere
Need Level 1: Individuals who require some assistance with activities of daily living and/or social and recreational services	**23**	**-**
Need Level 2: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week	**10**	**-**
Need Level 3: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week	**35**	**-**
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision	**30**	**3**
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)	**17**	**-**
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care	**50**	**-**
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing	**25**	**-**
Need Level 8: Individuals who require palliative care either in the home or in a facility	**1**	**-**
Total	**191**	**3**

Table 8.19: Estimated number of people requiring institutional care by need level and based on the example of a medium community

	Estimated number of people who lived within the community for at least 6 months in the12 months preceding the survey AND who needed facility care	Estimated number of people who did not live in the community for at least 6 months in the12 months preceding the survey BECAUSE they had to access facility care elsewhere
Need Level 1: Individuals who require some assistance with activities of daily living and/or social and recreational services	60	N/A
Need Level 2: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week	20	N/A
Need Level 3: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week	N/A	N/A
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision	10	N/A
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)	N/A	N/A
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care	20	N/A
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing	10	N/A
Need Level 8: Individuals who require palliative care either in the home or in a facility	8	N/A
Total	128	N/A

The following tables present the estimated number of people requiring home and/or community care and institutional care by continuing care group. The estimations for a large community are not available. According to the community level key stakeholders, with respect to both home and community care, 14 children with special needs, 56 adults with chronic diseases or conditions, 34 adults with mental health needs and 98 seniors (55 years and over) needed services at the time of the survey based on the example of a medium community. With respect to institutional care, no children with special needs, 30 adults with chronic diseases or conditions, 2 adults with mental health needs and 13 seniors aged 55 and over needed services at the time of the study, for a total estimation of 247 persons.

Table 8.20: Estimated number of persons in need of home and/or community care by continuing care group and based on the example of a medium community

	Children with Special Needs	Adults with Chronic Diseases or Conditions	Adults with Mental Health Issues	Seniors (55 years of age and older)
Need Level 1: Individuals who require some assistance with activities of daily living and/or social and recreational services	4	12	10	5
Need Level 2: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week	N/A	15	20	20
Need Level 3: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week	5	8	4	22
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision	N/A	N/A	N/A	3
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)	5	5	N/A	3
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care	N/A	15	N/A	29
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing	N/A	N/A	N/A	15
Need Level 8: Individuals who require palliative care either in the home or in a facility	N/A	1	N/A	1
Total	14	56	34	98

Table 8.21: Estimated number of persons in need of institutional care by continuing care group and based on the example of a medium community

	Children with Special Needs	Adults with Chronic Diseases or Conditions	Adults with Mental Health Issues	Seniors (55 years of age and older)
Need Level 1: Individuals who require some assistance with activities of daily living and/or social and recreational services	N/A	N/A	N/A	N/A
Need Level 2: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week	N/A	N/A	N/A	1
Need Level 3: Individuals who require both supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week	N/A	N/A	N/A	2
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision	N/A	25	2	8
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)	N/A	3	N/A	1
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care	N/A	N/A	N/A	N/A
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing	N/A	N/A	N/A	N/A
Need Level 8: Individuals who require palliative care either in the home or in a facility	N/A	2	N/A	1
Total	-	30	2	13

C. General information on formal continuing care services in the community

This section presents information related to continuing care services actually offered in communities. It consists of basic information on the service delivery and the costs associated to it. However, in order to preserve the privacy of communities having participated in the study, certain results pertaining to costs were not included in this report. They will however be integrated to the results in the study's national report.

Home and/or community care

Based on the example of a medium community, 147 persons were receiving home and/or community care in their community at the time of the survey (150 including those who had to leave their community to receive care). All of them actually received home and/or community continuing care services in the 12 months preceding the survey. In the example of a large community, 263 persons were receiving home and/or community care. More or less 275 actually received home and/or community continuing care services in the 12 months preceding the survey.

The annual operating expenditures for the home and community care program for fiscal year 2004/2005 in the case of a medium community are not available, and neither are the estimated amount of funding needed for one fiscal year nor the global costs per hour or per visit for care staff involved in the home and community care program due to the limited number of communities surveyed and in order to preserve their privacy.

The following tables indicate the total number of hours of service or visits provided in the 12 months preceding the survey for various types of employees providing care, based on the example of a medium and large community. In both cases, it can be seen that home support staff are the employees most requested for in home and/or community continuing care.

Table 8.22: Total number of hours of service or visits by various types of employees providing care in the 12 months preceding the survey based on the example of a medium community

	Number of		Number is		Estimated Amount of Funding Needed for One Fiscal Year
	Hours	Visits	Estimated	Actual	
Nurse (RN)	400	124			N/A
Nursing Assistant					-
Home Support Workers, Personal Care Workers	Support: 2,815 Care: 194	818 190			N/A
Traditional healers					-
Other care staff (personal care workers)	116	36			N/A
Total	3,525	1,168			
Average cost per hour or visit across all care staff	N/A	N/A			N/A

Table 8.23: Total number of hours of service or visits by various types of employees providing care in the 12 months preceding the survey based on the example of a large community

	Number of		Number is		Estimated Amount of Funding Needed for One Fiscal Year
	Hours	Visits	Estimated	Actual	
Nurse (RN)	**4,102.50**	**6,440**		√	**N/A**
Nursing Assistant					
Home support workers	**36,052.75**	**N/A**		√	**N/A**
Traditional healers					
Other care staff					
Total	**40,155.25**	**6,440**			
Average cost per hour or visit across all care staff	**N/A**	**N/A**		√	**N/A**

<u>Institutional care</u>

Out of the 4 communities in the study, 2 have supportive housing units, 1 has a group home, 1 a personal care home, 1 a seniors home and 1 a hospital on community. Most of those types of facilities were chosen based on the community's needs and by consulting the community members.

The 4 communities surveyed only have one facility. Half of these facilities are licensed and the provincial government is responsible for providing licensing. None of the 4 facilities is accredited.

The number of beds available in the facilities located in the medium and large communities varies between 2 and 25 in the 12 months preceding the survey.

Regarding the number of beds the facilities would need to meet the needs of the people who were receiving care at the time of the survey; it varies between 18 and 33 in medium and large communities.

Between 12 and 33 persons have stayed in a facility located in a medium or large community at some point in the 12 months preceding the survey.

The facilities in the medium and large communities were built between 1990 and 1999.

Three quarters of the facilities did not undergo any renovations in the 5 years preceding the survey. The facility that did undergo renovations added some sprinklers, an alarm system and a kitchen in order to bring it up to codes, provincial or other standards. These renovations cost approximately $12,000.

All the facilities needed renovations at the time of the survey but they were not made because of the cost. Four out of the five key stakeholders consider their rooms to be safe. One stakeholder did not answer.

The facilities' annual operating expenditures for fiscal year 2004/2005 are not available due to the limited number of communities surveyed and in order to preserve their privacy.

Table 8.24 shows the average number of full-time and part-time positions in a facility located in a medium community; table 8.25 is the same for a large community. In the first table, one can see that a facility in a medium community has an average of 12 full-time positions (7 of which are directly related to care services) and 7 part-time positions, for a total of 19. In a facility located in a large community there are 16 full-time positions (5 of which are directly related to care services) and 4 part-time positions, for a total of 20.

Table 8.24: Average number of full-time and part-time positions in a facility located in a medium community

	Staff	Full-time positions	Part-time positions
Care services	Nurses (RN)	2	-
	Nursing Assistants	2	4
	Other Care Staff (for example, Physiotherapists, Occupational Therapists, Social Workers)	-	-
	Traditional Healers	-	-
	Other positions	3	2
Non-care services	Dietary	1	1
	Housekeeping	2	-
	Administration	1	-
	Other services (activities, transportation)	1	-

Table 8.25: Average number of full-time and part-time positions in a facility located in a large community

	Staff	Full-time positions	Part-time positions
Care services	Nurses (RN)	3	4
	Nursing Assistants	-	-
	Other Care Staff (for example, Physiotherapists, Occupational Therapists, Social Workers)	2	-
	Traditional Healers	-	-
	Other positions	-	-
Non-care services	Dietary	3	-
	Housekeeping	5	-
	Administration	2	-
	Other services (activities, transportation)	1	-

The following table shows the average number of hours of care provided by each type of staff member, during a year, to each client of a facility located in a medium community. The information for large communities is not available. One can see that unlike home and community care, which are mostly provided by home support staff, institutional care is mostly provided by nursing assistants in medium communities. Moreover, one can see that, according to estimations by the community level key stakeholders, formal caregivers provided close to 3,525 hours of home care whereas they provided close to 11,596 hours of institutional care, which is almost three times more.

Table 8.26: Average number of hours of care provided in a year by each type of staff member to each client in a facility located in a medium community

	Number of		Number is		Estimated Amount of Funding Needed for One Fiscal Year
	Hours	Visits	Estimated	Actual	
Nurses (RN)	**1,820**			√	**N/A**
Nursing Assistants	**6,136**			√	**N/A**
Home support staff, Personal care worker	**-**				**N/A**
Traditional healers	**-**				**N/A**
Other care staff (personal care worker)	**3,640**			√	**N/A**
Total	**11,596**				**N/A**

D. General information on continuing care services provided by family caregivers in the community

The key stakeholders' level of familiarity with the provision of care services by family caregivers varies from "somewhat familiar" to "very familiar".

According to the key stakeholders, in communities, between 50.0% and 70.0% of clients receive care from family caregivers (ex. family members, close friends or others). Care is usually provided by the client's children (the daughters mostly) or spouse.

According to the key stakeholders, family caregivers provide their client with support for budgeting and invoice payment (going to the bank), grocery shopping and other errands, making medical or other appointments, housekeeping and meal preparation, personal care, light and heavy work, and mobility.

Family caregivers, still according to the key stakeholders interviewed, support the delivery of formal continuing care services by attending meetings with the staff, when needed, by contacting the staff for any changes in the client's needs, by keeping the staff informed of the discussions at medical appointments and by allowing them to enter the client's room.

The key stakeholders all agree that, in the next 10 years, the role of family caregivers will change in their community. In their opinion, the aging population will force family caregivers to be increasingly present with their parents because the places available in facilities are limited and not necessarily adapted to the needs of First Nations communities. The demand for family caregivers' services will therefore increase while the number of family caregivers will decrease.

E. Additional comments

After completing the questionnaires, one key stakeholder added it was very important that the formal care system and family caregivers work together in order to provide recipients with the best possible services. One stakeholder also mentioned it was very difficult to complete a questionnaire such as this one because the various departments are often under various authorities within one community; it is therefore difficult to obtain accurate information.

8.2.5 Summary: Community level results

5 key stakeholders interviewed:

- 2 communities provide continuing care services only to registered members
  1 community provides the services to any person living in the community
- they all offer continuing care services:
  to seniors, adults with chronic diseases or conditions, adults with mental health needs and children with special needs
  1 also offers follow-up at home after hospitalization
- people responsible for verifying the continuing care services provided:
  home and community care managers, multidisciplinary teams, health and/or social services directors, and managers of facilities

according to the community level key stakeholders

- services offered in the community:
  case management, information and referral, home aides, home nursing care and support, respite care, technical aids and equipment, medical and non-medical transportation, facility, foot care and health promotion, wellness and fitness program
- services not offered at all in the community or not offered in an adequate manner:
  home maintenance, day program, foster care for adults or seniors
- services usually offered outside communities:
  home and community rehabilitation, institutional mental health services for children, specialty hospital services, hospital liaison worker and foster care for children
- services not offered outside communities:
  alternative therapies, supportive housing, institutional respite care and traditional healer
- needs in terms of continuing care services seem high for all the services offered
- particularly high:
  meal program, foot care, specialty hospital services, hospital liaison worker, extended care facilities, palliative care support, institutional long-term care, family caregivers support, institutional palliative care and group home for children
- needs vary significantly from one community to another

concerning cultural adaptation

- stakeholders are divided as to whether home, community and institutional care are adapted to the culture of their community
- results also fragmented with respect to the participation of close ones to the provision of continuing care services to members of their own family
- communities do not have the human, material and financial resources necessary to culturally adapt their home and community care as well as institutional care

concerning funding

- continuing care services provided should be managed by First Nations communities
- continuing care services provided at the time of the study somewhat frequently or frequently met the needs of the population
- additional services are needed in their community
- communities need more funding
- all the services were necessary at the time of the study
- close family members receive no remuneration when they provide members of their family with continuing care services
- difficulties encountered by family caregivers are non-existent or limited funds and social issues:
  family caregivers must pursue their personal life. They have only little respite.
  The 40 hours of service per week limit is not sufficient to assist families with persons requiring significant continuing care services
- insufficient funding allocated to the provision of continuing care services in their community
  lack of qualified staff
- poor appreciation of the funding formula used for the provision of continuing care services in their community, especially for people with mental health needs
- renewable and recurrent funds is the most appropriate type of funding for their community

concerning coordination

- coordination is good between the various sectors
- people have to stop having conflicts and start developing better working relations
- the provincial health system does not seem to understand the reality of the situation
- lack of communication at certain times
- factors that influence the coordination of continuing care services within communities:
  lack of financial resources, lack of communication and cumbersome protocols
- outside communities:
  lack of understanding of the First Nations reality
  lack of collaboration between the various organizations and the recipients' families

according to the community level key stakeholders

- satisfying or very satisfying:
  access to continuing care services in the community, quality of care provided by care staff, fair treatment of individuals and accountability of communities to local leadership and Health Canada and/or DINAC
- opinions divided:
  facilitation of care outside the community, fair allocation of resources to continuing care, adequacy of continuing care services for people who receive care and for their family members and friends as well as accountability of Health Canada and/or DINAC to communities
- fragmented results demonstrate how needs and services offered vary in communities

in the case of a medium community

- more than 11.0% of members who lived in the community at least 6 out of the 12 months preceding the survey required continuing care services at the time of the survey
- more than 36.0% may require some in the future
- close to one quarter of individuals who needed continuing care services at the time of the survey are less than 55 years old, which means their needs for continuing care services could be long-term needs
- close to one quarter of the members who lived in the community at least 6 out of the 12 months preceding the survey would have needed formal home care services based on their actual needs in the 12 months preceding the survey, which is twice as much as those who actually received some
- an average of 12 full-time positions (7 of which are directly related to care services) and 7 part-time positions, for a total average of 19

in the case of a large community

- more than 3.0% of members who lived in the community at least 6 out of the 12 months preceding the survey required continuing care services at the time of the survey
- close to 15.0% of individuals who needed continuing care services at the time of the survey are less than 55 years old, which means their needs for continuing care services could be long-term needs
- an average of 16 full-time positions (5 of which are directly related to care services) and 4 part-time positions are open, for a total average of 20

concerning facilities

- home support staff and personal care workers are employees who provide most of the home and/or community care
- 2 communities have supportive housing units
  1 community a group home
  1 a personal care home
  1 a seniors home
- facilities were built between 1990 and 1999
- no renovations were made in the 5 years preceding the survey, with the exception of one facility that added sprinklers, an alarm system and a kitchen for an approximate value of $12,000.
- at the time of the study, all the facilities needed renovations that were not made because of the cost
- rooms are generally considered as safe
- number of beds available in facilities located in medium and large communities varies between 2 and 25
- number of beds these facilities would need to meet the needs of the population varies between 18 and 33
- institutional care is mostly provided by attendant care staff in medium communities
- in the year preceding the survey, formal caregivers provided close to 3,525 hours of home care whereas they provided close to 11,596 hours of institutional care, which is almost three times as much

concerning family caregivers

- between 50.0% and 70.0% of clients receive care from family caregivers, care which is usually provided by the client's children (the daughters mostly) or spouse
- in the next ten years, the role of family caregivers will change in communities:
  aging population will force family caregivers to be more present with their parents because the places available in facilities is limited and not necessarily adapted to the needs of First Nations communities
- demand for family caregivers services will increase while the number of family caregivers will decrease
- very important that the formal care system and family caregivers work together in order to provide recipients with the best possible services

9. Lessons Learned

The research entitled *Assessing Continuing Care Requirements in First Nations and Inuit Communities* led to several learning and positive experiences.

With respect to research:

1. This research project satisfied the various research partners, the federal government representatives (Health Canada and DINAC), the First Nations organization (FNQLHSSC) and the communities of the Quebec Region who took part in the project;

2. The FNQLHSSC's criteria for research were respected, that is the AFNQL's Research Protocol, OCAP principles as well as the conditions set out by the representatives of the Quebec Regional Table on Continuing Care;

3. This research project respected the autonomy of the communities involved at the regional level. The sharing of resources and the FNQLHSSC's flexibility allowed the communities to take over certain components of the study;

4. This research project represents a success model for research with First Nations, which involves collaboration between several partners (First Nations organizations, federal government, research consultants (Hollander Analytical Ldt.));

5. This research project demonstrates that equity and respect of partners involved at the national, regional and community level, as well as the transfer and sharing of powers are success factors in the field of research. Each partner's strengths were used in the course of the research project;

6. This research project should be identified as a model or benchmark with governments in order to encourage similar research experiences in the future;

7. Communication means (conference calls, meetings) facilitated the sharing of experience and expertise all along the project. They also facilitated good communication between the national and regional levels, which is an essential component for the success of such a research project;

8. This research project demonstrated the need for some First Nations communities to have a computer system to compile and manipulate their own data more easily at the community level.

With respect to data collection:

1. The training and technical support for interviewers at the community level were key elements that ensured the proper flow of data collection;

2. The fact that training was provided in the communities by the FNQLHSSC's research team presents several advantages. The research team was able to understand the environment in which the project was to be carried out and meet with the people in charge of continuing care at the community level and the various facilities. On a few occasions, the research team even had the opportunity to meet with local authority representatives.

10. Main Findings

First, lets remind that the goals of this research project were to:

- Determine the needs in terms of continuing care (such as established by the evaluation of levels of care) of the people living in First Nations and Inuit communities;
- Identify which continuing care services are currently provided in First Nations and Inuit communities;
- Develop the options and costs of delivering continuing care services in First Nations and Inuit communities.

The research was based on nine questions:

1. Based on the evaluation, how many people need continuing care (per type of care) in First Nations communities?

2. Which services do people need at each level of care in facilities and at home, and what is the demand for each of these services?

3. What is the contribution of family caregivers (either family members or friends)?

4. Are there differences in the types of services provided depending on the remoteness of the communities?

5. What are the clients' preferences regarding the place where the care is provided?

6. What is the clients' satisfaction level regarding the continuing care services received?

7. What is their quality of life?

8. Are the home and institutional care appropriate for the clients who receive them?

9. What is the cost of service delivery?

To achieve this, 192 clients receiving continuing care, 89 family caregivers, 3 regional level key stakeholders and 5 community level key stakeholders were interviewed. Here are the results from these interviews.

10.1 Main Findings for Clients

More than three quarters of the clients receive long-term care and home care. Half of them are over 75 years of age.

More than three quarters of the clients at home own their house, almost half of them lives alone. Homes that are owned by the clients usually require more major and minor repairs than homes owned by someone else. More than half of the homes require or have required modifications following the clients' physical condition.

Almost three quarters of the clients in facilities are alone in their room. Clients consider their room and facility to be safe and would recommend it to others.

Almost all clients are happy with their life. Clients at home receive support more often than those in facilities, with the exception of someone with whom to share meals and someone who helps out with the routine. Almost all client at home indicate they always or almost always have someone who shows them love and affection whereas less than three quarters of those in facilities can say the same. A higher percentage of short-term care clients indicate they always or almost always receive support compared to long-term care clients.

Almost three quarters of the clients indicate they have a family caregiver. Most of the time this role is filled by the clients' children, mainly by the daughters. Family caregivers provide care mostly for the mobility outside the house and inside and outside maintenance. Half of the family caregivers provide ten hours of care and more per week to their client and one fifth of them provide 60 hours of care and more.

Personal care workers and home support workers are the most solicited professionals for continuing care. Formal caregivers assist clients mainly with light housekeeping, cleaning and nursing or medical care. Three quarters of them provide nine hours of care per week or less to their client. Clients seem very satisfied with the caregivers' politeness and courtesy. Opinions are more divided with respect to the family's involvement in the planning of care.

If they were given the choice, almost three quarters of clients would prefer remaining in their home with appropriate care and services. Almost all of them would prefer living in their community rather than where services can be easily accessed, which involves they would have to leave the community.

Almost three quarters of the clients believe there is a need for other types of housing in their community.

More than half of the clients are in categories 1 and 2; one tenth is the categories 5 to 7. Activities of daily living are the autonomy clients lose first and communication, the one they lose last. Clients aged 18 to 54 and those aged 75 and over are mostly in categories 6 and 7. Clients in categories 1 and 2 mostly receive care at home while clients in categories 3, 4 and 5 mostly receive care in a facility.

The four clients aged 0 to 24 receive home long-term care. All the homes have needed modifications following the client's physical condition. The four clients are happy with their life. They all have a family caregiver, three of which are the clients' mother or parents. The four of them have a low or very low level of autonomy: they are in categories 5 to 7.

10.2 Main Findings for Family Caregivers

More than three quarters of family caregivers are part of the client's family and care for a client in long-term care. Almost three quarters assist a client at home and are female. Two thirds are aged under 55 and had a paid job at the time of the survey. One third of family caregivers has one or more dependent children in addition to the client targeted in this survey.

One quarter of family caregivers had to leave work suddenly to care for the client and had to miss work to assist their client with care.

Almost all of family caregivers receive assistance in the provision of care and support to their client. One third of family caregivers care for other people (not including the client targeted in this study).

Almost three quarters of family caregivers provide their client with ten hours of care per week and more while one fifth provides 60 hours of care and more per week.

Personal care workers and home support workers are the most solicited professionals for continuing care. Two thirds of them provide care to their client nine hours or less per week. Less than a third of family caregivers indicate they always or almost always have their say on who will provide their client with care, what services will be provided and when they will be provided. Family caregivers seem very satisfied with the caregivers' politeness and their respect for the client's language. Opinions are more divided though regarding the family's involvement in the planning of care.

If they were given the choice, almost two thirds of family caregivers would prefer for their clients to remain in their own home with appropriate care and services. More than one third of them would prefer for their client to be in a living situation with assistance, a facility or an institution. Almost all of them would prefer for their clients to live in their community rather than where services are easily accessed, which involves they would have to leave the community.

More than three quarters of family caregivers believe there is a need for other types of housing in their community.

Almost all family caregivers get satisfaction from assisting their client. Satisfactions are mixed though regarding the future of their client and access to respite care for both the client and themselves.

Family caregivers made suggestions to improve the care and quality of life of their client: foster socialization, set up activities, diversify services and care, increase the number of hours provided, involve the family more, repair or improve the home/room, set up diets or "meals on wheels" services, maintain services currently provided, improve communication between the various types of stakeholders, caregivers and the program management, facilitate access to respite care for family caregivers, build a home for people with disabilities and build a palliative care service.

10.3 Main Findings for Regional Level Key Stakeholders

In medium and large communities

Services usually offered are home nursing care and support services, medical transportation in the community, specialty hospital services, supportive housing, home respite care and facility respite care program outside the community.

Services that are usually missing include home maintenance services, day program, foster care for adults or seniors, institutional care, home mental health services for adults and children, hospital services and institutional palliative care.

The needs are high in terms of attendant care, home nursing care, day programs, technical aids and equipment, institutional care and services, home mental health services for adults, foster care for children, supportive housing and home and institutional palliative care.

In small communities

Services usually offered are home nursing care and home support services.

Services that are usually missing include home maintenance services, day programs, foster care for adults or seniors, institutional care, home respite care, home and community rehabilitation services, specialty hospital services, hospital liaison worker, long-term and extended care facilities, institutional respite care and home and institutional palliative care.

The needs are high in terms of attendant care, home nursing care, day programs, technical aids and equipment, institutional care and services, case managements, training and teaching for personal care staff, medical transportation services, home mental health services for adults, foster care for children, supportive housing and home and institutional palliative care.

However, the needs and services vary significantly from one community to the other depending on the size and the remoteness. Small communities seem to have less services than medium and large communities. Specialized health services are rarely available in Aboriginal settings and particularly for remote communities.

Outside communities, specialty hospital services, long-term care facilities and home respite care programs are often or always available.

Home and community continuing care services are fairly frequently adapted to the First Nations culture (notwithstanding the size of the community). Outside communities they are less adapted. Communities located near urban centres have more chances of seeing their characteristics taken into account. Opinions are divided regarding whether communities have the human, material and financial resources to culturally adapt their home and community care services. To summarize, services are adapted but insufficient.

All the continuing care services offered at the time of the study were necessary.

The additional continuing care services needed include long-term care facilities in the communities, additional funding to provide adequate palliative care and for the clientele requiring a significant amount of hours of services, type 3, 4 and 5 institutional care, day centres and health professional care in the communities.

Family is often the privileged resource to care for people in need of continuing care. The lack of financial resources puts significant pressure on caregivers, which leads them to often go beyond their limits, thus jeopardizing their own health. For this reason, several family caregivers would like to be paid for the time invested in the provision of care to their close ones. That way, they could provide services to their client without worrying about their financial situation.

Continuing care services in communities are fairly well coordinated overall. However, bureaucracy was mentioned as being associated to the fact that the programs are linked to two Ministries, as well as the lack of knowledge of facilities outside the communities on First Nations reality and characteristics. Moreover, the services seem well coordinated as long as the facilities are located in the community and the clients' needs are not too high.

Within communities, the factors that influence the coordination of continuing care services are the aging population, the increase in the prevalence of disabling diseases, the funding's inadequacy, the significant staff turnover as well as bureaucracy. Outside communities, the factors that influence the coordination of continuing care services are the increase in the number of users in the provincial network, underfunding as well as the lack of knowledge of the provincial network regarding the services offered in the communities.

Access to continuing care services in the community, the quality of care provided by care staff and the accountability to local leadership seem to be satisfying or very satisfying. Facilitation of care outside the community, the fair treatment of individuals and the allocation of resources to continuing care seem to be very unsatisfying or adequate. The continuing care services meet in a very poor or adequate manner the needs of the people who receive them.

According to the regional level key stakeholders, the strengths of the continuing care system for First Nations and Inuit (at the time of the study) were the adaptability of the program depending on each community's needs, the existence of 6 facilities funded by DINAC for type 1 and 2 clients, the involvement of the close ones for the provision of services, access to the provincial network for type 3 and 4 clients and for hospital care, Health Canada's home care, which allow each community to develop its own service plan and prioritize its needs, the presence of Aboriginal staff and the adaptation of services to the First Nations reality.

According to the regional level key stakeholders, the weaknesses of the continuing care system for First Nations and Inuit (at the time of the study) were the fact that the provincial network cannot adapt itself to the cultural component of First Nations and Inuit (even though long-term care facilities are described as living environments), the lack of funding and the lack of type 1 and 2 institutional resources and the absence of type 3, 4 and 5 care in the communities.

The stakeholders base themselves on the insufficient funding allocated to the delivery of continuing care services in the communities and the increasing needs of the home and facility clientele to claim that renewable and recurrent funds are the most indicated for communities. They give a poor appreciation of the funding formula used for the provision of continuing care services in the communities and are against the fact that it is based on the population rather than on actual needs. Therefore they suggest that it be weighed against the clientele requiring this type of services.

The regional level key stakeholders made a few suggestions: allocate funding that is more flexible and appropriate to existing services and programs as well as clarify and expand the responsibilities with respect to type 3, 4 and 5 institutional care and to services offered to the First Nations clientele living in a community.

They also suggested establishing performance indicators, adapted training programs and promoting health and prevention services as well as positions in the health and social services sectors in Aboriginal settings.

10.4 Main Findings for Community Level Key Stakeholders

In two communities, only registered members are eligible to continuing care services and one community accepts any person residing in the community. They all offer continuing care services to seniors, adults with chronic diseases or conditions, adults with mental health needs and children with special needs. One community also offers follow-up at home after hospitalization.

The people in charge of verifying the continuing care services provided are the home and community care managers, multidisciplinary teams, health and/or social services directors and managers of facilities.

The services offered in communities are case management services, information and referral, attendant care, home nursing care and support services, respite care, technical aids and equipment, medical and non-medical transportation, institutional care, foot care and health promotion, wellness and fitness programs.

The services not offered at all or not offered in an adequate manner in communities are home maintenance services, day programs and foster care for adults or seniors. Alternative therapies services, supportive housing, institutional respite care and traditional healer are not offered outside communities either.

Services usually offered outside communities include home and community rehabilitation services, institutional mental health services for children, specialty hospital services, hospital liaison workers and foster care for children.

Needs in terms of continuing care seem high for all of the services offered. They are particularly high with respect to meal programs, foot care, specialty hospital services, hospital liaison workers, extended care and palliative care facilities, institutional long-term care, support to family caregivers, institutional palliative care and group homes for children. The needs however vary significantly from one community to another.

Stakeholders are divided regarding whether home, community and institutional care are culturally adapted to their community. Results are also mixed concerning the close ones' participation in the provision of continuing care services to members of their own family.

Generally, communities do not have the human, material and financial resources to culturally adapt their home and community care services as well as those in facilities.

The community level key stakeholders are of the opinion that the continuing care services provided should be managed by the First Nations communities.

The continuing care services offered at the time of the study fairly frequently or frequently met the needs of the population. However, additional services are needed in their communities. Communities need more funding.

All the services were necessary at the time of the survey.

Generally, immediate family members receive no payment when they provide continuing care services to members of their own family. The difficulties encountered by family caregivers are non-existent or limited funds and social issues. Family caregivers must pursue their personal life, but they have very little respite. The 40 hours of service per week limit is not sufficient to assist families with members who have significant continuing care service needs.

On several occasions, the community level key stakeholders mentioned the insufficient funding allocated for the provision of continuing care services in their community and the lack of qualified staff. They give a poor appreciation of the funding formula used for the provision of continuing care services in their community, especially for people with mental health needs. They believe renewable and recurrent funds are the most indicated type of funding for their community.

Generally, the coordination goes fairly well between the various sectors. It was mentioned though that people should stop having conflicts and start developing better working relations, that the provincial health system did not seem to understand the reality of the situation and that communication lacked at certain times.

The factors that influence the coordination of continuing care services within communities are the lack of financial resources, the lack of communication and the cumbersome protocols. Outside communities, the lack of understanding of the First Nations reality and the lack of collaboration between the various organizations and the recipients' families.

Overall, continuing care services are satisfying or very satisfying regarding access to continuing care services in the community, the quality of care provided by the personal care staff, the fair treatment of individuals and the community's accountability to local leadership and to Health Canada and/or DINAC. Opinions are divided regarding the facilitation of care outside the community, fair allocation of resources to continuing care, adequacy of continuing care services for people who receive the care and for their family members and friends as well as the accountability of Health Canada and/or DINAC to communities. The fragmented results shows how the needs and services vary in the communities.

In the case of a medium community

Stakeholders estimated to more than 11.0% the number of members who lived in the community at least 6 out of the 12 months preceding the survey and who needed continuing care services at the time of the survey, and to more than 36.0% the number of members who might need some in the future. Moreover, almost one quarter of individuals who needed continuing care at the time of the survey are aged less than 55, which means their continuing care needs could be long-term needs.

According to community level key stakeholders, almost one quarter of the members who lived in the community at least 6 out of the 12 months preceding the survey would have needed formal home care services based on their actual needs in the 12 months preceding the survey, which is twice the number of those who actually received some.

In the facilities located in medium communities, an average of 12 full-time positions (7 of which are directly related to care services) and 7 part-time positions are open, for a total average of 19.

In the case of a large community

Stakeholders estimated to more than 3.0% the number of members who lived in the community at least 6 out of the 12 months preceding the survey and who needed continuing care services at the time of the survey. Almost 15.0% of individuals who needed continuing care at the time of the study are aged less than 55, which means their continuing care needs could be long-term needs.

In the facilities located in large communities, an average of 16 full-time positions (5 of which are directly related to care services) and 4 part-time positions are open, for a total average of 20.

Home support workers and personal care workers are the employees most solicited for home and/or community continuing care.

Two communities have housing with support services, one community has a group home, one has a personal care home, and one has a seniors home. The facilities were built between 1990 and 1999. They have not undergone any renovations in the 5 years preceding the survey, with the exception of one who added sprinklers, an alarm system and a kitchen for an approximate value of $12,000. At the time of the study, all facilities needed renovations that were not made because of the cost. Rooms are generally considered to be safe.

The number of beds available in the facilities located in medium and large communities varies between 2 and 25. The number of beds these facilities would need to meet the needs of the people varies between 18 and 33.

According to community level key stakeholders, institutional care is mostly provided by nursing assistants in medium communities. In the year preceding the survey, formal caregivers provided about 3,525 hours of home care while they provided about 11,596 hours of institutional care, which is almost three times as much.

In the communities, between 50.0% and 70.0% of clients receive care by family caregivers, care which is usually provided by the client's children (the daughters mostly) or spouse.

In the next ten years, the role of family caregivers will change in the communities. The aging population will force family caregivers to be increasingly present with their parents since the places available in facilities are limited and not necessarily adapted to the needs of First Nations communities. The demand for family caregivers' services will therefore increase while the number of family caregivers will decrease.

Stakeholders mentioned it was very important that the formal care system and family caregivers work together in order to provide clients with the best possible care.

10.5 Revisiting the Research Questions

1. **Based on the evaluation, how many people need continuing care (per type of care) in First Nations communities?**

The key stakeholders interviewed estimated that between 3.0% and 11.0% of the members who lived in a community (medium or large) at least 6 out of the 12 months preceding the survey needed continuing care at the time of the study and more than 36.0% might need some in the future. Moreover, between 15.0% and 25.0% of individuals who needed continuing care at the time of the survey were aged less than 55, which means their continuing care needs might last some time and possibly on a permanent basis.

2. **Which services do people need at each level of care in facilities and at home, and what is the demand for each of these services?**

Needs are different from one community to another. Therefore, it is impossible to determine the need at each level of care. However, the needs are higher with respect to attendant care, home nursing care, day programs, technical aids and equipment, institutional care or services, home mental health services for adults, foster care and group homes for children, supportive housing, home and institutional palliative care, case management, training and teaching for personal care staff, medical transportation services, meal programs, foot care, specialty hospital services, hospital liaison workers, extended care facilities, palliative care support, institutional long-term care and family caregivers support.

The demand is also high for long-term care facilities in the communities, palliative care, day centres, health professional care, care for the clientele requiring a significant number of hours of service, type 3, 4 and 5 institutional care, home maintenance services, day programs, foster care for adults or seniors, alternative therapy services, supportive housing, institutional respite care and traditional healer.

3. What is the contribution of family caregivers (either family members or friends)?

Family is the privileged resource to care for the people requiring continuing care. Almost three quarters of clients indicate they have a family caregiver. Between half and three quarters of family caregivers provide their client with ten hours of care per week and more and one fifth provide 60 hours and more per week. Comparatively to formal caregivers who provide care for 9 hours or less per week, the majority of the care services are in the hands of family caregivers.

This role is mostly filled by the client's children (the daughters mostly) or spouse. Three quarters of family caregivers are female. About three quarters of them provide a client with home long-term care. Two thirds are aged less than 55 and had a paid job at the time of the study. One third of family caregivers have one or more dependent children in addition to the client targeted in this study.

Generally, family caregivers are not paid when they provide a client with continuing care services. They face two main problems: the lack of financial resources and social issues. Family caregivers must pursue their personal life; therefore they have very little respite. The 40 hours of service per week limit is not sufficient to assist families with members who have significant continuing care needs. The lack of financial resources puts great pressure on family caregivers who then tend to go beyond their limits, thus jeopardizing their own health.

In the next few years, the aging population and the increase in the prevalence of disabling diseases will force family caregivers to be increasingly present with their close ones. The decline in families will result in an increased demand for family caregiver services while the number of family caregivers will decrease.

4. Are there differences in the types of services provided depending on the remoteness of the communities?

Needs and services offered vary significantly from one community to another based on the size and the remoteness. Small communities seem to have less care and services than medium and large communities; communities near urban centres seem to have more care and services than remote communities.

In medium and large communities, the services usually offered are home nursing care and support services, medical transportation in the community, specialty hospital services, supportive housing, home respite care and institutional respite care outside the community. The services usually missing are home maintenance services, day programs, foster care for adults and seniors, institutional care, home mental health services for adults and children, hospital services and institutional palliative care.

In small communities, the services usually offered are home nursing care and home support services. The services usually missing are home maintenance services, day programs, foster care for adults and seniors, institutional care, home respite care, home and community rehabilitation services, specialty hospital services, hospital liaison worker, long-term and extended care facilities, institutional respite care and home and institutional palliative care.

5. What are the clients' preferences regarding the place where the care is provided?

All the clients and family caregivers agree to say it is better for clients to remain in their community to receive care and services. Moreover, the majority indicate it is preferable for the clients to remain in their home with appropriate care and services.

6. What is the clients' satisfaction level regarding the continuing care services received?

Overall, clients and family caregivers are satisfied with the continuing care services received, especially the caregivers' politeness and courtesy and respect for their client's language. However, the family's involvement in the planning of care does not seem to satisfy the clients and family caregivers.

The level of satisfaction of the family caregivers and the stakeholders regarding the continuing care received is also to consider. More than two thirds of family caregivers claim they never or almost never have their say on the range of services offered to their client, on the choice of providers and the moment when the services will be provided which cause them dissatisfaction.

The key stakeholders seem satisfied with the access to continuing care in the community, the quality of care provided by personal care staff, the fair treatment of individuals the communities' accountability to local leadership and to Health Canada and/or DINAC.

The key stakeholders seem dissatisfied with the bureaucracy associated to the fact that the programs are linked to two departments, the lack of knowledge of the facilities located outside the communities on the First Nations reality and characteristics, the facilitation of care outside the community, the fair treatment of individuals and the allocation of resources to continuing care. According to them, continuing care services meet the needs of the clients in a very unsatisfactory or adequate manner.

7. What is their quality of life?

Almost all clients are happy with their life. However, clients at home generally receive more support than those in facilities. A higher percentage of short-term care clients claim they always or most of the time receive support than those in long-term care. However, indicating they are satisfied does not necessarily mean their needs are met but rather maybe that they are satisfied with what they receive.

Family caregivers made some suggestions to improve the care and quality of life of their client: foster socialization, set up activities, diversify services and care, increase the number of hours of care provided, involve the family more, repair or improve the home/room, set up diets or "meal on wheels" services, maintain the services currently provided, improve the communication between the various types of stakeholders, caregivers and program management, facilitate access to respite care for family caregivers, build a home for people with disabilities and build a palliative care service.

8. Are the home and institutional care appropriate for the clients who receive them?

According to the key stakeholders, the strengths of the continuing care system for First Nations and Inuit (at the time of the study) are the adaptability of the program based on the needs of each community, the existence of 7 facilities funded by DINAC for type 1 and 2 clients, the involvement of the close ones to provide services, the access to the provincial network for type 3 and 4 clients and for hospital care, Health Canada's home care, which enable each community to develop its own service plan and thus prioritize needs, the presence of Aboriginal staff and the adaptation of services to First Nations reality.

The weaknesses of the continuing care system for First Nations and Inuit (at the time of the study) are the fact that the provincial network cannot adapt itself to the First Nations and Inuit cultural component (even though long-term care facilities are described as living environments), the lack of funding and type 1 and 2 institutional resources as well as the absence of type 3, 4 and 5 levels of care in communities.

Opinions are divided as to whether home, community and institutional care are culturally adapted to the culture of First Nations and Inuit. They are also divided as to whether communities have the human, material and financial resources required to culturally adapt their home, community and institutional care.

Finally, they agree in saying that additional services are necessary in communities and they do require additional funding. To summarize, services seem to be adapted but not sufficiently funded.

9. What is the cost of service delivery?

On several occasions the key stakeholders mentioned the insufficient funding allocated for the provision of continuing care services in their community and the lack of qualified staff. A cost evaluation was not integrated in the course of this study.

However, the stakeholders did give a poor appreciation of the funding formula used for the provision of continuing care services in communities and are against the fact that it is based on population rather than on actual needs. They suggest it be weighed against the clientele requiring this type of services. Moreover, they base themselves on the insufficient funding allocated for the provision of continuing care services in communities and the increasing needs of the clientele at home and in facilities to claim that renewable funds are the most indicated for communities.

11. Recommendations

With respect to care and services actually offered

- Considering the reality of the Aboriginal population, the cultural adaptation must be maintained and reinforced.

- Considering the actual and increasing needs, care and services available in the communities must be maintained.

With respect to the organization of continuing care

- Considering the aging population and the increase in the prevalence of disabling diseases, which will result in a significant increase of the needs in continuing care in the next years, a long-term vision is necessary in the planning of services in order to meet the needs in continuing care.

- Considering the need to integrate care and services and to adopt a long-term vision in their planning, a policy must be developed to set standards in terms of care and service delivery and ensure the recognition of regional and community needs.

- Considering the ambiguities of governmental authorities in terms of continuing care, the responsibilities of each party involved must be clarified.

- Considering the variability of services offered from one community to another depending on their size and remoteness, measures must be implemented in order for communities to have access in a fair manner to services needed by their members and have each community's context taken into account.

- Considering the shortfalls in financial, human and material resources, which impact on the quality of the care and services provided, performance indicators must be developed at the regional level to ensure the quality of care and services in communities. At the community level, performance indicators must be improved and adapted to each community.

- Considering the bureaucracy associated to the management of health care and services in communities, where resources are already at a minimum level, the management framework must be reviewed to ensure its efficiency and flexibility.

- Considering the lack of resources in communities, accountability translates into a complex and frustrating process for administrators, therefore:
    - federal requirements in terms of accountability must be reviewed in order to streamline current requirements;
    - federal requirements in terms of accountability must be more flexible in order to correspond to the reality of the health services provided.

- Considering the reduced mobility of Elders living at home and their difficulties in accessing information, communication strategies must be developed in order for the people most isolated socially not to be excluded because of any lack of access to information regarding the care and services offered.

- Considering the presence of clients aged 0 to 24, with major incapacities and requiring long-term care that may be permanent, the needs of this group must be taken into account in the planning of care and services.

With respect to the funding of continuing care

- Considering the necessity to adopt a long-term vision in the planning of continuing care, funding must be recurrent, renewable and adjusted to the cost of living.

- Considering the various issues regarding continuing care funding in communities, the funding management must be taken over by First Nations communities themselves.

- Considering, firstly, that DINAC's program funding is allocated only for community members and that Health Canada's program funding is allocated for all residents (whether member or not), and that, secondly, commununities sometimes have to refuse care and services to non-member residents due to a lack of funds, funding should be increased to ensure that all residents have access to quality health care and services in an equitable manner and that communities do not have to choose between members and non-members.

- Considering the needs that vary from one year to another and unexpected situations that may arise in the delivery of continuing care, Health Canada and DINAC must implement measures that enable communities to retain surpluses from year to the next one.

- Considering the current underfunding and the several services missing in communities, the funding of continuing care services must be increased, particularly with respect to mental health services, palliative care, resources for family caregivers and services for persons with disabilities.

- Considering the importance of family and particularly the role of Elders within communities, and in order to respect the First Nations holistic approach to health, measures must be taken to allow clients to remain in their community to receive care and services up until the end.

- Considering the current per capita funding formula and the great variability of needs, the allocation of resources must be adapted to the needs of each community and take into account small communities' reality in order to ensure fairness among communities.

- Considering the current and increasing needs and the clients' will to remain in their community to receive care and services, resources must be invested in order to offer type 3, 4 and 5 levels of care in the communities.

With respect to recipients, their family and family caregivers

- Considering the aging population, the increase in the prevalence of disabling diseases and the decline of the birth rate, the demand for family caregivers will increase in the next years, therefore:
    - measures must be implemented to ensure the support, recognition and accompaniment of family caregivers;
    - the assessment of the client's needs must be done in collaboration with the family caregiver since he shares the recipient's daily life;
    - training and information sessions must be provided to family caregivers to improve and facilitate their contribution with clients;
    - additional resources must be invested in support services to family caregivers in order to ensure a full range of services (babysitting, respite, help, support in instrumental activities of daily life, psychosocial services and community organization);

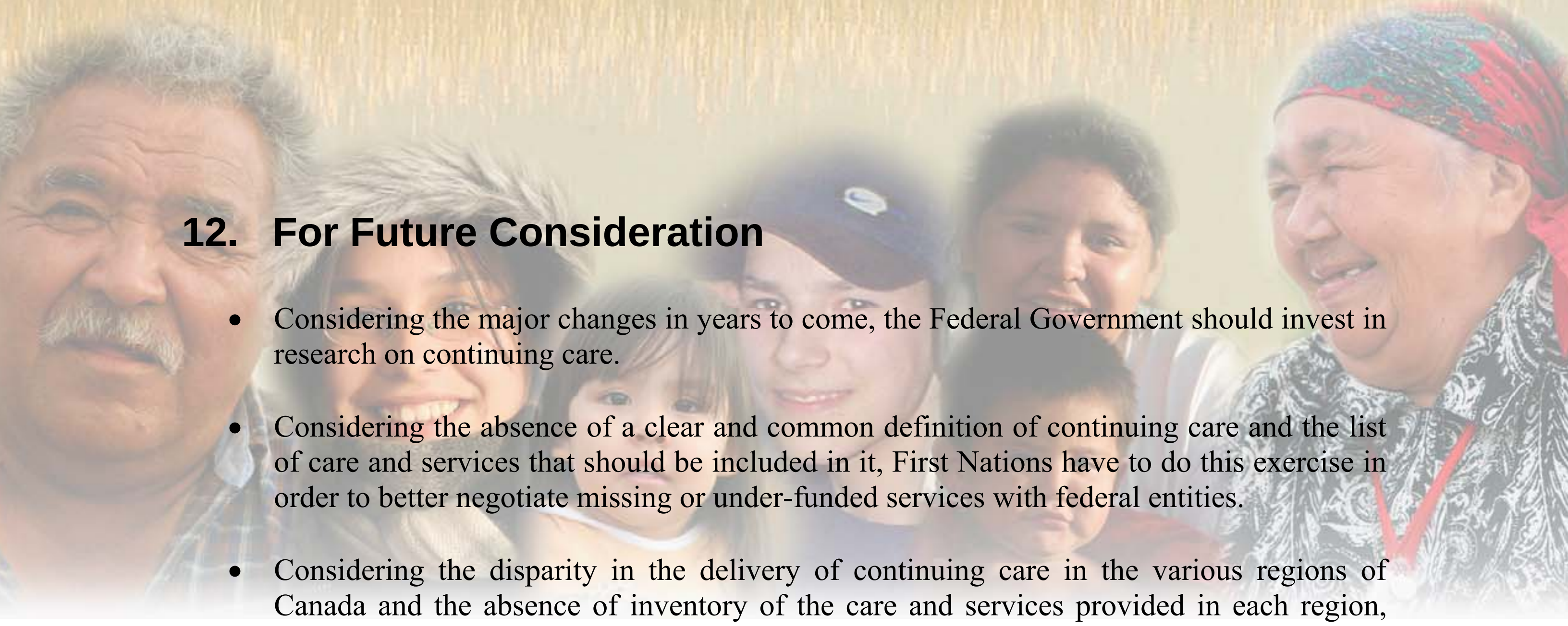
- Considering the impacts of the recipient's disease on his family, measures must be implemented to ensure the involvement, recognition and support of the family all along the continuing care process.

- Considering the unbalance between the contribution by family caregivers and that of formal caregivers, measures must be implemented to reduce the family caregivers' workload and increase the number of caregivers and hours of care provided by them.

- Considering the great proportion of family caregivers who are women and the important role they play in the family, measures must be implemented to reduce their workload and ensure support for them.

With respect to human resources

- Considering the aging population and the increase in the prevalence of disabling diseases, the demand for workers will increase in the next years, therefore:
    - adequate and /or additional training must be provided to workers, managers and program administrators in order to ensure the efficiency of services and management;
    - employment in the health and social services sectors must be promoted in order to ensure succession and meet the current and future needs in continuing care;
    - adequate remuneration amd social benefits must be offered to workers to promote these positions and reduce staff turnover;
    - the workers' working and living conditions must be improved to offset difficulties in staff recruitment and significant turnover.
- Considering the difficulties encountered by First Nations when staying in facilities outside communities, training must be provided to workers in order to make raise their awareness of First Nations realities.



12. For Future Consideration

- Considering the major changes in years to come, the Federal Government should invest in research on continuing care.

- Considering the absence of a clear and common definition of continuing care and the list of care and services that should be included in it, First Nations have to do this exercise in order to better negotiate missing or under-funded services with federal entities.

- Considering the disparity in the delivery of continuing care in the various regions of Canada and the absence of inventory of the care and services provided in each region, surveys must be conducted for the purpose of regional comparisons and therefore enable situating the region of Quebec compared to other regions.

- Considering the impossibility, in this research, to estimate the global costs of care and services inherent to continuing care, more in-depth research should be carried out.

- Considering the impossibility, in this research, to identify the family caregivers who receive a remuneration such as provided by DINAC and, therefore, to know the number of hours provided by family caregivers that were paid or not, these elements should be part of future research.

- Considering the absence of the formal caregivers' point of view in this research's data collection, the formal caregivers' point of view should be part of future research work.

Individuals Involved in the Research of the Quebec Region

FNQLHSSC staff

Côté, Mathieu-Olivier
Research Assistant

Gros-Louis McHugh, Nancy
Technical Coordinator - Information
& Research

Petitpas, Judith
Research Assistant

FNQLHSSC staff who collaborated in the research

Dickey, Daniel
Research Technical Assistant

Dussault, Marie-Josée
Home Care Coordinator

Garant, Sophie
Research Assistant

Pageau, Caroline
Home Care Coordinator

Picard, Jules
Coordonnateur Strategy and Policy Sector

Vincent, Mélanie
Social Services Coodinator

Members of the Quebec Regional Table on Continuing Care

Charade, Francine
FNIHB, Health Canada

Horn, Michael
Kahnawake Shakotiia' takehnhas
Community Services (KSCS)

Leclaire, Keith
Kahnawake Shakotiia' takehnhas
Community Services (KSCS)

Léveillée, Alain
Indian and Northern Affairs Canada (INAC)

McBride, Arden
Timiskaming First Nations

Paul, Denise
Mashteuiatsh Band Council

Picard, Lison
Huron-Wendat Nation Council

Picard, Sophie
Home Care Technical Coordinator
FNQLHSSC

Whiteduck, Lionel J.
Kitigan Zibi Band Council

Interviewers

Chief, Shelley
Commanda, Lisa
Deer, Janet
Ferguson, Elissia
Jacobs, Lori
King, Diane
Kostouliag, Sappho
Loft, Christine
McComber, Dawn
Odjick McGregor, Lisa
Picard, Thérèse
Picard, Valérie
Savard, Diane
Sioui, Isabelle
Wabie, Theresa
White, Lorraine

Supervisor

Styres, Joseph
Kahnawake

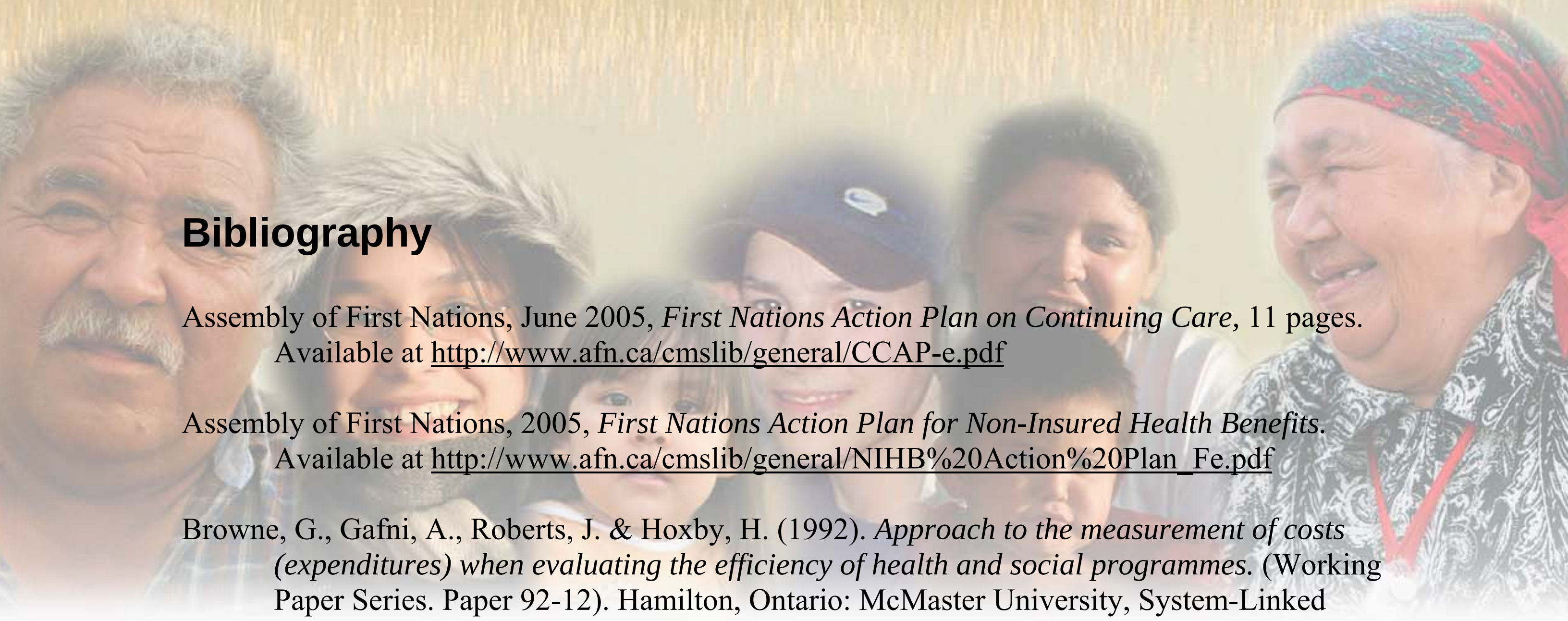
Other persons involved

Deer, Linda
Health Director Kahnawake

McComber, Dawn
Kahnawake

Norton, Susan
Kahnawake

Renaud, Chantal
FNIHB, Health Canada



Bibliography

Assembly of First Nations, June 2005, *First Nations Action Plan on Continuing Care,* 11 pages. Available at http://www.afn.ca/cmslib/general/CCAP-e.pdf

Assembly of First Nations, 2005, *First Nations Action Plan for Non-Insured Health Benefits.* Available at http://www.afn.ca/cmslib/general/NIHB%20Action%20Plan_Fe.pdf

Browne, G., Gafni, A., Roberts, J. & Hoxby, H. (1992). *Approach to the measurement of costs (expenditures) when evaluating the efficiency of health and social programmes.* (Working Paper Series. Paper 92-12). Hamilton, Ontario: McMaster University, System-Linked Research Unit on Health and social Service Utilization.

Office of the Auditor General, 2002, *Streamlining First Nations Reporting to Federal Organizations,* Government of Canada. Available at http://www.oag-bvg.gc.ca/domino/reports.nsf/html/20021201ce.html

Chapleski, E.E., Sobeck,J., & Fisher, C. (2003). Long-term care preferences and attitudes among Great Lakes American Indian families: Cultural context matters. *Case Management Journals*, *4* (2), 94-100.

Departmental Audit and Evaluation Branch, May 2003, *Evaluation of Adult Care Services,* Indian and Northern Affairs Canada, 67 pages.

Fast, J., summer 2005, « Les soins et la prise en charge: une réalité de la vie », *Transition,* Institut Vanier de la famille, vol. 35, no 2. Available at http://www.vifamily.ca/library/transition/352/352_fr.html.

First Nations and Inuit Regional Longitudinal Health Survey. (2002). *Adult questionnaire.* Available at www.ainc-inac.gc.ca

Frideres, J.S., 1994, *The future of our Past: Native Elderly in Canadian Society*, Writings in Gerontology, vol. 15, Ottawa, National Advisory Council on Aging.

Government of Canada, 1996, *Royal Commission Report on Aboriginal Peoples.* Available at http://www.ainc-inac.gc.ca/ch/rcap/sg/si27_e.html

Government of Canada, 2005, *Advancing the Inclusion of Persons with Disabilities*, Social Development Canada, Chapter 7. Available at http://www.dsc.gc.ca/fr/pip/bcph/documents/versIntegration05/chap7.shtml

Gibbons, A., 1999, *First Nations Institutional Care: A review of critical issues and trends.*

Hébert, R., Carrier, R., & Bilodeau, A. (1988). The Functional Autonomy Measurement System (SMAF): Description and validation of an instrument for the measurement of handicaps. *Age and Ageing, 17* (5), 293-302.

Hollander Analytical Services Ltd., July 2004, *Assessing Continuing Care Requirements in First Nations and Inuit Communities. Draft Work Plan and Detailed Schedule*, FNHIB, Health Canada, 44 pages.

Hollander, M., Chappell, N., Havens, B., McWilliam, C., & Miller, J.A. (2002). *Substudy 5*: *Study of the costs and outcomes of home care and residential long term care services*. National Evaluation of the Cost-Effectiveness of Home Care: Victoria.

CIHI, 2002, *Development of National Indicators and Reports for Home Care. Phase 2: Description of indicators – National Pilot Test.*

Canadian Health Information Institute, 2002, *Development of National Indicators and Reports for Home Care, Phase 2,* Ottawa, 23 pages.

Katenies Research and Management Services. 2002. *A First Nations Continuing Care Policy- an Intergenerational Perspectives.*

DINAC, February 2005, *Assisted Living Program- National Manual,* 96 pages.

DINAC, *Registered Indian Population Projections for Canada and Regions, 2000/2021,* Government of Canada, available at http://www.ainc-inac.gc.ca/pr/sts/ipp_e.pdf

DINAC, 1996, *Royal Commission Report on Aboriginal Peoples*, Government of Canada (http://www.ainc-nac.gc.ca/ch/rcap/index_e.html).

DINAC 1993, *The James Bay and Northern Quebec Agreement and The Northeastern Quebec Agreement.* Available at http://www.ainc-inac.gc.ca/pr/info/info14_e.html

Ministère de la santé et des services sociaux, 2003, *Chez soi: Le premier choix - La politique de soutien à domicile,* Government of Quebec, 43 pages.

National Aboriginal Health Organization (NAHO), 2003, *Ways of Knowing: A Framework for Health Research,* 31 pages (http://www.naho.ca/french/pdf/research_waysof.pdf).

NAHO, 2002, *Improving Population Health, Health Promotion, Disease Prevention and Health Protection Services and Programs for Aboriginal People*, available at www.naho.ca/english/pdf/research_pop_health.pdf

Penning, M. & Chappell, N.L. (1996). Home support services in the Capital Regional district: client survey. Final report. Victoria: Centre on Aging, University of Victoria.

Health Canada, 2004, First Nations and Inuit Home and Community Care Nursing Handbook – 2002/2003 Annual Report, Public Works and Government Services Canada, 72 pages.

Health Canada, 2004, *First Nations and Inuit Home and Community Care Program – Annual Report 2002/2003,* Minister of Public Works and Government Services, 72 pages.

Health Canada, 2000, *Service Delivery,* Government of Canada. Available at http://www.hc-sc.gc.ca/fnih-spni/alt_formats/fnihb-dgspni/pdf/pubs/home-domicile/handbook-guide_5_e.pdf

Health Canada, 1998, *Reaching Out: A Guide to Communicating with Aboriginal Seniors,* Minister of Public Works and Government Services, 55 pages.

Schnarch, B., January 2004, "Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research", *The Journal of Aboriginal Health*, National Aboriginal Health Organization, vol.1, no 1, p. 80-95.

Statistics Canada, 2003, Méthodes et pratiques d'enquête, 97.

United Nations. 2003. *The Ageing of the World's Populations: a demographic revolution*, disponible au www.un.org/esa/socdev/ageing/index.html

Websites

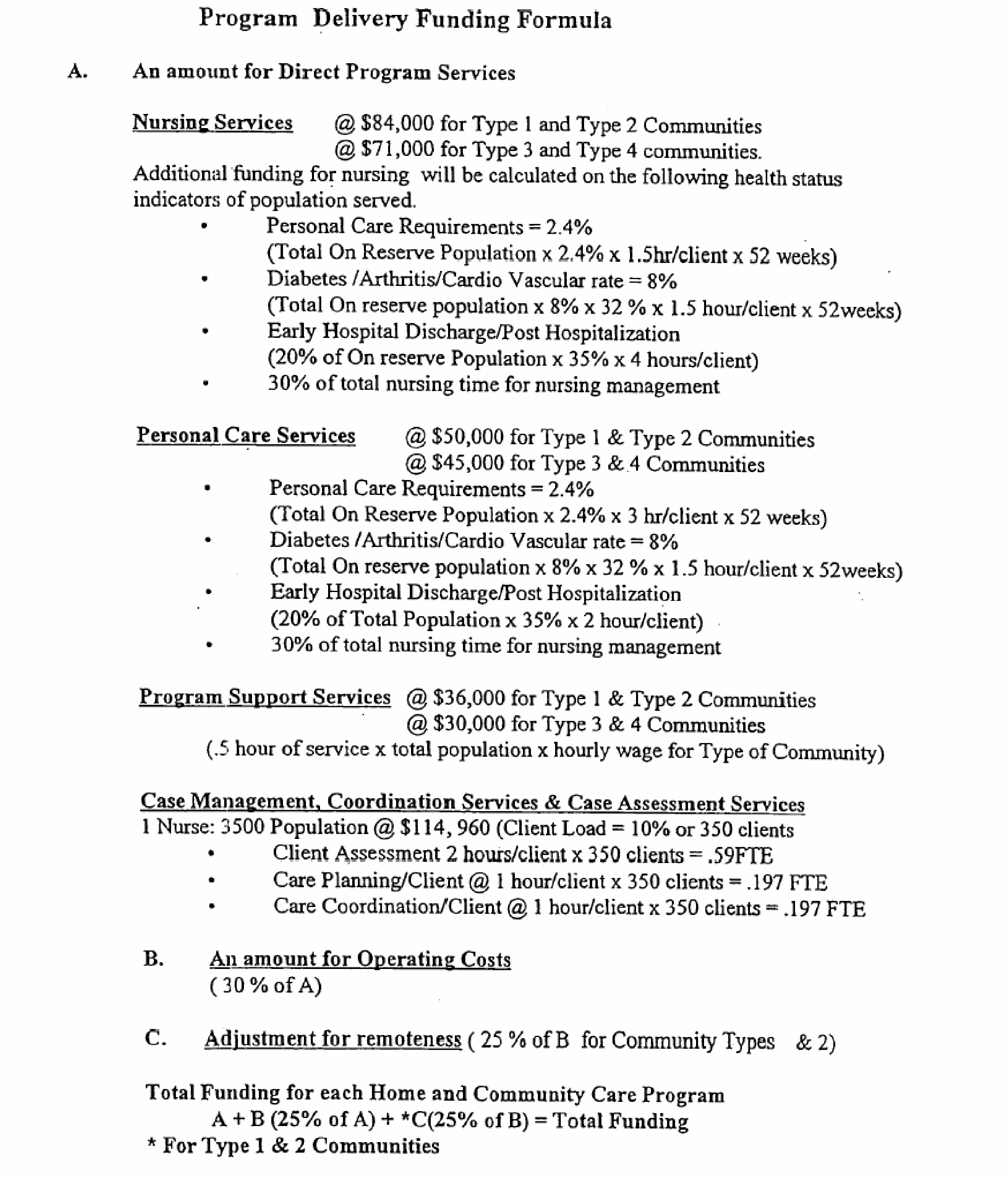
Canadian Hospice Palliative Care Association, 2006, http://www.chpca.net/home.htm

FNQLHSSC, 2006, *Indian Health Policy,* http://www.cssspnql.com

Groupe coopérateur multidisciplinaire en oncologie, 2006, http://www.canceronet.com/Gercor_ang/presentation/index.asp

Health Canada, 2004, *Frequently Asked Questions: Continuing Care*. Government of Canada, http://www.hc-sc.gc.ca/hcs-sss/home-domicile/index_e.html

Appendix 1. Funding Formula (Health Canada)



Program Delivery Funding Formula

A. An amount for Direct Program Services

Nursing Services @ $84,000 for Type 1 and Type 2 Communities
@ $71,000 for Type 3 and Type 4 communities.

Additional funding for nursing will be calculated on the following health status indicators of population served.

- Personal Care Requirements = 2.4%
  (Total On Reserve Population x 2.4% x 1.5hr/client x 52 weeks)
- Diabetes /Arthritis/Cardio Vascular rate = 8%
  (Total On reserve population x 8% x 32 % x 1.5 hour/client x 52weeks)
- Early Hospital Discharge/Post Hospitalization
  (20% of On reserve Population x 35% x 4 hours/client)
- 30% of total nursing time for nursing management

Personal Care Services @ $50,000 for Type 1 & Type 2 Communities
@ $45,000 for Type 3 & 4 Communities

- Personal Care Requirements = 2.4%
  (Total On Reserve Population x 2.4% x 3 hr/client x 52 weeks)
- Diabetes /Arthritis/Cardio Vascular rate = 8%
  (Total On reserve population x 8% x 32 % x 1.5 hour/client x 52weeks)
- Early Hospital Discharge/Post Hospitalization
  (20% of Total Population x 35% x 2 hour/client)
- 30% of total nursing time for nursing management

Program Support Services @ $36,000 for Type 1 & Type 2 Communities
@ $30,000 for Type 3 & 4 Communities
(.5 hour of service x total population x hourly wage for Type of Community)

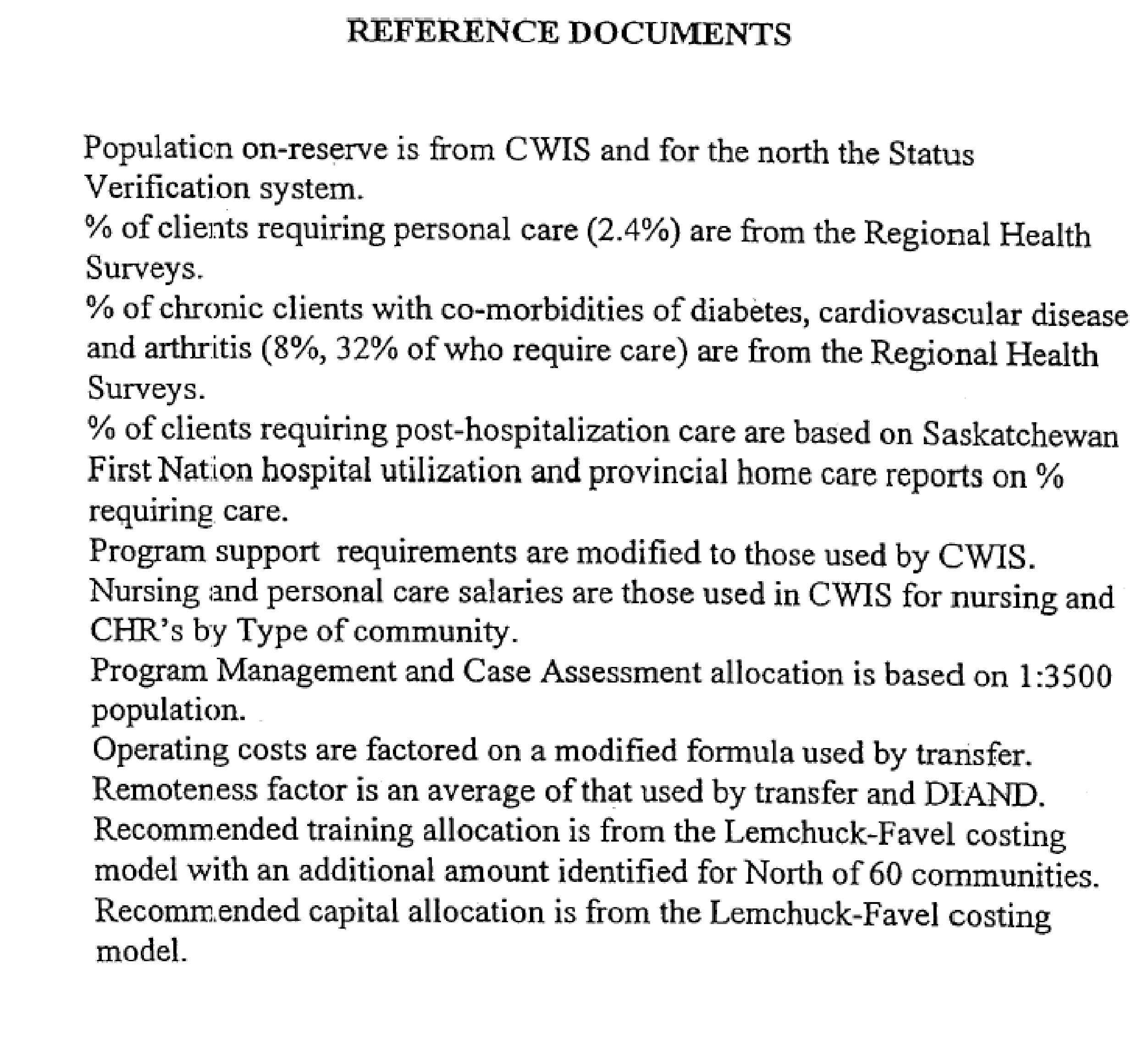
Case Management, Coordination Services & Case Assessment Services
1 Nurse: 3500 Population @ $114, 960 (Client Load = 10% or 350 clients

- Client Assessment 2 hours/client x 350 clients = .59FTE
- Care Planning/Client @ 1 hour/client x 350 clients = .197 FTE
- Care Coordination/Client @ 1 hour/client x 350 clients = .197 FTE

B. An amount for Operating Costs
(30 % of A)

C. Adjustment for remoteness (25 % of B for Community Types & 2)

Total Funding for each Home and Community Care Program
A + B (25% of A) + *C(25% of B) = Total Funding
* For Type 1 & 2 Communities



REFERENCE DOCUMENTS

Population on-reserve is from CWIS and for the north the Status Verification system.

% of clients requiring personal care (2.4%) are from the Regional Health Surveys.

% of chronic clients with co-morbidities of diabetes, cardiovascular disease and arthritis (8%, 32% of who require care) are from the Regional Health Surveys.

% of clients requiring post-hospitalization care are based on Saskatchewan First Nation hospital utilization and provincial home care reports on % requiring care.

Program support requirements are modified to those used by CWIS.

Nursing and personal care salaries are those used in CWIS for nursing and CHR's by Type of community.

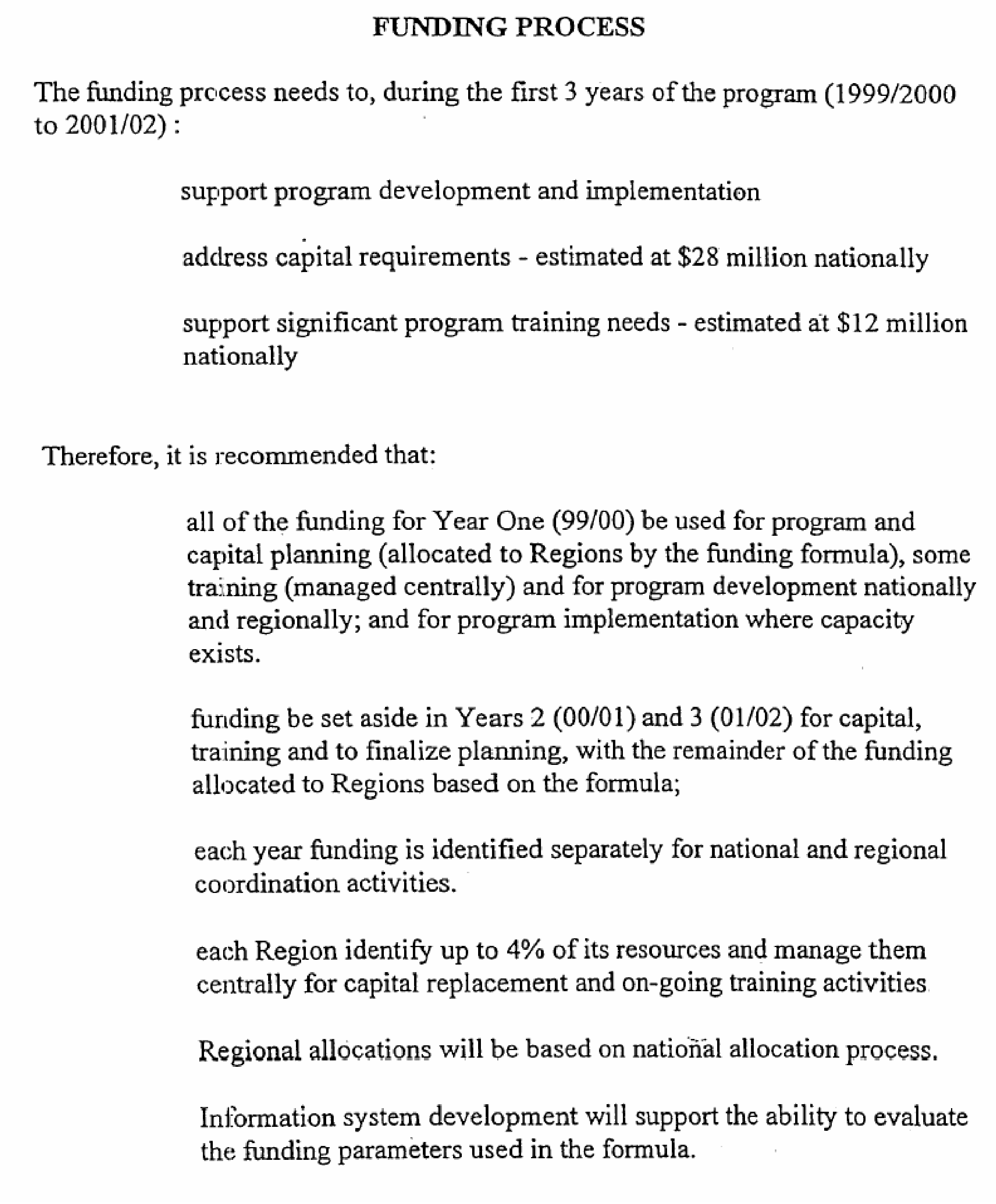
Program Management and Case Assessment allocation is based on 1:3500 population.

Operating costs are factored on a modified formula used by transfer.

Remoteness factor is an average of that used by transfer and DIAND.

Recommended training allocation is from the Lemchuck-Favel costing model with an additional amount identified for North of 60 communities.

Recommended capital allocation is from the Lemchuck-Favel costing model.



FUNDING PROCESS

The funding process needs to, during the first 3 years of the program (1999/2000 to 2001/02) :

support program development and implementation

address capital requirements - estimated at $28 million nationally

support significant program training needs - estimated at $12 million nationally

Therefore, it is recommended that:

all of the funding for Year One (99/00) be used for program and capital planning (allocated to Regions by the funding formula), some training (managed centrally) and for program development nationally and regionally; and for program implementation where capacity exists.

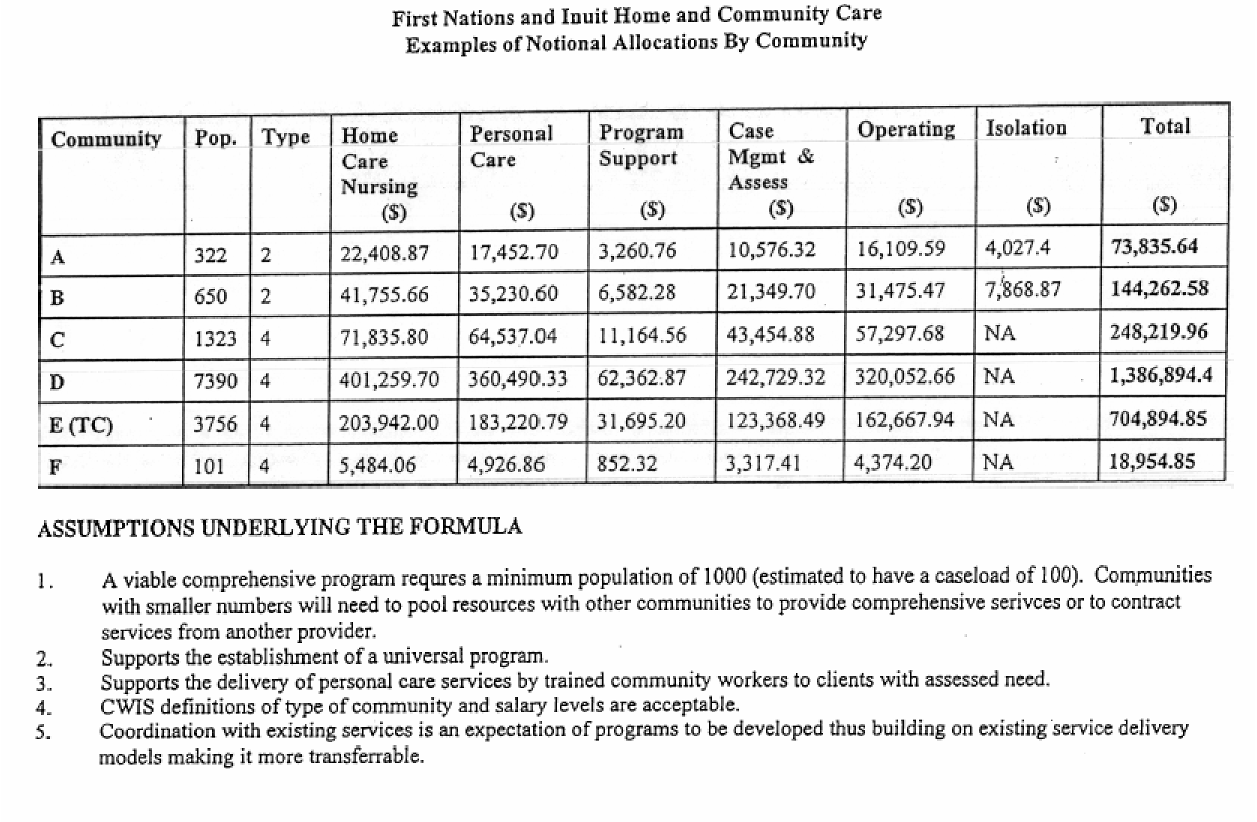
funding be set aside in Years 2 (00/01) and 3 (01/02) for capital, training and to finalize planning, with the remainder of the funding allocated to Regions based on the formula;

each year funding is identified separately for national and regional coordination activities.

each Region identify up to 4% of its resources and manage them centrally for capital replacement and on-going training activities

Regional allocations will be based on national allocation process.

Information system development will support the ability to evaluate the funding parameters used in the formula.



First Nations and Inuit Home and Community Care
Examples of Notional Allocations By Community

Community	Pop.	Type	Home Care Nursing ($)	Personal Care ($)	Program Support ($)	Case Mgmt & Assess ($)	Operating ($)	Isolation ($)	Total ($)
A	322	2	22,408.87	17,452.70	3,260.76	10,576.32	16,109.59	4,027.4	**73,835.64**
B	650	2	41,755.66	35,230.60	6,582.28	21,349.70	31,475.47	7,868.87	**144,262.58**
C	1323	4	71,835.80	64,537.04	11,164.56	43,454.88	57,297.68	NA	**248,219.96**
D	7390	4	401,259.70	360,490.33	62,362.87	242,729.32	320,052.66	NA	**1,386,894.4**
E (TC)	3756	4	203,942.00	183,220.79	31,695.20	123,368.49	162,667.94	NA	**704,894.85**
F	101	4	5,484.06	4,926.86	852.32	3,317.41	4,374.20	NA	**18,954.85**

ASSUMPTIONS UNDERLYING THE FORMULA

1. A viable comprehensive program requres a minimum population of 1000 (estimated to have a caseload of 100). Communities with smaller numbers will need to pool resources with other communities to provide comprehensive serivces or to contract services from another provider.
2. Supports the establishment of a universal program.
3. Supports the delivery of personal care services by trained community workers to clients with assessed need.
4. CWIS definitions of type of community and salary levels are acceptable.
5. Coordination with existing services is an expectation of programs to be developed thus building on existing service delivery models making it more transferrable.

Appendix 2. Participant Consent Form

Client Identification Number:___________________
Community: __________________________

AN ASSESSMENT OF CONTINUING CARE REQUIREMENTS IN FIRST NATIONS AND INUIT COMMUNITIES
PARTICIPANT CONSENT FORM

You are being invited and asked to participate in a research study. In this study, we will ask you a number of questions about continuing care services currently provided in First Nations and Inuit communities.

Research Team: This survey is a joint initiative of the following organizations:

First Nations of Quebec and Labrador Health and Social Services Commission

- *First Nations and Inuit Health Branch - Health Canada*
- *Social Policy and Programs Branch Indian and Northern Affairs Canada*

The First Nations of Quebec and Labrador Health and Social Services Commission oversees and deployed the study in the Quebec region. This study is funded by the *Social Policy and Programs Branch of Indian and Northern Affairs Canada*

Purpose of the study:

The objectives of this survey are to:

- Gather information on continuing care services currently provided and not provided in First Nations and Inuit communities.
- Study the continuing care needs of individuals living in First Nations and Inuit communities
- Assess the costs of providing continuing care services in First Nations and Inuit communities (homecare and long term facility)

Benefits:

There may or may not be direct benefit to you or your family from participating in this study. The information gathered in this study will assist First Nations, Heath Canada and INAC policy makers in developing a number of options for improving continuing care services in First Nations and Inuit communities.

Protecting your privacy:

Study results will be outlined in a report which will be provided to Health Canada's First Nations and Inuit Health Branch and to Indian and Northern Affairs Canada. Information from this study may be presented in public forums. However, your name or other identifying information will not be used or disclosed. Information obtained during the interview may be entered into a computer database. In order to make sure that you cannot be identified in any way, your name, address, personal health information and contact information will be kept separate from your answers. No one will have access to your personal information other than the research investigators. Your recorder may be inspected for quality assurance purposes. This consent form will be separated from the questionnaire and stored separately. It will be securely archived for five years and then destroyed.

Study Procedures, Length of study and Access to Results:

We would like to interview you and/or the person you are being asked to give proxy consent for. The interview shall be conducted in person. Interviews usually take about 2 hours and may be done in one or two sessions. Interview questions will address health status, quality of life and satisfaction with care. We may also ask to interview a friend or family member that assist you in different ways. The interviews will be conducted in several First Nations and Inuit communities during the summer 2005. Regional reports will be available in the Spring of 2006 and copies of these will be sent to the Band office and the Health Center. You can also obtain a copy by contacting the person named below.

Voluntary Participation / Withdrawal from the study:

Your decision to take part in this study is voluntary. Both you and your family member may refuse to participate or may change your mind at any time. Your decision not to participate or changing your mind will not affect in any way the health care services that you and your family receive.

Questions:

You are free to ask any questions that you may have about your rights as a research participant. If questions arise at any time during or after the study, you may contact Nancy Gros-Louis Mchugh at the First Nations of Quebec and Labrador Health and Social Services Commission at (418) 842-1540.

Study copy

Statement of Consent:

Participant:

I have read this consent form. I have had the opportunity to discuss the research study with a member of the research team. I have had my questions answered by them in a language I understand. The risks and benefits have been explained to me. I understand that information regarding my personal identity will be kept confidential. I understand that my participation in this study is voluntary and that I might choose to withdraw at any time. I freely agree to provide proxy consent for __ to participate in this research study. By signing this consent form, I have not waived any of the legal rights that, or that the person I am giving proxy consent for has, as a participant in a research study.

All Participants

1. I ☐ consent ☐ do not consent to be involved in the study.

2 I ☐ consent ☐ do not consent to provide my main caregiver's name and phone number for the study team to contact him/her for an interview.

3. I ☐ consent ☐ do not consent that a paid worker from the Health Centre of my community extracts information from my personal Multiclientele Autonomy Assessment (SMAF) and provides this information to the research team.

Adult participants (18 years and over)

Participant signature______________________________ Date:____/_____/____ (JJ/MM/AA)

Participant printed name ______________________________

For parent / legal guardian of an adult (If required)

Parent / legal guardian signature ______________________________ Date:____/_____/____ (JJ/MM/AA)

Parent / legal guardian printed name ______________________________

Children (Participants under 18 years of age)

Parent / legal guardian signature mandatory if child is under 18

Parent / legal guardian signature______________________________ Date:____/_____/____ (JJ/MM/AA)

Parent / legal guardian printed name ________________________

Member of research team

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and knowingly given their consent.

Researcher's signature______________________________ Date :____/_____/____ (JJ/MM/AA)

Researcher's printed name ______________________________

Study copy

Appendix 3. Family Caregiver Consent Form

Client Identification Number:___________________
Community: __________________________

AN ASSESSMENT OF CONTINUING CARE REQUIREMENTS IN FIRST NATIONS AND INUIT COMMUNITIES

CAREGIVERS CONSENT FORM

You are being invited and asked to participate in a research study. In this study, we will ask you a number of questions about continuing care services currently provided in First Nations and Inuit communities.

Research Team: This survey is a joint initiative of the following organizations:

First Nations of Quebec and Labrador Health and Social Services Commission

- *First Nations and Inuit Health Branch Health Canada*
- *Social Policy and Programs Branch Indian and Northern Affairs Canada*

The First Nations of Quebec and Labrador Health and Social Services Commission oversees and deployed the study in the Quebec region. This study is funded by the *Social Policy and Programs Branch of Indian and Northern Affairs Canada*

Purpose of the study:

The objectives of this survey are to:

- Gather information on continuing care services currently provided and not provided in First Nations and Inuit communities.
- Study the continuing care needs of individuals living in First Nations and Inuit communities
- Assess the costs of providing continuing care services in First Nations and Inuit communities (homecare and long term facility)

Benefits:

There may or may not be direct benefit to you or your family from participating in this study. The information gathered in this study will assist First Nations, Heath Canada and INAC policy makers in developing a number of options for improving continuing care services in First Nations and Inuit communities.

Protecting your privacy:

Study results will be outlined in a report which will be provided to Health Canada's First Nations and Inuit Health Branch and to Indian and Northern Affairs Canada. Information from this study may be presented in public forums. However, your name or other identifying information will not be used or disclosed. Information obtained during the interview may be entered into a computer database. In order to make sure that you cannot be identified in any way, your name, address, personal health information and contact information will be kept separate from your answers. No one will have access to your personal information other than the research investigators. Your recorder may be inspected for quality assurance purposes. This consent form will be separated from the questionnaire and stored separately. It will be securely archived for five years and then destroyed.

Study Procedures, Length of Study and Access to Results:

Having received the consent from Mr/Ms.____, to contact you, we would now like to interview you as a caregiver for that person. The interview shall be conducted in person. Interviews usually take about 2 hours. The interview questions will address health status, quality of life and satisfaction with care. The interviews will be conducted in several First Nations and Inuit communities during the summer 2005. Regional reports will be available in the Spring of 2006 and copies of these will be sent to the Band office and the Health Centre. You can also obtain a copy by contacting the person named below.

Voluntary Participation / Withdrawal from the study:

Your decision to take part in this study is voluntary. Both you and your family member may refuse to participate or may change your mind at any time. Your decision not to participate or changing your mind will not affect in any way the health care services that you and your family receive.

Study copy

Questions:

You are free to ask any questions that you may have about your rights as a research participant. If questions arise at any time during or after the study, you may contact Nancy Gros-Louis Mchugh at the First Nations of Quebec and Labrador Health and Social Services Commission at (418) 842-1540.

Statement of Consent:

Participant:

I have read this consent form. I have had the opportunity to discuss the research study with a member of the research team. I have had my questions answered by them in a language I understand. The risks and benefits have been explained to me. I understand that information regarding my personal identity will be kept confidential. I understand that my participation in this study is voluntary and that I might choose to withdraw at any time.

All Participants

1) I ☐ consent ☐ do not consent to be involved in the study.

Adult participants (18 years and over)

Participant signature______________________________ Date:____/_____/____ (JJ/MM/AA)

Participant printed name ______________________________

Children (Participants under 18 years of age)

Parent / legal guardian signature mandatory if child is under 18

Parent / legal guardian signature______________________________ Date:____/_____/____ (JJ/MM/AA)

Parent / legal guardian printed name ______________________________

Member of research team

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and knowingly given their consent.

Researcher’s signature______________________________ Date:____/_____/____ (JJ/MM/AA)

Researcher’s printed name ______________________________

Study copy

Appendix 4. Client Questionnaire

FN#______________________________

Location :

☐ Home

☐ Facility

☐ Other _______

Care Status

☐ Long term client

☐ Short term client

Client ID# _________________________

Interviewer ID# _____________________

Language used to conduct interview:

☐ English

☐ French

☐ Algonquin

☐ Mohawk

☐ Other______________________

Interpreter:

Yes

No

CLIENT INTERVIEW

Assessing Continuing Care Requirements in First Nations and Inuit Communities

Interviewer's comments: ____

____

____

Information provided by (check all that apply):

- ☐ Client
- ☐ Family Member/Caregiver
- ☐ Paid Health Care Personnel/Formal Caregiver (e.g., home support worker, care aide, nurse)

☐ **OTHER ________________**

WHERE CLIENT IS LIVING:

- ☐ Client living at home

- ☐ Client living in a facility
- ☐ Client living in the hospital in the community
- ☐ Other: _________________________

A. Demographics

Interviewer: The following questions apply to the individual who is receiving continuing care services. You may need to change the wording of some of the questions slightly if you are interviewing a proxy for a child or for an adult who is very frail.

I'd like to begin by asking a few questions about yourself.

1. Gender:
Interviewer: Check off the appropriate response without asking gender.

- ☐ Male
- ☐ Female

2. What is your age?
Interviewer: Ask for the respondent's age, but then mark the choice that applies.

- ☐ 0 - 5
- ☐ 6 – 10
- ☐ 11 – 17
- ☐ 18 - 24
- ☐ 25 34
- ☐ 35 - 44
- ☐ 45 - 54
- ☐ 55 - 64
- ☐ 65 - 74
- ☐ 75 -80
- ☐ 81 - 85
- ☐ 85 - 90
- ☐ 91 +
- ☐ Refused
- ☐ Don't Know

3. What language(s) do you speak?
Interviewer: Please identify all that apply:

- ☐ English
- ☐ French
- ☐ Algonquin
- ☐ Mohawk
- ☐ Other (please specify)
- ☐ Refused

4. What language(s) do you understand?
Interviewer: *Please identify all that apply:*

☐ English
☐ French
☐ Algonquin
☐ Mohawk
☐ Other (please specify) _______________
☐ Refused

5. What language do you use most often in daily life?
Interviewer: Try to have the respondent identify the one language used most often. If they use two languages equally often, please note that.

☐ English
☐ French
☐ Algonquin
☐ Mohawk
☐ Other (please specify) _______________
☐ Refused

6. What is the highest level of schooling that you have completed?
Interviewer: *Ask for the respondent's highest level of schooling, then mark the choice that applies.*

☐ No formal schooling (traditional school)
☐ Kindergarten – Grade 3
☐ Grades 4 - 7
☐ Some High School (Grades 8-12)
☐ High School Graduate (completed Grade 12)
☐ Some technical school, trade school, college, or university
☐ Completed bachelor's degree or equivalent (including technical/trade school)
☐ Completed graduate degree or equivalent (e.g., Masters, PhD, MD)
☐ Other ________________
☐ Refused
☐ Don't know

Comments: ____
____
____

7. Are you currently working for pay?

☐ Yes
☐ No
☐ Refused
☐ Don't know

Comments: ____
____
____

8. On average, how many paid hours do you work per week?
Interviewer: If the respondent is not working for pay, please enter zero (0) for number of hours).
_______ *Number of hours*

☐ Refused
☐ Don't know

Comments: ____
____
____

9. In the last year, have you received income from any of the following sources?
Interviewer: Please ask the general question first and then read out any choices that the respondent has not identified. Please identify all that apply:

☐ Paid employment
☐ Earnings from self-employment
☐ Employment insurance
☐ Social assistance
☐ Royalties, trusts and land claims payments
☐ Old Age Pension/Security
☐ Benefits from Canada or Quebec Pension Plan
☐ Guaranteed Income Supplement or Spouse's Allowance
☐ Retirement, pensions, superannuation, annuities
☐ Veteran's pension
☐ Child Tax Benefit
☐ Child support/alimony
☐ Worker's compensation
☐ Disability allowance
☐ Education or training allowance
☐ Other (specify) ________________
☐ Refused
☐ Don't know

Comments: ____
____
____

10. How many people, including yourself, usually live in this household?
Interviewer: Include all people who reside in the household at least half of the time.

________________ *number*

☐ Refused
☐ Not applicable *(facility)*
☐ Don't know

Comments: ____
____
____

B. HOUSING FOR THOSE AT HOME

Interviewer: If the respondent lives in a facility, go to Section C.

Now I'd like to ask you a few questions regarding your home.

11. Is your home

☐ Rented by you or another member of this household?
☐ Owned by you or another member of this household?
☐ Owned by the Band?
☐ Other (specify) ________________
☐ Refused
☐ Not applicable
☐ Don't know

Comments: ____
____
____

12. Approximately how old is your home?

_________ (in years)

☐ Refused
☐ Not applicable
☐ Don't know

Comments: ____
____
____

13. Is your home in need of renovations?
Interviewer: Renovations include major changes or additions to the home.

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

Comments: ____
____
____

14. How many rooms are in your home?
Interviewer: *Include kitchen, bedrooms, living rooms and finished basement rooms, but do not count bathrooms, halls, laundry rooms and attached shed.*

________ rooms

☐ Refused
☐ Not applicable *(in facility)*
☐ Don't know

Comments: ____
____
____

15. Does your home have:

	Yes	**No**	**Refused**	**Not applicable**	**Don't Know**
A fridge?					
A stove for cooking? If yes, specify whether wood, electric or propane.	W/E/P				
Electricity?					
Water delivery?					
Cold running water?					
Hot running water?					
A flush toilet?					
A septic tank or sewage service (any kind)?					
Garbage collection service?					
A heating system (specify) _____________					
A sidewalk outside?					
Telephone with services					

Comments: ____
____
____

16. Is this dwelling in need of repairs?
Interviewer: Repairs involve fixing what is already present. They don't include additions or other major renovations. If the respondent comments on the need for renovations, please include the information in Question 13 above. Major repairs include: defective plumbing or electrical wiring, structural repairs to walls, floors, ceilings, etc. Minor repairs include: missing or loose floor tiles, bricks, shingles, defective step, railing, siding, etc.

☐ Yes, major repairs
☐ Yes, minor repairs
☐ No, only regular maintenance is needed (painting, furnace cleaning, etc.)
☐ Refused
☐ Not applicable *(in facility)*
☐ Don't know

Comments: ____
____
____
____
____

17a. Do you or did you need modifications to your home as a result of a physical condition or health problem (e.g. ramp, handholds in bathroom)?
Interviewer: Modifications involve changes to what is already present because of a physical condition or health problem.

☐ Yes , specify:____
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

Comments: ____
____
____

17b. If modifications have been made, please describe the modifications.
Interviewer: If no modifications have been made, please note "No modifications".
____
____
____
____
____
____
____

18. **If modifications are needed but have <u>not been made</u>, please explain why they were not made:**
Interviewer: If no modifications were needed, please mark "Not applicable".

☐ Cost
☐ No one to do the work
☐ Just haven't gotten around to it
☐ Refused by the Band Council
☐ Other (please explain) ______________________________
Refused
☐ Not applicable
☐ Don't know

Comments:______________________________
____
____

19. **Water damage from broken pipes, leaks or flood and moisture in the air can cause mold and mildew to form. In the past 12 month, has there been mold or mildew in your home?**

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

20. **Do you consider the main water supply in your home safe for drinking?**

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

C. HOUSING FOR THOSE IN A FACILITY

Interviewer: If the respondent lives in a home, assure that you have completed section B, than go to section D.

Now I'd like to ask you a few questions regarding your stay in this facility____ *(seniors home, group home, elders home, hospital, etc.)*

21. Do you share your room with someone?

☐ Yes Relation:__________________________
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

Comments:____
____
____

22. Do you have a spouse or relative in an adjoining room?
Interviewer: If the respondent does not have a spouse or a relative in the facility, check "Not Applicable". If the respondent has a spouse or a relative in the facility ____ (seniors home, group home, elders home ,hospital, etc.), but not in an adjoining room check "No".

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

Comments:____
____

23. Is your room in need of repairs?
Interviewer: Repairs involve fixing what is already present. They don't include additions or other major renovations. If the respondent comments on the need for renovations, please include the information in the "Comments" section. Major repair include: defective plumbing or electrical wiring, structural repairs to walls, floors, ceilings, etc. Minor repairs include: missing or loose floor tiles, bricks, shingles, defective step, railing, siding, etc.

☐ Yes, major repairs
☐ Yes, minor repairs
☐ No, only regular maintenance is needed (painting, furnace cleaning, etc.)
☐ Refused
☐ Not applicable
☐ Don't know

Comments: ____
____

24. Does your room need improvements in any of the following:

	Yes	No	Don't Know	N/A	If yes, please explain type of improvement required
Air circulation					
Lighting					
Mirror					
Taps					
Temperature control (hot/cold)					
Room size					
Noise level					
Floor					
Other (specify)					

Comments: ____
____
____

25. Do you think your room needs modifications in any of the following areas?
Interviewer: *Modifications involve changes to what is already present because of a physical condition or health problem.*

	Yes	No	Don't Know	N/A	If yes, please explain type of improvement required
Width of doorways					
Size of bathroom					
Handrails					
Toilet height or location					
Bathtub type, size or location					
Room size					
Other (specify)					

Comments: ____

____

____

____

____

____

____

26a. **Overall, do you consider your room to be safe?**
Interviewer: *If the respondent indicates that his/her room is not safe, ask what could be done to make it safer.*

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

Comments:____
____
____
____
____
____
____
____
____
____

26b. **Overall, do you consider the facility______** *(seniors home, group home, elders home,hospital, etc.)* **to be safe?**
Interviewer: *If the respondent indicates that the facility______ (seniors home, group home, elders home, hospital, etc.) is not safe, ask what could be done to make it safer.*

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

Comments:____
____
____
____

27. How would you rate the different departments in the facility ______ *(seniors home, group home, elders home, hospital, etc.)***?**

	Poor	**Fair**	**Good**	**Excellent**	**Refused**	**Don't Know/ Unsure**	**N/A**	**Comments**
NURSING								
Dietary								
Housekeeping								
Laundry								
Maintenance								
Administration								
Social activities								
Other (specify)								

28. Overall, how would you rate the staff with regard to the following?

	Poor	**Fair**	**Good**	**Excellent**	**Refused**	**Don't Know/ Unsure**	**N/A**	**Comments**
COURTESY								
Friendliness								
Helpfulness								
Professionalism								
Other (specify)								

29. Overall, how would you rate the facility______ *(seniors home, group home, elders home, hospital, etc.)* **with regard to the following?**

	Poor	**Fair**	**Good**	**Excellent**	**Refused**	**Don't Know/ Unsure**	**N/A**	**Comments**
FOOD								
Facilities								
Services								
Activities								
Safety								
External Sidewalks								
Staff								
Visitors								
Other (specify)								

30a. Do you feel the facility ______ *(seniors home, group home, elders home, hospital, etc.)* **should offer more services?**

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

30b. If yes, what additional services would you suggest?
Interviewer: Don't read list, mark all that apply.

☐ Social worker
☐ Psychotherapist
☐ Physiotherapist
☐ Recreationist
☐ Massage therapist
☐ Visiting physician
☐ Pastoral worker/Spiritual care provider
☐ Podiatrist
☐ Other, specify: ________________
☐ Refused
☐ Not applicable
☐ Don't know

31. Would you recommend the facility ______ *(seniors home, group home elders home, hospital, etc.)* **to others?**

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

Comments: ____
____
____
____
____
____
____
____
____

Interviewer:

Rest for the client

Please propose to the client to take a small break or to complete the interview at another moment. Schedule another appointment right away.

D. USE OF HEALTH RELATED SERVICES

Now I'm going to ask you questions about health related services. I will ask both about the formal care system as well as about family caregivers. For this study, a family caregiver may include a family member, a friend, a neighbor, or any other individual who provides care and/or support to you. A family caregiver does not include any person who provides care arranged through the formal care system.

32. Do you have a family caregiver, that is, a family member, friend, neighbor, or other individual who provides care and /or support to you outside of the formal care system?
Interviewer: Prompt with: who comes in often, e.g., in the evenings, on the weekends? Who brings you things?

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

33. What is the relationship to you of your family caregiver(s)?
Interviewer: Check all that apply. If the respondent does not have a family caregiver, check "Not applicable".

☐ Wife
☐ Husband
☐ Daughter
☐ Son
☐ Daughter-in-law
☐ Son-in-law
☐ Sister
☐ Brother
☐ Mother
☐ Father
☐ Other relative *(specify)* ___________________________
☐ Friend
☐ Neighbor
Refused
☐ Not applicable
☐ Don't know

Comments:____
____
____
____
____

34. How long have you been receiving help/support from your family caregiver(s)?
Interviewer: If the respondent does not have a family caregiver, check "Not applicable".

☐ Less than one year
☐ 1 to 2 years
☐ More than 2 years but less than 5 years
☐ More than 5 years
☐ Refused
☐ Not applicable
☐ Don't know

35. Thinking of your main/primary family caregiver, how far away from you does this person live?
Interviewer: If more than one person is depended upon equally and the respondent cannot identify a main caregiver, check all that apply. If the respondent does not have a family caregiver, check "Not applicable".

☐ Same house
☐ Very close
☐ Same community
☐ Far away ________________ (approximate distance in km or time)
☐ Refused
☐ Not applicable
☐ Don't know

36. Because of a physical condition or health problem, do you currently receive help with any of the following:

Interviewer: If help is currently received from the formal care system, please try to identify who provides the help. Use the following legend: HSW = Homemaker/Home Support Worker; M = Maintenance; HCA = Home Care Aide; HCN = Home Care Nurse; FCN = Foot Care Nurse; PHN = Public Health Nurse; WC = Wellness Coordinator; P = Physician; OT = Occupational Therapist; PT = Physiotherapist; MT = Massage Therapist; WW = Welfare Worker; TH = Traditional Healer; SC = Spiritual Care; O = Other.

Activity	**Yes/No**			**Who usually helps (check all that apply)**			**Thinking of your family caregiver(s), they may have helped you in the past as part of your relationship. If so, how much of their help now is due to your increased need for care?**							**What do you require in the way of additional help?**
	Yes	**No**	**Don't Know**	**No one**	**Family Caregiver**	**Formal Care System**	**None/ Almost N**	**A little**	**A lot**	**All/Almost All**	**Refused**	**Not applicable**	**Don't Know**	
Eating, including assistance with eating, meal planning, meal preparation														
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting														
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services														
Other tasks, such as budgeting, bill payments, completing forms														
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry														
House maintenance inside, including minor house repairs, painting, heavier cleaning														

Activity	Yes/No			Who usually helps (check all that apply)			Thinking of your family caregiver(s), they may have helped you in the past as part of your relationship. If so, how much of their help now is due to your increased need for care?							What do you require in the way of additional help?
	Yes	No	Don't Know	No one	Family Caregiver	Formal Care System	None/ Almost	A little	A lot	All/Almost All	Refused	Not applicable	Don't Know	
House maintenance and chores outside, including carrying water or wood, chopping wood, shoveling snow, lawn care														
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside														
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places (e.g., homes of friends or medical appointments)														
Nursing or medical care, including installing prosthesis or orthosis, skin care (care or prevention of skin ulcers), foot care, planning or taking medications, any special medical treatments (e.g., oxygen therapy, dialysis)														
Identifying professionals who could provide services and/or medical equipment														
Coordinating and arranging medical appointments and medical or nursing services (including nursing care, physiotherapy, occupational therapy)														
Obtaining medical equipment, medical supplies and medicine														
Obtaining traditional healer/traditional medicines														

Activity	**Yes/No**			**Who usually helps (check all that apply)**			**Thinking of your family caregiver(s), they may have helped you in the past as part of your relationship. If so, how much of their help now is due to your <u>increased</u> need for care?**							**What do you require in the way of additional help?**
	Yes	**No**	**Don't Know**	**No one**	**Family Caregiver**	**Formal Care System**	**None/ Almost**	**A little**	**A lot**	**All/Almost All**	**Refused**	**Not applicable**	**Don't Know**	
Other (specify)														

37. Thinking of all the <u>family caregivers</u> who come to provide you with care or support, how many hours do they usually spend providing care or support in an average week?
<u>Interviewer:</u> If there is no family caregiver, check "Not Applicable".

☐ Not applicable

Type of Caregiver	Tasks	# of hours / week
Family Member		
Other Relatives (cousin, uncle, etc.)		
Friends		
Volunteers		
Spiritual Care (volunteer position)		
Other (specify)		

38. Thinking of all the people who come to help you from the formal care system, overall how many hours do they usually spend providing care or support in an average week?

Type of Caregiver	**Tasks**	**# of hours / week**
Homemaker/Home Support Worker		
Maintenance		
Home Care Aide		
Home Care Nurse		
Foot Care Nurse		
Public Health Nurse		
Wellness Coordinator Community worker		
Physician		
Occupational Therapist		
Physiotherapist		
Massage Therapist		
Welfare Worker		
Traditional Healer		
Spiritual Care (paid position)		
Other (specify)		

E. OTHER HEALTH RELATED SERVICES

39 In the last <u>month</u>, did you receive any supplies, aids or devices (i.e. wheelchair, walker, cane, syringe, dressings, pillows, tissues etc.)

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please identify the item, who provided it, and any estimated cost paid by you or your family (including partial payment and rental).
Interviewer: Please include drugs/medications covered under NIHB as well as those not covered under NIHB. Please use the following legend to identify who covered the item: C = client; CG = caregiver; O = Other individual; HC = home care program; F = facility; H = hospital NIHB = Non-Insured Health Benefits; DK = don't know

Item	**Who Was it Covered By**	**Approx cost including rental**	**Refused**	**Not Applicable**	**Don't Know**
Wheelchair					
Walker					
Cane					
Dressings					
Syringes					
Ergonomic Pillows					
Ostomy material					
Diabetic foods					
Drugs/medications					
Traditional medicines					
Vision care					
Other (specify)					

40. In the last month, did you purchase – or did anyone buy for you – any supplies, aids or devices (walker, cane, syringe, dressings, pillows, tissues etc.) that cost less than $100?

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please identify and provide estimated cost paid by you or your family

Item purchased	Approximate Cost ($)	Refused	Not Applicable	Don't Know

41. In the last year, did you purchase – or did anyone buy for you – any aids or devices that cost more than $100 (i.e. wheelchair, house renovations, specialized vehicles, special clothing).
Interviewer: The cost may include rental.

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please identify the item, give the approximate cost paid by you or your family, and when the purchase/rental was made:

Item purchased or rented	Approximate Cost ($)	Purchased	Rented	Refused	Not Applicable	Don't Know

42. In the last <u>month</u>, have you been referred to a service <u>outside</u> the community?

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please give the approximate cost paid by you or your family:

<u>Interviewer:</u> If there was no cost, put zero (0) under Approximate Cost. If the respondent has not been referred to a service outside the community, mark "Not Applicable".

Service	**Approximate Cost ($)**	**Refused**	**Not Applicable**	**Don't Know**

43. If you were referred for services outside the community, were you satisfied with the care you received?

<u>Interviewer:</u> If the person was not referred for services outside the community, check "Not Applicable".

☐ Yes
☐ No
☐ Refused
☐ Not Applicable
☐ Don't Know

Comments:____
____
____

F. SATISFACTION WITH HEALTH RELATED SERVICES

<u>Interviewer</u>: If the respondent is a proxy, skip to Question 47.

44. Thinking of the care and support provided by your <u>family caregiver(s)</u>:

	Never	Sometimes	Always or Almost Always	Refused	Not Applicable	Don't Know
Do you receive the care/service you need often enough?						
Is the care you need available at the time you need it?						
Is the length of time that you receive the care long enough?						
Is the care you receive provided by the right person(s)?						
Do the people who provide you with care respect, understand and listen to you?						
Are the people who provide you with care sensitive to your needs, beliefs and practices?						
Do you receive care from someone you feel comfortable with?						
Does your family feel it's their responsibility to look after you?						

Comments: ____
____
____
____
____
____

45. Thinking of the care and support you receive from the formal care system:

	Never	Sometimes	Always or Almost Always	Refused	Not Applicable	Don't Know
Do you receive the care/service when you need it?						
Is the care you need available at the time you need it?						
Is the length of time that you receive the care long enough?						
Do the people who provide you with care respect understand and listen to you?						
Are the people who provide you with care sensitive to your needs, beliefs, and practices?						
Do you receive care from someone you feel comfortable with?						
Is it easy to access the care/service you need?						
How often do you pay for this care?						
If you pay for the care, can you afford it?						
Are you satisfied with where the services are provided (e.g., inside your home, outside your home, outside of the community?						

Comments: ____

46. **Thinking <u>only of the caregiving arranged through the formal care system</u>:**

How often do you have a say in:	**Never**	**Sometimes**	**Always**	**Refused**	**Not applicable**	**Don't know**
1. **who** will provide you with services (i.e., the specific person who helps)?						
2. **what** services are provided (i.e., what tasks are performed)?						
3. **when** services are provided (i.e., days, time during day)?						

Comments:____

____

____

____

____

How often would you say that workers:	**Never**	**Sometimes**	**Always**	**Refused**	**Not applicable**	**Don't Know**
4. are easy to get along with?						
5. come when you expect them to (i.e. they arrive and leave on time)?						
6. are polite and courteous?						
7. respect you, understand you and listen to you?						
8. do a good job; one that meets your standards?						
9. are willing to help you with things they are not expected to, but which you might need?						
10. know when to assist and when to let you do things yourself?						
11. are skillful in teaching you to look after some of your own needs?						
12. speak the language(s) with which you are most comfortable?						

Comments:____

____

____

____

____

How often:	**Never**	**Sometimes**	**Always**	**Refused**	**Not applicable**	**Don't know**
13. Does the same person come to provide you with help (except if they are sick, on holidays, etc.)?						
14. do you receive adequate notice of a change when someone else will come to help you?						
15. does the helper know if there are any changes in the kind of care he/she should be providing?						
16. is family involved in the planning of all the care you receive?						

Comments:____

____

____

____

____

47. During the last year, have you experienced any difficulties in receiving care?

	Yes	**If yes, approx how many times?**	**No**	**Refused**	**Not applicable**	**Don't know**
Getting adapted transport						
Arranging transportation						
Affording transportation costs						
Getting traditional care (e.g., healer, medicines, ceremonies)						
Affording medication, medical supplies, medical equipment						
Affording direct cost of care/service						
Affording childcare costs						
Receiving respect, being understood, or being listened to						
Obtaining spiritual care/support						
Obtaining service in my area						
Obtaining service when it was needed						
Other (specify)						

Comments:____

____

____

____

____

48. In the last year, have you refused any treatment or service?

☐ Yes
☐ No
☐ Don’t know

If yes, why? ______________________________

____
____
____
____
____
____
____

49. In the last year, have you been refused any treatment or service?

☐ Yes
☐ No
☐ Don’t know

If yes, why? ______________________________

____
____
____
____
____
____
____

G. LOCATION OF SERVICES

<u>Interviewer</u>: *If the respondent is a proxy, skip to Section I. Explain that this section will help us to plan for the future and to help other people. A personal care home offers some assistance with housekeeping, meals, etc. but essentially the person lives independently. An elders/seniors home provides seniors with assistance with activities of daily living, personal care, etc. A group home/foster home generally includes four or fewer people, is part of someone else's home, and that individual provides some assistance with personal care tasks, meals, etc.*

50. Are you aware of other housing options?

☐ Yes
☐ No
☐ Refused
☐ Not Applicable
☐ Don't Know

Comments:____
____
____

51. If you had complete choice for your living situation, what kind of housing situation would you prefer?

☐ Living in your own home with appropriate care and support services
☐ Living in the home of a family member
☐ Living in an assisted living situation
    ☐ Personal care home
    ☐ Elders home/Seniors home
    ☐ Group home/foster home
    ☐ Hospital in the community
    ☐ Hospital outside the community
    ☐ Other (specify) __________________
☐ Living in a facility or institutional setting
☐ Other (specify)_________________________

52. Where would you prefer that housing be available?

☐ In your community
☐ Where services can be accessed easily, even if it means living outside your community
☐ Other (specify)_____________________

Comments:____
____
____

53. Who would you prefer to receive care/support from?
Interviewer: check all that apply.

.

☐ Family
☐ Friend
☐ Neighbor
☐ Community health center
☐ Community hospital
☐ The formal care system (provincial system)
☐ Other (specify) ____________________________

Comments:____
____
____

54. Do you feel there is a need for other housing options in your community?

☐ Yes
☐ No
☐ Refused
☐ Not Applicable
☐ Don't Know

Comments:____
____
____

55. If your health deteriorates, what would you want to do about the services and care you receive and where you receive them?
Interviewer: This question is not on palliative care as it is covered in the next question.

____
____
____
____
____
____
____
____

56. If you require palliative/end-of-life care in the future, what would you want to do about the services and care you receive and where you receive them?

____
____
____
____
____
____
____
____

H. HEALTH, QUALITY OF LIFE

Interviewer: If the respondent is a proxy, skip to Section I.

57. What things affect your health?
Interviewer: Don't read list out loud. Don't prompt. Check all that apply.

☐ Physical, emotional, mental, spiritual balance
☐ Emotional well-being
☐ Regular exercise
☐ Good sleep
☐ Good sex life
☐ Social supports
☐ Reduced stress
☐ Diet
☐ Stress/worry (Please identify what interviewee says)
☐ Medication (please state) ______________________
☐ Financial
☐ Bereavement (personal)
☐ Bereavement (community)
☐ Non-voluntary separation from spouse to get into institutional/facility setting
☐ Other (specify) ______________________________________
☐ Lack of proper sleep/rest
☐ Lack of exercise/activity
☐ Politics
☐ Other (specify) _________________
☐ Refused
☐ Don't know

58. Would you say that your overall health is:

☐ Excellent
☐ Very Good
☐ Good
☐ Fair
☐ Poor
☐ Refused
☐ Not applicable
☐ Don't know

Comments:____
____
____

59. What things make you happy?

60. What things make you unhappy?

61 In general, would you say you are happy with your life?

☐ Yes
☐ No
☐ Refused
☐ Don't know

Comments:

62. People sometimes look to others for companionship, assistance, guidance or other types of support. Could you tell me how often each of the following kinds of supports is available to you when you need them?

	All of the time	Most of the time	Some of the time	Almost none of the time	Refused
Someone you can count on to listen to you talk when you need to talk					
Someone you can count on when you need help					
Someone to take you to the doctor when you need it					
Someone who shows you love and affection					
Someone who can give you help with you daily routine					
Someone to have good time with					
Someone to share your meals with					
Someone to take you to the church					

I. ADDITIONAL COMMENTS

Interviewer: Follow-up on issues that may have been raised during the interview.

63. Do you have any other comments about the care or services you need or receive?

____

____

____

____

____

____

____

____

____

____

____

____

____

____

____

____

____

Thank you very much for your participation.

Interviewer: Please ensure that all questions have been asked, that not one was missed and that all appropriate boxes were checked off.

Appendix 5. Family Caregiver Questionnaire

FN#________________________________

Location :

☐ Home

☐ Facility

☐ Other _______

Care Status

☐ Long term client

☐ Short term client

Client ID# ___________________________

Interviewer ID# _______________________

Language used to conduct interview:

☐ English

☐ French

☐ Algonquin

☐ Mohawk

☐ Other_______________________

Interpreter:

Yes

☐ No

FAMILY CAREGIVER INTERVIEW
Assessing Continuing Care Requirements in First Nations and Inuit Communities

Interviewer's comments: ____

____

____

A. PROVISION OF ASSISTANCE

I would like to begin by asking you about the assistance you provide to ___________ *(name of client)*.

1. Overall, how long have you been providing care and support for ___________?

☐ Less than one year
☐ 1 to 2 years
☐ More than 2 years but less than 5 years
☐ More than 5 years
☐ Refused
☐ Don't know

2. What is your relationship to _________?

☐ Wife
☐ Husband
☐ Daughter
☐ Son
☐ Daughter-in-law
☐ Son-in-law
☐ Sister
☐ Brother
☐ Mother
☐ Father
☐ Other relative *(specify)* _________
☐ Friend
☐ Neighbor
☐ Other
☐ Refused
☐ Don't know

3. How far away from you does ________ live?

☐ Same house
☐ Very close
☐ Same community
☐ Far away ________________ (approximate distance in km or time)
☐ Refused
☐ Don't know

I will be asking questions both about caregivers from the formal care system and about family caregivers. For this study, I will use the term “ family caregiver” to mean a family member, a friend, a neighbor or any other individual who provides care and/or support to ______. Family caregivers does not include any person who provides care arranged through the formal care system.

4. Do you consider yourself to be _________’s main/primary family caregiver?

Interviewer: The main/primary family caregiver is likely to be the person who provides the client with most of the help, who may provide care in evenings and on weekends, and who brings the client things.

☐ Yes
☐ No
☐ Refused
☐ Don’t know

5. If you are not _____’s main/primary family caregiver, who do you consider the main/primary family caregiver to be?

Interviewer: If the respondent has indicated that he/she is the main/primary family caregiver, mark “Not Applicable”.

☐ Wife
☐ Husband
☐ Daughter
☐ Son
☐ Daughter-in-law
☐ Son-in-law
☐ Sister
☐ Brother
☐ Mother
☐ Father
☐ Other relative *(specify)* _________
☐ Friend
☐ Neighbor
☐ Refused
☐ Not applicable
☐ Don’t know

6. Does anyone help you provide care and support for ________?

☐ Yes
☐ No
☐ Refused
☐ Don’t know

Comments: ____

____

____

____

7. Who helps you to provide care and support to _______?
<u>Interviewer</u>: Identify all of the individuals who help the respondent provide care to ___, in terms of their relationship to ___, not their relationship to the respondent. Mark all of the choices that apply. Do not include the respondent. If the respondent has indicated that no one helps him/her provide care for _______, check "Not applicable".

☐ Wife
☐ Husband
☐ Daughter
☐ Son
☐ Daughter-in-law
☐ Son-in-law
☐ Sister
☐ Brother
☐ Mother
☐ Father
☐ Other relative *(specify)* _________
☐ Friend
☐ Neighbor
☐ Person from formal care system
☐ Refused
☐ Not applicable
☐ Don't know

8. Do you provide care for anyone else?

☐ Yes
☐ No
☐ Refused
☐ Don't know

Comments: ____

____

____

____

9. In addition to ______ how many people do you provide care or support for?
<u>Interviewer:</u> If the respondent does not provide care for anyone else, indicate zero (0).

__________________ (number)

☐ Refused
☐ Don't know

Comments: ____

____

____

____

B. TYPE OF CARE PROVIDED

Now I'm going to ask you about the type of tasks ____ is assisted with and how much time is spent assisting ____ with each task in an average week. I'll also ask you how much of the help given to ___ by family caregivers is due to _____'s increased need for care.

10. Does ________ currently receive help with any of the following:
Interviewer: If the respondent is not a family member, the questions can be rephrased to include the friend/neighbour. Ask question B when the response to A is "Yes". Ask question C only when a family caregiver (including the respondent) is identified as providing some help. If help is currently received from the formal care system, please try to identify who provides the help. Use the following legend: HSW = Homemaker/Home Support Worker; M = Maintenance; HCA = Home Care Aide; HCN = Home Care Nurse; FCN = Foot Care Nurse; PHN = Public Health Nurse; WC = Wellness Coordinator; P = Physician; OT = Occupational Therapist; PT = Physiotherapist; MT = Massage Therapist; WW = Welfare Worker; TH = Traditional Healer; SC = Spiritual Care; O = Other.

Is ___ assisted with:	**A. Person receives assistance**			**B. Who usually helps (check all that apply)**			**C. Given that you and/or other family caregivers may have helped ___ in the past as part of normal family relationships, how much of the help now is additional help due to ____'s increased need for care?**							**What additional help does _____ require?**
	Yes	**No**	**Don't Know**	**No one**	**Family Caregiver**	**Formal Care System**	**None/ Almost None**	**A little**	**A lot**	**All/Almost All**	**Refused**	**Not applicable**	**Don't Know**	
Eating, including assistance with eating, meal planning, meal preparation														
Personal care, including washing, bathing, dressing, grooming, brushing teeth, brushing hair, toileting														
Communication with respect to vision, hearing, speaking, and making oneself understood by others, using the telephone, using interpretive services														
Other tasks, such as budgeting, bill payments, completing forms														

Is ___ assisted with:	**A. Person receives assistance**			**B. Who usually helps (check all that apply)**			**C. Given that you and/or other family caregivers may have helped ___ in the past as part of normal family relationships, how much of the help now is additional help due to ____'s increased need for care?**							**What additional help does _____ require?**
	Yes	**No**	**Don't Know**	**No one**	**Family Caregiver**	**Formal Care System**	**None/ Almost None**	**A little**	**A lot**	**All/Almost All**	**Refused**	**Not applicable**	**Don't Know**	
Light housekeeping and home maintenance, including light cleaning, washing dishes and laundry														
House maintenance inside, including minor house repairs, painting, heavier cleaning														
House maintenance and chores outside, including carrying water or wood, chopping wood, shoveling snow, lawn care														
Mobility inside the house/facility, including positioning in bed, getting in and out of bed, transferring from bed to chair, walking inside, using stairs, propelling wheelchair inside														
Mobility outside the house/facility including walking, propelling wheelchair, grocery shopping, other shopping, getting to other places (e.g., homes of friends or medical appointments)														
Nursing or medical care, including installing prosthesis or orthosis, skin care (care or prevention of skin ulcers), foot care, planning or taking medications, any special medical treatments (e.g., oxygen therapy, dialysis)														
Identifying professionals who could provide services and/or medical equipment														
Coordinating and arranging medical appointments and medical or nursing services (including nursing care, physiotherapy, occupational therapy)														

Is ___ assisted with:	**A. Person receives assistance**			**B. Who usually helps (check all that apply)**			**C. Given that you and/or other family caregivers may have helped ___ in the past as part of normal family relationships, how much of the help now is additional help due to ____'s increased need for care?**							**What additional help does _____ require?**
	Yes	**No**	**Don't Know**	**No one**	**Family Caregiver**	**Formal Care System**	**None/ Almost None**	**A little**	**A lot**	**All/Almost All**	**Refused**	**Not applicable**	**Don't Know**	
Obtaining medical equipment, medical supplies and medicine														
Obtaining traditional healer/traditional medicines														
Other (specify)														

11. Thinking of all the <u>family caregivers</u> (including yourself) who provide _____ with care or support, how many hours do they usually spend providing care or support in an average week?

Type of Caregiver	**Tasks**	**# of hours / week**	**Not applicable**
Respondent			
Other Family Member			
Other Relatives			
Friends			
Volunteers			
Spiritual Care (volunteer position)			
Other (specify)			

12. Thinking of all the people who come to help ____ from <u>the formal care system</u>, overall how many hours do they usually spend providing care or support in an average week?

Type of Caregiver	Tasks	# of hours / week	Not applicable
Homemaker/Home Support Worker			
Maintenance			
Home Care Aide			
Home Care Nurse			
Foot Care Nurse			
Public Health Nurse			
Wellness Coordinator			
Physician			
Occupational Therapist			
Physiotherapist			
Massage Therapist			
Welfare Worker			
Traditional Healer			
Spiritual Care (paid position)			
Other (specify)			

C. OTHER HEALTH RELATED SERVICES

13. In the last <u>month</u>, did _____ receive any supplies, aids or devices (i.e. wheelchair, walker, cane, syringe, dressings, etc.)

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please identify the item, who provided it, and any estimated cost paid by you, ____, or other family members (including partial payment and rental).
<u>Interviewer</u>*: Please include drugs/medications covered under NIHB as well those not covered under NIHB. Please use the following legend to identify who covered the item: C = client; CG = caregiver; O = Other individual; HC = home care program; PCH = personal care home; NIHB = Non-Insured Health Benefits; DK = don't know*

Item	**Who Was it Covered By**	**Approx cost including rental**	**Refused**	**Not Applicable**	**Don't Know**
Wheelchair					
Walker					
Cane					
Dressings					
Syringes					
Ergonimic pillows					
Ostomy material					
Diabetic foods					
Drugs/medications					
Traditional medicines					
Vision care					
Other (specify)					

14. In the last <u>month,</u> did you, ____ or any other family members purchase for _____ any supplies, aids or devices (walker, cane, syringe, dressings, pillows, tissues etc.) that cost <u>less</u> than $100?

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please identify and provide estimated cost paid by you, ______ or other family members.
<u>Interviewer:</u> If no supplies, aids or devices were purchased, check "Not Applicable."

Item purchased	Approximate Cost ($)	Refused	Not Applicable	Don't Know

15. In the last <u>year</u>, did you, ____, or any other family members purchase for _______ any aids or devices that cost <u>more</u> than $100 (i.e. wheelchair, house renovations, specialized vehicles, special clothing).
<u>Interviewer:</u> The cost may include rental.

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please identify the item, give the approximate cost paid by you or your family, and when the purchase/rental was made:
<u>Interviewer:</u> If no aids or devices were purchased,, check "Not Applicable."

Item purchased or rented	Approximate Cost ($)	Purchased	Rented	Refused	Not Applicable	Don't Know

16. In the last <u>month</u>, has ___ been referred to a service <u>within</u> the community?

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please give the approximate cost paid by you or your family:
Interviewer:* *If there was no cost, put zero (0) under Approximate Cost. If the respondent has not been referred to a service within the community, mark "Not Applicable".

Service	Approximate Cost ($)	Refused	Not Applicable	Don't Know

17. In the last <u>month</u>, has ____ been referred to a service <u>outside</u> the community?

☐ Yes
☐ No
☐ Refused
☐ Not applicable
☐ Don't know

If yes, please give the approximate cost paid by you or your family:
Interviewer:* *If there was not cost, put zero (0) under Approximate Cost. If the respondent has not been referred to a service outside the community, mark "Not Applicable".

Service	Approximate Cost ($)	Refused	Not Applicable	Don't Know

18. **If _____ was referred for services outside the community, were you satisfied with the care _____ received?**
Interviewer: If the person was not referred for services outside the community, check "Not Applicable".

☐ Yes
☐ No
☐ Refused
☐ Not Applicable
☐ Don't Know

Comments:____
____
____

D. SATISFACTION WITH HEALTH RELATED SERVICES

19. **Thinking of the care and support ______ receives from the formal care system:**

	Never	**Sometimes**	**Always /Almost Always**	**Refused**	**Not applicable**	Don't Know
Does ____ receive the care/service when he/she needs it?						
Is the care/service ____ needs available at the time he/she needs it?						
Is the length of time that ____ receives the care long enough?						
Do the people who provide ____ with care respect, understand and listen to him/her?						
Are the people who provide ____ with care sensitive to his/her needs, beliefs and practices?						
Is it easy to access the care ____ needs?						
How often do you, ____, or another family caregiver pay for this care?						
If you, _____, or another family caregiver ever pays for the care, can you/they afford it?						
Are you satisfied with where the services are provided to _____ (e.g., inside his/her home, outside his/her home, outside of the community)?						

Comments:____
____
____

20. The following questions also apply to care services provided through the community:

How often do you have a say in:	**Never**	**Sometimes**	**Always**	**Refused**	**Not applicable**	**Don't Know**
1. **who** will provide ____ with services (i.e., the specific person who helps)?						
2. **what** services ____ gets (i.e., what tasks are performed)?						
3. **when** the services are provided (i.e., days, time during day)?						

Comments:____

____

____

How often would you say that workers:	**Never**	**Sometimes**	**Always**	**Refused**	**Not applicable**	**Don't Know**
4. are easy to get along with?						
5. come when they are expected (i.e. they arrive and leave on time)?						
6. are polite and courteous?						
7. respect ___, understand him/her and listen to him/her?						
8. do a good job; one that meets your standards?						
9. are willing to help ____ with things they are not expected to, but which ___ might need?						
10. know when to assist ___ and when to let ___ do things him/her self?						
11. are skillful in teaching ___ to look after some of his/her own needs?						
12. speak the language(s) with which ____ is most comfortable?						

Comments:____

____

____

How often:	**Never**	**Sometimes**	**Always**	**Refused**	**Not applicable**	**Don't Know**
13. does the same person come to provide ___ with help (except if they are sick, on holidays, etc.)?						
14. does ___ receive adequate notice of a change when someone else will come to help ____?						
15. does the helper know if there are any changes in the kind of care he/she should be providing?						
16. is family involved in the planning of all the care ____ receives?						

Comments:____

____

____

21. During the last year, did ______ experience any difficulties in receiving care?

	Yes	**If yes, approx how many times?**	**No**	**Refused**	**Not applicable**	**Don't Know**
Getting adapted transport						
Arranging transportation						
Affording transportation costs						
Getting traditional care (e.g., healer, medicines, ceremonies)						
Affording medication, medical supplies, medical equipment						
Affording direct cost of care/service						
Affording childcare costs						
Receiving respect, being understood, or being listened to						
Obtaining spiritual care/support						
Obtaining service in his/her area						
Obtaining service when it was needed						
Other (specify)						

Comments:____

____

____

22. In the last year, have you refused any care or services on behalf of __________?

☐ Yes
☐ No
☐ Don't know

If yes, why? ____
____
____
____
____
____
____
____

23. In the last year, have you been refused any care or services on behalf of __________?

☐ Yes
☐ No
☐ Don't know

If yes, why? ____
____
____
____
____
____

E. LOCATION OF SERVICES

Interviewer: Explain that this section will help us to plan for the future and to help other people. A personal care home offers some assistance with housekeeping, meals, etc. but essentially the person lives independently. An elders/seniors home provides seniors with assistance with activities of daily living, personal care, etc. A group home generally includes four or fewer people, is part of someone else's home, and that individual provides some assistance with personal care tasks, meals, etc.

24. Are you aware of other housing options?

☐ Yes
☐ No
☐ Refused
☐ Not Applicable
☐ Don't Know

Comments:____
____
____

25. If you had complete choice of _______'s living situation, what kind of housing situation do you think would be best for ____:

- ☐ Living in his/her own home with appropriate care and support services
- ☐ Living in the home of a family member
- ☐ Living in an assisted living situation
  - ☐ Personal care home
  - ☐ Elders/seniors home
  - ☐ Group home
  - ☐ Other (specify)
- ☐ Living in a facility or institutional setting
- ☐ Other (specify)_________________________

26. Where would you prefer that housing be available for ____:

- ☐ In his/her community
- ☐ Where services can be accessed easily, even if it means living outside _____'s community
- ☐ Other (specify) __________________________

27. From whom would you prefer ____ receive care/support?

- ☐ Family, friend, neighbor only
- ☐ Help from the formal care system only
- ☐ Help from both family and the formal care system
- ☐ Other (specify)___________________________

28. Do you feel there is a need for other options in your community?

- ☐ Yes
- ☐ No
- ☐ Refused
- ☐ Not Applicable
- ☐ Don't Know

Comments:____
____
____

29. If ______'s health deteriorates, what would you want to do about the services and care ____ receives and where he/she receives them?

Interviewer: This question is not on palliative care as it is covered in the next question. If the respondent is a formal caregiver, note "Not applicable" and go to Question 7.

____
____
____
____
____
____
____
____

30. If _____ requires palliative/end-of-life care in the future, what would you want to do about the services and care ____ receives and where he/she receives them?

F. EFFECTS OF CAREGIVING

31.

Now, I'm going to ask you some questions regarding how caregiving affects you as the caregiver.

Interviewer: If client is in home care, use the following introduction: **Since you began caregiving at home, how has assisting ____ affected the following aspects of your life?**

If client is in facility care, use the following introduction: **Since ___ was placed in the facility, how has assisting ___affected the following aspects of your life? How often do you feel:**

	Never	**Rarely**	**Sometimes**	**Often**	**Always or Almost Always**	**Refused**	**Not applicable**	**Don't know**
that you get satisfaction about caring for ________?								
that ___ is dependent on you?								
that ___ seems to expect you to take care of him/her as if you were the only one he/she could depend on?								
afraid of what the future holds for___?								
pulled between caring for ___ and trying to meet other responsibilities for your family or work?								
strained when you are around ___?								
that because of the time you spend with ___ that you don't have enough time for yourself?								
that you don't have enough money to care for ___ in addition to the rest of your expenses?								
that ____ asks for more help than he/she needs?								
you should be doing more for ___?								
that ___ currently affects your relationship with other family members or friends in a negative way?								
uncertain about what to do about ___?								
you could do a better job in caring for ____?								
burdened in caring for ___?								

	Never	Rarely	Sometimes	Often	Always or Almost Always	Refused	Not applicable	Don't know
that you do not have as much privacy as you would like because you are caring for ____?								
that your social life has suffered because you are caring for ___?								
that you will be unable to take care of ___ much longer?								
angry when you are around ___?								
your health has suffered because of your involvement with ____?								
embarrassed over ___ behavior?								
you would like to leave the care of ____ to someone else?								
you have lost control of your life since you've become a caregiver?								
uncomfortable about having friends over because of ___?								
that caring for ___ has negatively affected your paid job?								
that you have lost work time in order to care for ___?								
that caring for ___ is a financial burden?								
do you have access to respite care?								
that ______ has access to respite care?								
that you have support in caring for______?								

32. What suggestions do you have to improve the care and quality of life of _______?

____
____
____
____
____
____
____
____
____
____

G. DEMOGRAPHIC INFORMATION

Now I would like to ask a few questions about you.

33. Gender:
Interviewer: Check off the appropriate response without asking gender.

☐ Male
☐ Female

34. What is your age?
Interviewer: Ask for the respondent's age, but then mark the choice that applies.

☐ 18 – 24
☐ 25 – 34
☐ 35 – 44
☐ 45 – 54
☐ 55 – 64
☐ 65 – 74
☐ 75+
☐ Refused
☐ Don't Know

35. What languages do you speak?
Interviewer: Please identify all that apply:

☐ English
☐ French
☐ Algonquin________________)
☐ Mohawk
☐ Other (Please specify) ______________
  ☐ Refused

36. What languages do you understand?
Interviewer: Please identify all that apply:

☐ English
☐ French
☐ Algonquin________________)
☐ Mohawk
☐ Other (Please specify) ______________
  ☐ Refused

37. What language do you use most often in daily life?

<u>Interviewer:</u> Try to have the respondent identify the one language used most often. If they use two languages equally often, please note that.

☐ English
☐ French
☐ Algonquin________________)
☐ Mohawk
☐ Other (Please specify) _______________
☐ Refused

38. What is the highest level of schooling that you have completed?
<u>Interviewer:</u> Ask for the respondent's highest level of schooling, then mark the choice that applies.

☐ No formal schooling (traditional school)
☐ Kindergarten – Grade 3
☐ Grades 4 - 7
☐ Some High School (Grades 8-12)
☐ High School Graduate (completed Grade 12)
☐ Some technical school, trade school, college, or university
☐ Completed bachelor's degree or equivalent (including technical/trade school)
☐ Completed graduate degree or equivalent (masters, PhD, MD)
☐ Other (specify) ________________
☐ Refused
☐ Don't know

39. Are you currently working for pay?

☐ Yes
☐ No
☐ Refused
☐ Don't know

Comments:____
____
____

40. On average, how many paid hours do you work per week?
<u>Interviewer:</u> If the respondent is not working for pay, please enter zero(0) for number of hours.
_______ Number of hours

☐ Refused
☐ Don't know

Comments:____
____
____

41. In the last year, have you received income from any of the following sources?
Interviewer: *Please ask the general question first and then read out any choices that the respondent has not identified. Please identify all that apply:*

☐ Paid employment
☐ Earnings from self-employment
☐ Employment insurance
☐ Social assistance
☐ Royalties, trusts and land claims payments
☐ Basic Old Age Security
☐ Benefits from Canada or Quebec Pension Plan
☐ Guaranteed Income Supplement or Spouse's Allowance
☐ Retirement, pensions, superannuation, annuities
☐ Veteran's pension
☐ Child Tax Benefit
☐ Child support/alimony
☐ Worker's compensation
☐ Disability allowance
☐ Education or training allowance
☐ Other (specify) ________________
☐ Refused
☐ Don't know

Comments:____
____
____

42. Do you have any dependent children?

☐ Yes, how many______________
☐ No
☐ Refused
☐ Don't know

43. Because of the care you provide to ___:

	Yes	No	Refused	Not applicable	Don't Know
Have you had to change where you live?					
Have you had to change your job or employer?					
Have you had to change your job situation (for example, from full to part-time employment or changing the number of hours you work)?					
Found that your performance at work was affected?					
Had to take time off work to help _____ receive care?					
Had to leave work suddenly to take care of ___?					
Lost wages because of helping _______?					
Quit your job?					
Considered quitting your job?					

Comments:____

____

F. ADDITIONAL COMMENTS

Interviewer: Follow-up on issues that may have been raised during the interview.

44. Do you have any other comments about the care or services that ___ needs or that you need to provide care or support to ____?

____

____

____

____

____

____

____

____

____

____

____

____

____

Thank you very much for your participation.

Interviewer: Please ensure that all questions have been asked, that not one was missed and that all appropriate boxes were checked off.

Appendix 6. Functional Status Questionnaire

Interviewer ID# ____________

Information provided by :

- ☐ Home support worker
- ☐ Facility Director
- ☐ Health Director
- ☐ Social Services Director
- ☐ Other ______________

FUNCTIONAL STATUS

Assessing Continuing Care Requirements in First Nations and Inuit Communities

Activities of Daily Living

1. Eating:

☐ Feeds self independently

☐ Feeds self with difficulty

☐ Feeds self but needs stimulation or supervision OR food must be prepared or cut or pureed first

☐ Needs some assistance to eat OR dishes must be presented one after another

☐ Must be fed totally by another person OR has a naso-gastric tube or a gastrostomy
    ☐ naso-gastric tube ☐ gastrostomy

2. Washing

☐ Washes self independently

☐ Washes self with difficulty

☐ Washes self but needs cueing OR needs supervision OR needs preparation OR needs help for the complete weekly bath only (including washing feet and hair)

☐ Needs help for the daily wash but participates actively

☐ Must be washed by another person

3. Dressing

☐ Dresses self independently

☐ Dresses self with difficulty

☐ Dresses self but needs cueing OR needs supervision OR clothing must be prepared and presented OR needs help for finishing touches only (buttons, laces)

☐ Needs help dressing

☐ Must be dressed by another person

4. Grooming (brushes teeth, combs hair, shaves, trims finger and toe nails)

☐ Grooms self independently

☐ Grooms self with difficulty

☐ Needs cueing OR needs supervision for grooming

☐ Needs some assistance for grooming

☐ Must be groomed by another person

5. Urinary Function

☐ Normal voiding

☐ Occasional incontinence OR dribbling OR needs frequent cueing to avoid incontinence

☐ Frequent urinary incontinence

☐ Complete and habitual urinary incontinence OR wears an incontinence pad or an indwelling catheter or a urinary condom
  ☐ incontinence pad ☐ night incontinence
  ☐ urinary condom ☐ day incontinence
  ☐ indwelling catheter

6. Bowel Function

☐ Normal bowel function

☐ Occasional incontinence OR needs cleansing enema occasionally

☐ Frequent incontinence OR needs cleansing enema regularly

☐ Always incontinent OR wears an incontinence pad or an ostomy
  ☐ incontinence pad ☐ night incontinence
  ☐ ostomy ☐ day incontinence

7. Toileting

☐ Uses toilet independently (including getting on/off toilet, wiping self and managing clothing)

☐ Uses toilet with difficulty

☐ Needs supervision for toileting OR uses commode, urinal or bedpan

☐ Needs help using toilet, commode, bedpan or urinal

☐ Does not use toilet, uses commode, bedpan or urinal
☐ commode ☐ bedpan ☐ urinal

Mobility

1. Transfers (bed to chair or wheelchair and vice versa)

☐ Gets in and out of bed or chair independently

☐ Gets in and out of bed or chair with difficulty

☐ Gets in and out of bed/chair independently, but needs cueing, supervision or guidance; Specify ________________________

☐ Needs help to get in and out of bed/chair

☐ Bedridden (must be lifted in and out of bed)
☐ particular positioning
☐ lift ☐ transfer board

2. Walking Inside

☐ Walks independently (with or without cane, prosthesis, orthosis or walker)

☐ Walks independently with difficulty

☐ Walks independently but needs guidance, cueing or supervision in certain circumstances OR has an unsafe gait

☐ Needs help of another person to walk

☐ Does not walk without aid
☐ cane ☐ tripod ☐ quadripod ☐ walker

3. Installing Prosthesis or Orthosis

☐ Does not wear prosthesis or orthosis

☐ Installs prosthesis or orthosis independently

☐ Installs prosthesis or orthosis with difficulty

☐ Installing of prosthesis or orthosis needs checking OR needs some assistance

☐ Prosthesis or orthosis must be installed by another person
Type of prosthesis or orthosis

____

____

4. Propelling a Wheelchair Inside

☐ Does not need a wheelchair

☐ Propels wheelchair independently

☐ Propels wheelchair with difficulty

☐ Needs to have wheelchair pushed

☐ Unable to use wheelchair (must be transported on stretcher)
  - ☐ standard wheelchair
  - ☐ wheelchair with unilateral axis
  - ☐ motorized wheelchair
  - ☐ three-wheeled scooter
  - ☐ four-wheeled scooter

5. Negotiating Stairs

☐ Goes up and down stairs independently

☐ Goes up and down stairs with difficulty

☐ Requires cueing, supervision or guidance to negotiate stairs OR does not safely negotiate stairs

☐ Needs help of another person to go up and down stairs

☐ Does not negotiate stairs

6. Getting Around Outside

☐ Walks independently (with or without cane, prosthesis, orthosis or walker)

☐ Walks independently with difficulty

☐ Uses a wheelchair or three/four-wheeled scooter independently OR walks independently but needs guidance, cueing or supervision in certain circumstances OR has an unsafe gait

☐ Uses a wheelchair with difficulty

☐ Needs help of another person to walk or to use wheelchair

☐ Cannot move around outside (must be transported on a stretcher)

<u>Communication</u>

1. Vision

☐ Sees adequately with or without corrective lenses

☐ Vision problems but sees enough for ADLs

☐ Only sees outlines of objects and needs guidance in ADLs

☐ Blind
☐ corrective lenses ☐ magnifying glass

2. Hearing

☐ Hears adequately with or without hearing aid

☐ Hears if spoken to in a loud voice OR needs hearing aid put in by another person

☐ Only hears shouting or certain words OR reads lips OR understands gestures

☐ Completely deaf and unable to understand what is said to him/her
☐ hearing aid

3. Speaking

☐ Speaks normally

☐ Has a speech/language problem but is able to express him/herself

☐ Has a major speech/language problem but able to express basic needs OR answer simple questions (yes, no) OR uses sign language

☐ Does not communicate
Technical aid: ☐ computer
☐ communication board

<u>Mental Functions</u>

1. Memory

☐ Normal memory

☐ Minor recent memory deficit (names, appointments, etc.) but remembers important facts

☐ Serious memory lapses (shutting off stove, taking medications, putting things away, eating, visitors, etc.)

☐ Almost total memory loss or amnesia

2. Orientation

☐ Well oriented to time, place and persons

☐ Sometimes disoriented to time, place and persons

☐ Only oriented for immediate events (e.g., time of day) and in the usual living environment and with familiar persons

☐ Complete disorientation

3. Comprehension

☐ Understands instructions and requests

☐ Slow to understand instructions and requests

☐ Partial understanding even after repeated instructions OR is incapable of learning

☐ Does not understand what goes on around him/her

4. Judgment

☐ Evaluates situations and makes sound decisions

☐ Evaluates situations but needs help in making sound decisions

☐ Poorly evaluates situations and only makes sound decisions with strong suggestions

☐ Does not evaluate situations and is dependent on others for decision making

5. Behaviour

☐ Appropriate behaviour

☐ Minor behavioural problems (whimpering, emotional lability, stubbornness, apathy) requiring occasional supervision or a reminder or stimulation

☐ Major behaviour problems requiring more intensive supervision (aggressive towards self or others, disturbs others, wanders, yells out constantly)

☐ Dangerous, requires restraint OR harmful to others or self-destructive OR tries to run away

Instrumental Activities of Daily Living

1. Housekeeping

☐ Does housekeeping alone (including daily housework and occasional heavy jobs)

☐ Does housekeeping with difficulty

☐ Does housekeeping (including washing the dishes) but needs cueing or supervision to ensure cleanliness OR needs help for occasional heavy jobs (floors, windows, painting, lawn, shoveling snow, etc.)

☐ Needs help for daily housework

☐ Does not do housework

2. Meal Preparation

☐ Prepares own meals independently

☐ Prepares own meals with difficulty

☐ Prepares meals but needs cueing to maintain adequate nutrition

☐ Only prepares light meals OR reheats pre-prepared meals (including handling the plates)

☐ Does not prepare meals

3. Shopping

☐ Plans and does shopping independently (e.g., food, clothes, etc.)

☐ Plans and does shopping with difficulty

☐ Plans and shops independently but needs to be delivered service

☐ Needs help to plan or to shop

☐ Does not shop

4. Laundry

- ☐ Does all laundry independently
- ☐ Does laundry independently with difficulty
- ☐ Does laundry but needs cueing or supervision to maintain standards of cleanliness
- ☐ Needs help to do laundry
- ☐ Does not do laundry

5. Telephone

- ☐ Uses telephone independently (including the use of a directory)
- ☐ Uses telephone with difficulty
- ☐ Answers telephone but only dials a few memorized numbers or emergency numbers
- ☐ Communicates by telephone but does not dial numbers or lift the receiver off the hook
- ☐ Does not use the telephone

6. Transportation

- ☐ Able to use transportation alone (car, adapted vehicle, taxi, bus, etc.)
- ☐ Able to use transportation with difficulty
- ☐ Must be accompanied to use transportation OR uses paratransit independently
- ☐ Uses car or paratransit only if accompanied and has help getting in and out of the vehicle
- ☐ Must be transported on a stretcher

7. Medication Use

- ☐ Takes medication unaided according to prescription OR does not need medication
- ☐ Takes medication with difficulty
- ☐ Needs supervision (including supervision form afar) to ensure compliance to prescription OR uses a medication dispenser aid (prepared by someone else)
- ☐ Takes medication if prepared daily
- ☐ Must be given each dosage of medication (as prescribed)
  - ☐ medication dispenser aid

8. Budgeting

- ☐ Manages budget independently (including banking)
- ☐ Manages budget with difficulty
- ☐ Needs help for certain major transactions
- ☐ Needs help for some regular transactions (cashing checks, paying bills) but uses pocket money wisely
- ☐ Does not manage budget

Right to Refuse Care

1. In the last 12 months, has the client refused care or services in any area?

- ☐ Has not refused care or services
- ☐ Has refused care or services occasionally (less than 6 times)
- ☐ Has refused care or services several times (more than 6 times)
- ☐ Don’t know

2. If the client has refused care or services in any area, what reason(s), if any, were given?

Appendix 7. Key Stakeholder at the Regional Level Questionnaire

Assessing Continuing Care Requirements in First Nations and Inuit Communities
Interview with Key Stakeholders at the National and Regional Levels

Throughout this interview we use the term "continuing care". In this project, the term "continuing care" refers to a range of medical and social services for individuals who do not have, or who have lost, some capacity to care for themselves. These individuals include: seniors; adults with chronic diseases or conditions; adults with mental health needs; and children with special needs. Continuing care services often begin in the home, and progress through a continuum up to the more intensive levels of care normally associated with facility care, including palliative care. Although it is recognized that palliative care may be part of the continuum, it is not a major focus in this study. Continuing care services may be provided in the home, in supportive living environments, or in institutional settings such as group homes or personal care homes. The emphasis in this study is on continuing care services that are provided within First Nations and Inuit communities.

Section A. Background Information

1. What organization do you represent?

☐ Health Canada (national level)
☐ Health Canada (regional level) (specify ___________)

☐ INAC (national level)
☐ INAC (regional level) (specify ______________)

☐ First Nations or Inuit Organization (national level)
☐ First Nations or Inuit Organization (regional level) (specify ____________)

☐ Provincial Government (specify province ______________)

☐ Other (specify ___________________________)

2. What is your position?

☐ Director
☐ Manager
☐ Program officer
☐ Other (specify _________________)

3. In what area(s) do you work?

☐ Health
☐ Social Services
☐ Policy Development
☐ Program Development
☐ Other (specify _____________________)

4. How long have you been in your position?

☐ Less than 12 months
☐ 1 to 2 years
☐ More than 2 years but less than 5 years
☐ More than 5 years

5. How familiar are you with continuing care services in First Nations and/or Inuit communities?

☐ Not familiar
☐ Slightly familiar
☐ Somewhat familiar
☐ Very familiar

Section B. Continuing Care Services in First Nations and/or Inuit Communities

6. The tables below list the continuing care services that are funded through Health Canada's Home and Community Care Program and/or INAC's Assisted Living Program. Table 6a asks you about services in medium and large communities. Table 6b asks about these services in small communities. For the purposes of this study, small communities are considered to be those with 500 people or less, medium communities are those with 501 to 1000 people, and large communities are those with 1001 people or more. (Interviewer: confirm that the community sizes make sense to the interviewee, as they may vary by region.)

First, please indicate how frequently each service is present in First Nations and/or Inuit communities. Then, indicate your overall impression of the extent to which each of these services is provided in an effective manner. By "effective manner" we mean a combination of: in an appropriate setting, at an appropriate time, for an appropriate length of time, and/or by an appropriate provider.

6a. Medium and Large Communities

	How Often Service is Present						How Often Service is Provided in an Effective Manner					
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure
Case Management (assessment, case management, program management)												
Information / Referral Services												
Education and Teaching of Personal Care Staff												
Meal Programs												
Attendant Care												
In-Home Nursing Care												
Home Support Services-(personal care, housekeeping, meal preparation)												
Home Maintenance (water, wood, minor repairs)												
Day Programs (includes activity programs)												
Respite Care – in home												
Technical Aids, Equipment & Supplies												
Non-Medical Transportation Services												
Foster Care (Adults/Elderly)												
Institutional Services/Facility Care												
Other (specify):												

Comments: ____

6b. Small Communities

	How Often Service is Present						**How Often Service is Provided in an Effective Manner**					
	Never	**Rarely**	**Sometimes**	**Often**	**Always or Almost Always**	**Don't know/ Unsure**	**Never**	**Rarely**	**Sometimes**	**Often**	**Always or Almost Always**	**Don't know/ Unsure**
Case Management (assessment, case management, program management)												
Information / Referral Services												
Education and Teaching of Personal Care Staff												
Meal Programs												
Attendant Care												
In-Home Nursing Care												
Home Support Services(personal care, housekeeping, meal preparation)												
Home Maintenance (water, wood, minor repairs)												
Day Programs (includes activity programs)												
Respite Care – in home												
Technical Aids, Equipment & Supplies												
Non-Medical Transportation Services												
Foster Care (Adults/Elderly)												
Institutional Services/Facility Care												
Other (specify):												

Comments: ____

7a. To what extent do you feel that the home and community continuing care services funded by Health Canada's Home and Community Care Program and/or INAC's Assisted Living Program are culturally adapted to First Nations and/or Inuit?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don't Know/ Unsure

Comments: ____
____
____
____

7b. Does your answer depend upon the size of the community?

☐ Yes
☐ No
☐ Don't Know/ Unsure

Comments: ____
____
____
____

7c. In your opinion, do First Nations and/or Inuit communities have the human, material and financial
resources to culturally adapt their home and community care services?

☐ Yes
☐ No
☐ Don't Know/ Unsure

Comments: ____
____
____
____
____
____

8a. To what extent do you feel that the facility continuing care services funded by INAC's Assisted Living Program are culturally adapted to First Nations and/or Inuit?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don't Know/ Unsure

Comments: ____
____
____
____

8b. Does your answer depend upon the size of the community?

☐ Yes
☐ No
☐ Don't Know/ Unsure

Comments: ____
____
____
____

8c. In your opinion, do First Nations and/or Inuit communities have the human, material and financial
resources to culturally adapt their facility services?

☐ Yes
☐ No
☐ Don't Know/ Unsure

Comments: ____
____
____
____
____
____

9. In your opinion, what is the <u>need</u> in First Nations and/or Inuit communities for the continuing care services funded by <u>Health Canada's Home and Community Care Program and/or INAC's Assisted Living Program</u>?

	Medium and Large Communities				**Small Communities**			
	Low	**Moderate**	**High**	**Don't know/ Unsure**	**Low**	**Moderate**	**High**	**Don't know/ Unsure**
Case Management (assessment, case management, program management)								
Information / Referral Services								
Education and Teaching of Personal Care Staff								
Meal Programs								
Attendant Care								
In-Home Nursing Care								
Home Support Services (personal care, housekeeping, meal preparation)								
Home Maintenance (water, wood, minor repairs)								
Day Programs (includes activity programs)								
Respite Care – in home								
Technical Aids, Equipment & Supplies								
Non-Medical Transportation Services								
Foster Care (Adults/Elderly)								
Institutional Services/Facility Care								
Other (specify):								

Comments: ____

____

____

____

10. How do people care for those in need of continuing care services according to traditional ways?

____

____

____

____

____

____

11a. In your opinion, how often are immediate family members involved in the provision of continuing care services to their own family members?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don’t Know/ Unsure

Comments: ____
____
____
____

11b. Does your answer depend on whether the individual is receiving continuing care services in the home or elsewhere in the community, or in a facility?

☐ Yes
☐ No
☐ Don’t Know/Unsure

Comments: ____
____
____
____

12. Several other continuing care services may be funded through federal, provincial, regional, municipal and/or First Nations /Inuit community programs. The first table asks you about services in medium and large communities, and the second table asks about services in small communities. Again, please indicate how frequently these services are present in or outside of First Nations and/or Inuit communities. Then, indicate your overall impressions of the extent to which each service is provided in an effective manner; that is, in an appropriate setting, at an appropriate time, for an appropriate length of time, and/or by an appropriate provider.

12a. Medium and Large Communities

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Home/Community Rehabilitation (Physiotherapy/ Occupational Therapy /Respiratory Therapy)																			
Alternative Therapies (e.g., massage)																			
Foot Care																			
Mental Health Services for Adults – in home																			
Mental Health Services for Adults – in foster care																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Mental Health Services for Adults – in institution/facility																			
Mental Health Services for Children – in home																			
Mental Health Services for Children – in foster care																			
Mental Health Services for Children – in institution/facility																			
Day Hospitals																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Specialty Hospital Services (e.g., pediatrics, geriatrics)																			
Hospital Liaison Worker/Discharge Planner																			
Foster Care (Children)																			
Supportive Housing																			
Group Homes																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Long Term Care Facilities (Nursing Homes) that cover all care levels																			
Extended or Chronic Care Facilities																			
Respite Care – in home																			
Respite Care – in institution																			
Palliative Care – in home																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Palliative Care – in institution																			
Palliative Care – in hospital																			
Palliative Care Support																			
Technical Aids, Equipment and Supplies																			
Medical Transportation																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Adapted Vehicle for Medical Transportation																			
Special needs/education programs for children																			
Health Promotion, Wellness and Fitness Programs																			
Traditional Counseling/Healing																			
Other (specify):																			

Comments:

12b. Small Communities

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						**Available Outside First Nations and Inuit Communities**						**Provided in an Effective Manner Overall**						
	Never	**Rarely**	**Sometimes**	**Often**	**Always or Almost Always**	**Don't Know/ Unsure**	**Never**	**Rarely**	**Sometimes**	**Often**	**Always or Almost Always**	**Don't know/ Unsure**	**Never**	**Rarely**	**Sometimes**	**Often**	**Always or Almost Always**	**Don't know/ Unsure**	
Home/Community Rehabilitation (Physiotherapy/ Occupational Therapy /Respiratory Therapy)																			
Alternative Therapies (e.g., massage)																			
Foot Care																			
Mental Health Services for Adults – in home																			
Mental Health Services for Adults – in foster care																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Mental Health Services for Adults – in institution/facility																			
Mental Health Services for Children – in home																			
Mental Health Services for Children – in foster care																			
Mental Health Services for Children – in institution/facility																			
Day Hospitals																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don’t Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don’t know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don’t know/ Unsure	
Specialty Hospital Services (e.g., pediatrics, geriatrics)																			
Hospital Liaison Worker/Discharge Planner																			
Foster Care (Children)																			
Supportive Housing																			
Group Homes																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Long Term Care Facilities (Nursing Homes) that cover all care levels																			
Extended or Chronic Care Facilities																			
Respite Care – in home																			
Respite Care – in institution																			
Palliative Care – in home																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Palliative Care – in institution																			
Palliative Care – in hospital																			
Palliative Care Support																			
Technical Aids, Equipment and Supplies																			
Medical Transportation																			

Service	How Often Service is																		Funding Source(s)
	Provided In First Nations and/or Inuit communities						Available Outside First Nations and Inuit Communities						Provided in an Effective Manner Overall						
	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	Never	Rarely	Sometimes	Often	Always or Almost Always	Don't know/ Unsure	
Adapted Vehicle for Medical Transportation																			
Special needs/education programs for children																			
Health Promotion, Wellness and Fitness Programs																			
Traditional Counseling/Healing																			
Other (specify):																			

Comments:

13. To what extent do you feel that the <u>home and community</u> continuing care services provided by federal, provincial, regional and municipal programs are culturally adapted to First Nations and/or Inuit;

13a. Within First Nations and/or Inuit communities?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Does Not Apply
☐ Don't Know/ Unsure

Comments: ____
____
____
____

13b. Outside the communities (e.g., when individuals leave their communities to obtain services)?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don't Know/ Unsure

Comments: ____
____
____
____

13c. Would your answers vary depending upon the size and/or location of the place people need to go to get those services (e.g., urban centre, rural community)?

☐ Yes
☐ No
☐ Don't Know/Unsure

Comments: ____
____
____
____

14. To what extent do you feel that the <u>facility</u> continuing care services provided by federal, provincial, regional and municipal programs are culturally adapted to First Nations and/or Inuit:

14a. Within First Nations and/or Inuit communities?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Does Not Apply
☐ Don't Know/ Unsure

Comments: ____
____
____
____

14b. Outside the communities (e.g., when individuals leave their communities to obtain services)?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don't Know/ Unsure

Comments: ____
____
____
____

14c. Would your answers vary depending upon the size and/or location of the place people need to go to get those services (e.g., urban centre, rural community)?

☐ Yes
☐ No
☐ Don't Know/Unsure

Comments: ____
____
____
____

15. In your opinion, what is the <u>need</u> for First Nations and/or Inuit communities to have access to the continuing care services provided by federal, provincial, regional, and municipal programs?

Service	**Within First Nations /Inuit Communities**				**Outside First Nations /Inuit Communities**			
	Low	**Moderate**	**High**	**Don't know/ Unsure**	**Low**	**Moderate**	**High**	**Don't know/ Unsure**
Home/Community Rehabilitation (Physiotherapy / Occupational Therapy /Respiratory Therapy)								
Alternative Therapies (massage)								
Foot Care								
Mental Health Services for Adults – in home								
Mental Health Services for Adults – in foster care								
Mental Health Services for Adults – in institution/facility								
Mental Health Services for Children – in home								
Mental Health Services for Children – in foster care								
Mental Health Services for Children – in institution/facility								
Day Hospitals								
Specialty Hospital Services (e.g., pediatrics, geriatrics)								
Hospital Liaison Worker/Discharge Planner								
Foster Care (Children)								
Supportive Housing								
Group Homes								
Long Term Care Facilities (Nursing Homes) that cover all care levels								
Extended or Chronic Care Facilities								
Respite Care – in home								
Respite Care – in institution								
Palliative Care – in home								
Palliative Care – in institution								
Palliative Care – in hospital								
Palliative Care Support								
Technical Aids, Equipment and Supplies								
Medical Transportation								
Adapted Vehicle for Medical Transportation								
Special needs/education programs for children								
Health Promotion, Wellness and Fitness Programs								
Traditional Counseling./Healing								
Other (specify):								

16a. To what extent are the continuing care services currently provided in First Nations and/or Inuit communities adequate to meet the needs of the population?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don't Know/ Unsure

Comments: ____
____
____
____

16b. In your opinion, are additional continuing care services needed?

☐ Yes
☐ No
☐ Don't Know/Unsure

If yes, please specify: ____
____
____
____

16c. In your opinion, are there any continuing care services currently provided which are <u>not</u> needed?

☐ Yes
☐ No
☐ Don't Know/Unsure

If yes, please identify and explain why you feel they are not needed:

____
____
____
____
____
____
____
____

17a. Are you aware of any recent steps that have been taken at any level (federal, provincial, regional, municipal and/or First Nations or Inuit community), to improve the <u>delivery</u> of continuing care services in First Nations and/or Inuit communities in response to increased need, increasing costs, etc.?

☐ Yes
☐ No
☐ Don't Know/Unsure

If yes, please describe these steps.

____
____
____
____

17b. If steps have been taken how well, in your opinion, have they worked?

☐ Very Poorly
☐ Poorly
☐ Adequately
☐ Well
☐ Very Well
☐ Don't Know/Unsure

Comments: ____
____
____
____

18a. In this study, the term "coordination" refers to the ability of individuals requiring continuing care services to move easily along a continuum of care. Are you aware of any recent steps that have been taken at any level (federal, provincial, regional, municipal and/or First Nations /Inuit community) to improve health and/or social service <u>coordination</u> for continuing care services in First Nations and/or Inuit communities?

☐ Yes
☐ No
☐ Don't Know/Unsure

If yes, please describe these steps.

____
____
____
____

18b. If steps have been taken, how well, in your opinion, have they worked?

☐ Very Poorly
☐ Poorly
☐ Adequately
☐ Well
☐ Very Well
☐ Don't Know/Unsure

Comments: ____
____
____
____

19a. How would you describe the adequacy of funding for the provision of continuing care services in First Nations and/or Inuit communities?

☐ Insufficient Funding
☐ The Right Amount of Funding
☐ Too Much Funding
☐ Don't Know/Unsure

Please explain.
____
____
____
____

19b. Which kind of funding is best for First Nations and/or Inuit communities with respect to the delivery of continuing care services?

☐ Recurrent Funding
☐ Non-recurrent Funding
☐ Other (specify) ____________________________________

Please explain.
____
____
____
____
____
____
____
____

19c. How would you rate the funding formula for the provision of continuing care services in First Nations and/or Inuit communities?

☐ Very Poor
☐ Poor
☐ Adequate
☐ Good
☐ Very Good

Comments: ____
____
____
____

20. How easy is it for the individuals who are responsible for continuing care services to move funding from one type of continuing care service to another, for example, from home care to facility care?

☐ Not Permitted
☐ Very Difficult
☐ Somewhat Difficult
☐ Neither Difficult nor Easy
☐ Easy
☐ Very Easy
☐ Don't Know/Unsure

Comments: ____
____
____
____

21. In general, how well are continuing care services coordinated within First Nations and/or Inuit communities? That is, are these services offered in such a way that individuals can move easily along a continuum of care, for example, from home care to facility care?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain
____
____
____
____

22. In general, how well are home and community continuing care services coordinated with other health and social services within First Nations and/or Inuit communities?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don’t Know/Unsure

Please explain
____
____
____
____

23. In general, how well are facility continuing care services coordinated with other health and social services within First Nations and/or Inuit communities?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don’t Know/Unsure

Please explain
____
____
____
____

24. In general, how well are home and community continuing care services provided within First Nations and/or Inuit communities coordinated with health and social services provided outside of the communities?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don’t Know/Unsure

Please explain
____
____
____
____

25. In general, how well are facility continuing care services provided within First Nations and/or Inuit communities coordinated with health and social services provided outside of the communities?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain

____
____
____
____

26. In general, how well are health and social services coordinated with the education system for children with special needs?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain

____
____
____
____

27. What factors, if any, do you feel influence the coordination of continuing care services within First Nations and/or Inuit communities?

____
____
____
____

28. What factors, if any, do you feel influence the coordination of continuing care services offered in First Nations and/or Inuit communities with those offered outside of the community?

____
____
____
____

29. Please indicate how well the following components of continuing care are met in First Nations and/or Inuit communities:

Components	**Very Poorly**	**Poorly**	**Adequately**	**Well**	**Very Well**	**Don't know/ Unsure**
Access to continuing care services within the community (e.g., able to obtain home care services)						
Facilitation of care outside of the community (e.g., able to obtain long term care)						
Coordination of continuing care services across types of services (e.g., moving from home care to facility care)						
Quality of care provided by care staff						
Fairness in how people are treated (e.g., equal access to care)						
Fairness in how resources are allocated for continuing care (e.g., funding responds directly to community needs)						
Continuing care services meet the needs of the people receiving care						
Continuing care services meet the needs of family members/close friends of people in care						
Accountability to the leadership (e.g. Chief and Council)						
Accountability <u>to</u> Health Canada and/or INAC from First Nations/Inuit communities						
Accountability <u>from</u> Health Canada and/or INAC to First Nations/Inuit communities						

Comments: ____

30. Overall, what would you say are the <u>strengths</u> of the existing continuing care system for First Nations and/or Inuit individuals?

31. Overall, what would you say are the <u>weaknesses</u> of the existing continuing care system for First Nations and/or Inuit individuals?

32a. In your view, what steps should be taken to improve the existing system of continuing care for First Nations and/or Inuit individuals? For example, what policy, programming or funding changes would be helpful?

32b. What is the capacity of First Nations and/or Inuit communities to manage their own continuing care services?

Section C. Additional Resources

33a. Are you aware of any key indicators and/or benchmarks for First Nations and/or Inuit continuing care services?

☐ Yes
☐ No
☐ Don't Know/Unsure

If yes, what are these?

33b. What additional indicators and/or benchmarks for First Nations and/or Inuit continuing care services are required?

34. Do you know of any exemplary First Nations and/or Inuit programs which include a full range of continuing care services?

☐ Yes
☐ No
☐ Don't Know/ Unsure

If yes, could you please provide us with a name and contact information to learn more about the program(s).

35a. Are you aware of any unpublished literature regarding continuing care services for First Nations and/or Inuit individuals?

☐ Yes
☐ No
☐ Don't Know/Unsure

35b. If yes, would you please provide us with a copy or with a name and contact information for someone we could contact regarding this material?

36. Do you have any other comments?

Thank you very much for your participation!

Appendix 8. Key Stakeholder at the Community Level Questionnaire

Assessing Continuing Care Requirements in First Nations and Inuit Communities

Interview with Key Stakeholders at the Community Level

Throughout this interview, we use the term "continuing care". In this project, the term "continuing care" refers to a range of holistic medical and social services for individuals who do not have, or who have lost, some capacity to care for themselves. These individuals include: seniors; adults with chronic diseases or conditions; adults with mental health needs; and children with special needs. Continuing care services often begin in the home and progress through a continuum up to the more intensive levels of care normally associated with facility care, including palliative care. Although it is recognized that palliative care may be a part of the continuum, it is not a major focus in this study. Continuing care services may be provided in the home, in supportive living environments, or in institutional settings such as group homes or personal care homes. The emphasis in this study is on continuing care services that are provided within First Nations and Inuit communities.

Section A. Background Information

1. What is the name of your First Nations or Inuit Community: _____________

2a. Would you consider your community to be:

☐ Small
☐ Medium
☐ Large

2b. How large is your service catchment area?

Number of individuals (total) ___________
Number of registered individuals __________
Number of non-registered individuals __________
Number of locations _____________

3. Is your community located:

☐ In a remote area
☐ In a rural area
☐ Near an urban centre

4. What is your position?

☐ Health Director
☐ Community Health Nurse
☐ Manager of Home/Community Care
☐ Manager of Facility
☐ Other (Specify) ____________________________

5. How long have you been in your position?

☐ Less than 12 months
☐ 1 to 2 years
☐ More than 2 years but less than 5 years
☐ More than 5 years

6. How familiar are you with continuing care services in your community?

☐ Not familiar
☐ Slightly familiar
☐ Somewhat familiar
☐ Very familiar

Section B. Continuing Care Services in Your Community

7. In your community, who is eligible for continuing care services?

Group/ Individual	**Eligible**		
	Yes	**No**	**Don't Know/ Unsure**
Only registered members of the community			
Members from another First Nations /Inuit community			
Any person resident in the community (for example, First Nations , Inuk, Métis or non-aboriginal person)			
Other (Specify)			

8. In your community, are continuing care services available for:

Individuals	Services are Available		
	Yes	No	Don't Know/ Unsure
Seniors			
Adults with chronic diseases or conditions			
Adults with mental health needs			
Children with special needs			
Other (Specify)			

9. In your community, who is responsible for determining whether individuals who are eligible to receive services actually receive them? *(check all that apply)*

☐ Chief or Council
☐ Health Director
☐ Social Services Director
☐ Community Health Nurse
☐ Nurse in Charge
☐ Public Health Nurse
☐ Manager of Home/Community Care
☐ Manager of Facility
☐ Multidisciplinary Team
☐ Joint Multiple Agencies
☐ Other (specify) ______________________)

10. What is the assessment process for determining whether someone receives continuing care services?

____
____
____
____
____
____
____
____
____
____
____
____

11. The table below lists the continuing care services that are funded by Health Canada's Home and Community Care Program and/or INAC's Assisted Living Program. Please indicate if the service is present in your community. If the service is present, please indicate if it is provided: in an appropriate setting, at an appropriate time, for an appropriate length of time, and/or by an appropriate provider. (Interviewer: code "Always" or "Almost Always" as "Always"; code "Don't Know" and "Unsure" as "Don't Know".)

Service	**Service is Present**			**How Often Service is Provided in an Appropriate Setting**						**How Often Service is Provided at an Appropriate Time**						**How Often Service is Provided for an Appropriate Length of Time**						**How Often Service is Provided by an Appropriate Provider**					
	Yes	No	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always	Don't Know	Never	Rarely	Sometimes	Often	Always	Don't Know	Never	Rarely	Sometimes	Often	Always	Don't Know	Never	Rarely	Sometimes	Often	Always	Don't Know
Case Management (assessment, case management, program management)																											
Information / Referral Services																											
Education and Teaching of Personal Care Staff																											
Meal Program																											
Attendant Care																											
In-Home Nursing Care																											
Home Support Services (personal care, housekeeping, meal preparation)																											
Home Maintenance (water, wood, minor repairs)																											
Day Program (includes activity programs)																											
Respite Care – in home																											
Technical Aids, Equipment & Supplies																											
Non-Medical Transportation Services																											
Foster Care (Adults/Elderly)																											
Institutional services/Facility Care																											
Other (specify):																											

12. To what extent do you feel that the home and community continuing care services funded by Health Canada's Home and Community Care Program and/or INAC's Assisted Living Program are culturally appropriate for people in your community?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don't Know/ Unsure

Comments: ____
____
____
____

13. To what extent do you feel that the facility continuing care services funded by INAC's Assisted Living Program are culturally appropriate for people in your community?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don't Know/ Unsure

Comments: ____
____
____
____

14a. Does your community have the human, material and financial resources to make home and community care services culturally appropriate for people in your community?

☐ Yes
☐ No
☐ Don't Know/ Unsure

Comments: ____
____
____
____

14b. Does your community have the human, material and financial resources to make facility services culturally appropriate for people in your community?

☐ Yes
☐ No
☐ Don't Know/ Unsure

Comments: ____
____
____
____

15. What is the <u>need</u> in your community for the continuing care services funded by Health Canada's Home and Community Care Program and/or INAC's Assisted Living Program?

Service	**Low**	**Moderate**	**High**	**Don't know/ Unsure**
Case Management (assessment, case management, program management)				
Information / Referral Services				
Education and Teaching of Personal Care Staff				
Meal Programs				
Attendant Care				
In-Home Nursing Care				
Home Support Services (personal care, housekeeping, meal preparation)				
Home Maintenance (water, wood, minor repairs)				
Day Programs (includes activity programs)				
Respite Care – in home				
Technical Aids, Equipment & Supplies				
Non-Medical Transportation Services				
Foster Care (Adults/Elderly)				
Institutional Services/Facility Care				
Other (specify):				

16. What traditional, cultural ways are used to provide care to those requiring continuing care services?

____
____
____
____
____
____
____
____

17a. How often are immediate family members involved in the provision of continuing care services to their own family members in your community?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don’t Know/ Unsure

Comments: ____
____
____
____

17b. Does your answer depend on whether the individual is receiving continuing care services in the home or elsewhere in the community, or in a facility?

☐ Yes
☐ No
☐ Don’t Know/ Unsure

Comments: ____
____
____
____

17c. In general, do immediate family members receive payment for providing continuing care services to their own family members?

☐ Yes
☐ No
☐ Don’t Know/ Unsure

Comments: ____
____
____
____

17d. What are the most frequent difficulties family caregivers encounter in trying to provide continuing care services to their own family members in your community?

☐ No or limited funds
☐ Social problems
☐ An addiction
☐ Violence towards elders
☐ Other (specify) ____________

Comments: ____
____
____
____

18. Several other continuing care services may be funded through federal, provincial, regional, municipal and/or First Nations /Inuit community programs. Again, please indicate if the service is present in your community or accessible to your community. Then, for services that are present or accessible, please indicate if the service is provided: in an effective manner; that is, in an appropriate setting, at an appropriate time, for an appropriate length of time, and/or by an appropriate provider. (Interviewer: code "Always" or "Almost Always" as "Always"; code "Don't Know" and "Unsure" as "Don't Know".)

Service	**Present in Community**			**Available Outside Community**			**Provided in an Effective Manner**					**Funding source(s)**
	Yes	No	Don't Know/ Unsure	Yes	No	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always	
Home/Community Rehabilitation (e.g. Physiotherapy/ Occupational Therapy/ Respiratory Therapy												
Alternative Therapies (e.g. massage)												
Foot Care												
Mental Health Services for Adults – in home												
Mental Health Services for Adults – in foster care												
Mental Health Services for Adults – in institution/facility												

Service	Present in Community			Available Outside Community			Provided in an Effective Manner					Funding source(s)
	Yes	No	Don't Know/ Unsure	Yes	No	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always	
Mental Health Services for children – in home												
Mental Health Services for Children – in foster care												
Mental Health Services for Children – in institution/facility												
Day Hospitals												
Specialty Hospital Services (e.g., pediatrics, geriatrics)												
Hospital Liaison Worker/Discharge Planner												
Foster Care (Children)												
Supportive Housing												
Group Homes												
Long Term Care Facilities (Nursing Homes) that cover all care levels												
Extended or Chronic Care Facilities												
Respite Care – in home												
Respite Care – in institution												
Palliative Care – in home												
Palliative Care – in institution												
Palliative Care – in institution												
Palliative Care Support												

Service	**Present in Community**			**Available Outside Community**			**Provided in an Effective Manner**					**Funding source(s)**
	Yes	No	Don't Know/ Unsure	Yes	No	Don't Know/ Unsure	Never	Rarely	Sometimes	Often	Always	
Technical Aids, Equipment and Supplies												
Medical Transportation												
Adapted Vehicle for Medical Transportation												
Special needs/education programs for children												
Health Promotion, Wellness, and Fitness Programs												
Traditional Counselling/Healing												
Other (specify)												

Comments: ____

19. To what extent do you feel that the home and community continuing care services provided by federal, provincial, regional and municipal programs are culturally appropriate for people in your community?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Does Not Apply
☐ Don't Know/ Unsure

Comments: ____
____
____
____

20. To what extent do you feel that the facility continuing care services provided by federal, provincial, regional and municipal programs are culturally appropriate for the people in your community?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Does Not Apply
☐ Don't Know/ Unsure

Comments: ____
____
____
____
____
____
____
____
____
____
____
____
____

21a. In your opinion, what is the <u>need</u> for people in your community to have access to the continuing care services provided by federal, provincial, regional and municipal programs?

Service	Within First Nations /Inuit Community				Outside First Nations /Inuit Community			
	Low	Moderate	High	Don't know/ Unsure	Low	Moderate	High	Don't know/ Unsure
Home/Community Rehabilitation (Physiotherapy / Occupational Therapy/ Respiratory Therapy)								
Alternative Therapies (massage)								
Foot Care								
Mental Health Services for Adults – in home								
Mental Health Services for Adults – in foster care								
Mental Health Services for Adults – in institution/facility								
Mental Health Services for Children – in home								
Mental Health Services for Children – in foster care								
Mental Health Services for Children – in institution/facility								
Day Hospitals								
Specialty Hospital Services (e.g., pediatrics, geriatrics)								
Hospital Liaison Worker/Discharge Planner								
Foster Care (Children)								
Supportive Housing								
Group Home								
Long Term Care Facility (Nursing Homes)								
Extended or Chronic Care Facility								
Respite Care – in home								
Respite Care – in institution								
Palliative Care – in home								
Palliative Care – in institution								
Palliative Care – in hospital								
Palliative Care Support								
Technical Aids, Equipment and Supplies								
Medical Transportation								
Adapted Vehicle for Medical Transportation								
Special needs/education programs for children								
Health Promotion, Wellness and Fitness Programs								
Traditional Counseling/Healing								
Other (specify):								

21b. In your opinion, should continuing care services provided by federal, provincial, regional and municipal programs be managed by First Nations communities?

☐ Yes
☐ No
☐ Don’t Know

Comments: ____
____
____
____

22a. In general, to what extent are the continuing care services currently provided in your community adequate to meet the needs of the population?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always or Almost Always
☐ Don’t Know/ Unsure

Comments: ____
____
____
____
____
____

22b. Are additional continuing care services needed in your community?

☐ Yes
☐ No
☐ Don’t Know/Unsure

If yes, please specify: ____
____
____
____
____
____

22c. Are there any continuing care services currently provided in your community which are <u>not</u> needed?

☐ Yes
☐ No
☐ Don’t know/ Unsure

If yes, please identify and explain why you feel they are not needed:

23a. Are you aware of any recent steps that have been taken at any level (federal, provincial, regional, municipal and/or community) to improve the <u>delivery</u> of continuing care services in your community?

☐ Yes
☐ No
☐ Don’t know/Unsure

If yes, please describe these steps.

23b. If steps have been taken, how well have they worked?

☐ Very Poorly
☐ Poorly
☐ Adequately
☐ Well
☐ Very Well
☐ Don’t Know/ Unsure

Comments: ______________________________

24a. In this study, the term “coordination” refers to the ability of people requiring continuing care services to move easily along a continuum of care. Are you aware of any recent steps that have been taken at any level (federal, provincial, regional, municipal and/or community) to improve health and social service coordination for continuing care services in your community?

☐ Yes
☐ No
☐ Don’t Know/Unsure

If yes, please describe these steps.

____
____
____
____

24b. If steps have been taken, how well have they worked?

☐ Very Poorly
☐ Poorly
☐ Adequately
☐ Well
☐ Very Well
☐ Don’t Know/ Unsure

Comments: ______________________________________
____
____
____

25a. How would you describe the adequacy of funding for the provision of continuing care services in your community?

☐ Insufficient Funding
☐ The Right Amount of Funding
☐ Too Much Funding
☐ Don’t know/ Unsure

Please explain

____
____
____
____

25b. Which kind of funding is best for your community with respect to the delivery of continuing care services?

☐ Recurrent funding
☐ Non-recurrent funding
☐ Other (specify) ____

Please explain

____
____
____
____

25c. How would you rate the funding formula for the provision of continuing care services in your community?

☐ Very Poor
☐ Poor
☐ Adequate
☐ Good
☐ Very Good

____
____
____
____

26. How easy is it for the people who are responsible for continuing care services in your community to move funding from one type of continuing care service to another, for example, from home care to facility care?

☐ Not Permitted
☐ Very Difficult
☐ Somewhat Difficult
☐ Neither Difficult nor Easy
☐ Easy
☐ Very Easy
☐ Don't Know/Unsure

Comments: ____

____
____
____
____
____

27. In general, how well are continuing care services coordinated in your community? That is, are these services offered in such a way that people can move easily along a continuum of care, for example, from home care to facility care?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain

28. In general, how well are <u>home and community</u> continuing care services coordinated with other health and social services in your community?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain:

29. In general, how well are <u>facility</u> continuing care services coordinated with other health and social services in your community?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain

30. In general, how well are home and community continuing care services provided in your community coordinated with health and social services provided outside of your community?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain

31. In general, how well are facility continuing care services provided in your community coordinated with health and social services provided outside of your community?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain

32. In general, how well are health and social services coordinated with the education system for children with special needs?

☐ Poorly coordinated
☐ Somewhat coordinated
☐ Well coordinated
☐ Don't Know/Unsure

Please explain

33. What factors, if any, do you feel influence the coordination of continuing care services in your community?

____
____
____
____
____
____

34. What factors, if any, do you feel influence the coordination of continuing care services offered in your community with those offered outside your community?

____
____
____
____
____
____

35. Please indicate how well the following components of continuing care are met in your community:

Components	**Very Poorly**	**Poorly**	**Adequately**	**Well**	**Very Well**	**Don't know/ Unsure**
Access to continuing care services within your community (e.g., able to obtain home care services)						
Facilitation of care outside of your community (e.g., able to obtain long term care)						
Coordination of continuing care services across types of services (e.g., moving from home care to facility care)						
Quality of care provided by care staff						
Fairness in how people are treated (e.g., equal access to care)						
Fairness in how resources are allocated (e.g., funding responds directly to community needs)						
Continuing care services meet the needs of the people receiving care						
Continuing care services meet the needs of family members/close friends of people in care						
Accountability to the leadership (e.g. Chief and Council)						
Accountability to Health Canada and/or INAC						
Accountability from Health Canada and/or INAC						

Section C. Additional Resources

36. Are you aware of any key indicators and/or benchmarks for First Nations and/or Inuit continuing care services?

☐ Yes
☐ No
☐ Don’t know/ Unsure

If yes, what are these?

____
____
____
____

37. What additional indicators and/or benchmarks for First Nations and/or Inuit continuing care services are required?

____
____
____
____

38. Do you know of any exemplary First Nations and/or Inuit programs which include a full range of continuing care services?

☐ Yes
☐ No
☐ Don’t Know/ Unsure

If yes, could you please provide us with a name and contact information to learn more about the program(s)?

____
____
____
____
____
____
____
____
____
____
____
____
____

39. Are you aware of any unpublished literature regarding continuing care services for First Nations and/or Inuit individuals?

☐ Yes
☐ No
☐ Don't Know/ Unsure

If yes, would you please provide us with a copy or with a name and contact information for someone we could contact regarding this material?

40. Do you have any other comments?

Thank you for your participation!

Appendix 9. Key Stakeholder at the Community Level Questionnaire - Supplement

Interview With Key Stakeholders At The Community Level – Supplement

Introduction

As part of the Continuing Care Research and Costing Project that the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) is conducting on behalf of Health Canada and INAC, we would like to obtain some basic information about the continuing care services in your community and about the people who use them.

This document contains a number of tables that we would like you to complete. Once completed, the information in the tables you provide to the FNQLHSSC will be used for the research study **(in aggregate/group form only)** in order to produce estimated service utilization ratios which will help the researchers understand what services are used, by whom, what gaps exist, and what may be required in the way of funding and human resources to address the gaps. Your community will also be able to use the information for planning purposes.

To Complete the Attached Tables

In order to complete the attached tables, you will need to know how we are using certain terms. While the terms may be familiar to you, FNQLHSSC may be using them in a manner which is different from what you are used to. For the purposes of this study:

- The term **continuing care** refers to a range of holistic medical and social services for individuals who do not have, or who have lost, some capacity to care for themselves.
  - These individuals may be children with special needs, adults with chronic diseases or conditions, adults with mental health needs or seniors.
  - Continuing care services may be provided in the home, in supportive living environments, or in institutional settings such as group homes or personal care homes.
- The term facility refers to a range of housing options, outside of a private home, where continuing care services may be provided. It includes, but is not limited to, supportive living settings, group homes and personal care homes.
- The term need refers to a formal care service that is considered to be required by an individual and by a health professional (such as the community health nurse or a social worker) if a health care assessment were to be conducted.
  - It is not necessary for an individual to have asked for a service.

- The term does not apply to a service where an individual feels that the service is required, but a health professional would not share the same view.

- The term formal care service refers to a service that is provided by a paid health care provider (such as a home support worker, a community health nurse, or a care attendant in a facility).

- The term family caregiver refers to a family member, close friend, or other individual who provides assistance to an individual requiring continuing care services.

Format of the Document

There are five parts to this document:

- Part A asks for estimates of the number of community members
- Part B asks for estimates of the number of people needing **formal** continuing care services in your community
- Part C asks for general information regarding **formal** continuing care services in your community
- Part D asks for general information regarding continuing care services provided by family caregivers in your community
- Part E asks for any additional comments

In completing each of the parts, please include all of the following groups of individuals:

- Children with special needs
- Adults with chronic diseases or conditions
- Adults with mental health needs
- Seniors

Part A. Estimates of the Number of Community Members

In this section, we ask you for numbers of people in three groups:

- Total number of First Nations and/or Inuit individuals who lived within the community for at least 6 months in the last 12 months, and who are members of the community
- Community members who lived within the community for at least 6 months in the last 12 months and who required continuing care services, either in the home/community or in a facility
- Community members who did not live within the community for at least 6 months in the last 12 months, **because** they had to access continuing care services elsewhere.

We also ask you for the number of people with chronic diseases who do not require continuing care services at the moment (but who may in the future).

1. Tables 1 to 2

In Table 1, we ask for the number of individuals in these three groups as a combination of age and gender. Information provided in the form requested in Table 1 would be most helpful for the study. However, if it is not possible for you to provide the information requested in Table 1, please complete Table 2. Table 2 requests the number of individuals in each age group, and in each gender group. Please complete **either** Table 1 **or** Table 2. It is **not** necessary to complete both tables. Information regarding the actual numbers of people in each of the groups would be appreciated. However, it is recognized that it may be difficult to provide this information for a number of reasons. Therefore, estimated numbers are fine.

Please complete Table 1, if possible.

Table 1: Number of Community Members by Age and Gender

Combined Age and Gender Groups	TOTAL number of community members who lived within the community for at least 6 months in the last 12 months	Number of community members who lived within the community for at least 6 months in the last 12 months AND required continuing care services	Number of community members who did not live within the community for at least 6 months in the last 12 months BECAUSE they had to access continuing care services elsewhere
0-17 Years of Age			
. Male			
. Female			
18-44 Years of Age			
. Male			
. Female			
45-54 Years of Age			
. Male			
. Female			
55-64 Years of Age			
. Male			
. Female			
65-74 Years of Age			
. Male			
. Female			
75 Years of Age & Older			
. Male			
. Female			

The numbers in Table 1 are:

☐ Actual
☐ Estimated
☐ Combination of Actual and Estimated
☐ Other (specify) ____________________

Please complete Table 2 **if** you did **not** complete Table 1.

Table 2: Number of Community Members by Age and by Gender

Age and Gender Groups	TOTAL number of community members who lived within the community for at least 6 months in the last 12 months	Number of community members who lived within the community for at least 6 months in the last 12 months AND required continuing care services	Number of community members who did not live within the community for at least 6 months in the last 12 months BECAUSE they had to access continuing care services elsewhere
Age Groups			
0 – 17 Years of Age			
18 – 44 Years of Age			
45 – 54 Years of Age			
55 – 64 Years of Age			
65-74 Years of Age			
75 Years of Age & Older			
Total			
Gender Groups			
Male			
Female			
Total			

The numbers in Table 2 are:

☐ Actual
☐ Estimated
☐ Combination of Actual and Estimated
☐ Other (specify) ____________________

2. Table 3

In Table 3, we ask you for the number of individuals who have a chronic condition, but who do not require continuing care services at this time, but who may require services in the future.

Table 3: Number of Community Members with a Chronic Condition Who <u>Do Not</u> Require Continuing Care Services at this Time

Age Groups	Diabetes	Heart Conditions (e.g. cardiovascular disease)	Lung Conditions (e.g., asthma)	Other Physical Conditions (e.g. arthritis)	Mental Health Condition	HIV/AIDS	Other
0 – 17 Years of Age							
18 – 44 Years of Age							
45 – 54 Years of Age							
55 – 64 Years of Age							
65-74 Years of Age							
75 Years of Age & Older							
Total							

The numbers in Table 3 are:

☐ Actual
☐ Estimated
☐ Combination of Actual and Estimated
☐ Other (specify) ____________________

Part B. Estimates of the Number of People Needing Formal Continuing Care

Services in Your Community

In this section, we ask you to complete five tables. For Tables 4 to 7, we ask you to provide estimates of people by Need Level.

Please do the best you can to **estimate** the number of people **you believe** need formal home/community and facility services, irrespective of what services may currently be available. That is, please make your estimates based **only** on client needs, not on eligibility criteria, the availability of health care personnel, and/or the availability of existing health care services.

Your estimated numbers should include:

- Community members who received continuing care services (either in the home or elsewhere in the community, or in a facility) in the last 12 months

and

- Community members who did not receive continuing care services in the last 12 months, but who (in your opinion) should have received continuing care services.

The community members may live within a First Nations or Inuit community or they may have left the community **in order to** access continuing care services elsewhere.

2. Tables 4 to 7

In order to make comparisons between home and community clients and those living in care facilities or supportive housing using similar information, it is important to use the same categorization system. Since different provinces use different classification systems, it has been necessary to develop definitions specifically for the Continuing Care Research and Costing Project. These definitions are presented in the left column of the following tables. Please use these definitions to categorize individuals according to their need for continuing care services. Note that the Need Levels go from a relatively low level of need (Need Level 1) to a very high level of need (Need Level 8) and apply to home and community care clients **as well as** those living in care facilities or supportive housing. Please do the best you can to categorize individuals according to **your estimate** of their need for care **at the present time**. We know that your estimated need for care may not be consistent with an individual's formal "Type of Care" designation.

You may wish to begin by making a list, or referring to an existing list, of:

- everyone in your community who received any amount of continuing care during the last 12 months;
- everyone in your community who you believe should have received continuing care during the last 12 months but did not; and
- everyone who had to leave the community in order to receive continuing care.

You could then categorize the combined number of individuals who received services, and those who should have received services, according to Need Level, type of client, and so on.

Table 4: Estimates of the Number of People Needing Home and/or Community Care by Need Level

Note: This table only applies to people needing **home and/or community care**. You may wish to have a staff member from the home/community care program assist you in completing the table.

Your Estimate of Need Level	**Estimated number of people who lived within the community for at least 6 months in the last 12 months AND who needed home and/or community care**	**Estimated number of people who did not live in the community for at least 6 months in the last 12 months BECAUSE they had to access home and/or community care elsewhere**
Need Level 1: Individuals who require *some* assistance with activities of daily living and/or social and recreational services		
Need Level 2: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week		
Need Level 3: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week		
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision		
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)		
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care		
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing		
Need Level 8: Individuals who require palliative care either in the home or in a facility		

Table 5: Estimates of the Number of People Needing Facility Care by Need Level

Note: This table only applies to people needing **facility** care. You may wish to have a staff member from the facility assist you in completing the table.

Your Estimate of Need Level	**Estimated number of people who lived within the community for at least 6 months in the last 12 months AND who needed facility care**	**Estimated number of people who did not live in the community for at least 6 months in the last 12 months BECAUSE they had to access facility care elsewhere**
Need Level 1: Individuals who require *some* assistance with activities of daily living and/or social and recreational services		
Need Level 2: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week		
Need Level 3: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week		
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision		
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)		
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care		
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing		
Need Level 8: Individuals who require palliative care either in the home or in a facility		

Table 6: Estimates of the Number of People Needing Home and/or Community Care by Group

Note: This table only applies to people needing **home and/or community care**. You may wish to have a staff member from the home/community care program assist you in completing the table. If someone falls into more than one continuing care group, please count them in the group that best applies to him/her. Please do not count the individual more than once.

	Continuing Care Group			
Your Estimate of Need Level	**Children with Special Needs**	**Adults with Chronic Diseases or Conditions**	**Adults with Mental Health Issues**	**Seniors (55 years of age and older)**
Need Level 1: Individuals who require *some* assistance with activities of daily living and/or social and recreational services				
Need Level 2: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week				
Need Level 3: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week				
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision				
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)				
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care				
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing				
Need Level 8: Individuals who require palliative care either in the home or in a facility				

Table 7: Estimates of the Number of People Needing Facility Care by Group

Note: This table only applies to people needing **facility** care. You may wish to have a staff member from the facility assist you in completing the table. If someone falls into more than one continuing care group, please count them in the group that best applies to him/her. Please do not count the individual more than once.

Your Estimate of Need Level	**Continuing Care Group**			
	Children with Special Needs	**Adults with Chronic Diseases or Conditions**	**Adults with Mental Health Needs**	**Seniors (55 years of age and older)**
Need Level 1: Individuals who require *some* assistance with activities of daily living and/or social and recreational services				
Need Level 2: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 1 to 2 times per week				
Need Level 3: Individuals who require *both* supervision and assistance with activities of daily living and/or social and recreational services 3 or more times per week				
Need Level 4: Individuals who require the availability of personal care on a 24-hour basis under medical and nursing supervision				
Need Level 5: Individuals who require rehabilitative care to restore or improve functional ability (this may include mental health services)				
Need Level 6: Chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care				
Need Level 7: Individuals who require medical investigation, diagnosis or treatment and are critically, acutely or seriously ill or convalescing				
Need Level 8: Individuals who require palliative care either in the home or in a facility				

Part C. General Information Regarding Formal Continuing Care Services in Your Community

The previous questions asked you for *estimated* numbers of individuals in your community who you believe require continuing care services. This section asks you about **actual** continuing care services in your community**.** This information will be helpful in providing some basic, aggregated/grouped information about actual service delivery and costs in First Nations and Inuit communities.

Home and Community Care

1. How many people are **currently** receiving home and community care services in your community? That is, what is the **actual** number of people who are receiving home and community care services at this point in time?

   _________ people

2. How many people **actually** received home and community care services at some point in time in the last 12 months? Please count each person only once.

   ________ people

The following questions ask about costs and number of hours of service for your home and community care program. The information requested in these questions can be used to estimate overall costs for home care and the amount of service provided per client, and to make comparisons across similar First Nations and Inuit communities. Although you may already provide the actual costs and number of hours of service in materials provided to the government, we would appreciate it if you could provide us with the relevant information in this document as well.

3. What were the annual operating expenditures for your home and community care program for the 2004/2005 fiscal year? How much funding do you believe you need?

Expenditure	**Cost for 2004/2005 fiscal year**	**Cost for 2004/2005 fiscal year is**		**Estimated Amount of Funding Needed for One Fiscal Year**
		Estimated	**Actual**	
Capital costs (e.g., rent or mortgage)				
Salaries and benefits for care related staff				
Salaries and benefits for administrative and other staff				
Staff training				
Traditional ceremonies				
Other (please specify)				
Total overall annual expenditures				

4. What are the current overall costs per hour or visit for care staff involved in your home and community care program? How much funding do you believe you need?

Type of Staff	**Cost Per**		**Cost is**		**Estimated Amount of Funding Needed for One Fiscal Year**
	Hour	**Visit**	**Estimated**	**Actual**	
Nurse (RN)					
Nursing Assistant					
Home Support Staff					
Traditional Healers					
Other care staff (please specify)					
Cost per hour or visit across all care staff					

5. What were the total numbers of hours of service or visits provided in the last 12 months by various types of staff? How much funding do you believe you need to provide the number of hours of service or visits required by home and community care clients in your community?

Type of Staff	**Number of**		**Number is**		**Estimated Amount of Funding Needed for One Fiscal Year**
	Hours	**Visits**	**Estimated**	**Actual**	
Nurse (RN)					
Nursing Assistant					
Home Support Staff					
Traditional Healers					
Other care staff (please specify)					
Total, across all staff					

Facility Care

6. What type of facility exists in your community? Mark all that apply.

Supportive Living ____
Group Home ____
Personal Care Home ____
Other (please specify) ______________

7. How was the decision to have one type of facility over another type determined in your community?

____
____
____

If you have more than one facility in your community, please answer the following questions for *each* facility.

8. Is the facility in your community licensed?

Facility 1 (name): ____

☐ Yes
☐ No
☐ Currently trying to obtain
☐ Don't Know/Unsure

If yes, who is it licensed by (for example, First Nations government, provincial government)?

____
____

Facility 2 (name): ____

☐ Yes
☐ No
☐ Currently trying to obtain
☐ Don't Know/Unsure
☐ Not applicable

If yes, who is it licensed by (for example, First Nations government, provincial government)?

____
____

9. Is the facility in your community accredited?

Facility 1

- ☐ Yes
- ☐ No
- ☐ Currently trying to obtain
- ☐ Don't Know/Unsure

If yes, who has provided the accreditation (for example, First Nations government, provincial government, Canadian Council on Health Services Accreditation)?

____

____

Facility 2

- ☐ Yes
- ☐ No
- ☐ Currently trying to obtain
- ☐ Don't Know/Unsure
- ☐ Not applicable

If yes, who has provided the accreditation (for example, First Nations government, provincial government, Canadian Council on Health Services Accreditation)?

____

____

10a. In the last 12 months, how many beds were in the facility (facilities) in your community?

Facility 1

_________ number of beds currently available

Facility 2

_________ number of beds currently available

☐ Not applicable

10b. How many beds would you need to meet the needs of the people who are currently receiving continuing care services?

Facility 1

_________ estimated number of beds required

Facility 2

_________ estimated number of beds required

☐ Not applicable

11. How many people resided in the facility (facilities) in your community at some point in the last 12 months? Please count each person only once.

Facility 1

_________ number of people

Facility 2
_________ number of people

☐ Not applicable

12. In what year was the facility in your community built?

Facility 1

_________ year facility was built (or best estimate)

Facility 2

_________ year facility was built (or best estimate)

☐ Not applicable

13. Has Facility 1 undergone any renovations in the last five years?

☐ Yes
☐ No
☐ Don't Know/Unsure

a) If yes,

What changes have been made?

____
____
____

b) Were some or all of the renovations done **in order to** bring the building up to code or to meet provincial or other standards?

☐ Yes
☐ No
☐ Don't Know/Unsure

c) Approximately how much have the renovations cost over the last five years?
$_________

14. Has Facility 2 undergone any renovations in the last five years?

☐ Yes
☐ No
☐ Don't Know/Unsure
☐ Not applicable

a) If yes, what changes have been made?

____
____
____

b) Were some or all of the renovations done **in order to** bring the building up to code or to meet provincial or other standards?

☐ Yes
☐ No
☐ Don't Know/Unsure

c) Approximately how much have the renovations cost over the last five years?
$_________

15. If modification are needed but have not been made, please explain why they were not made?

☐ Cost
☐ No one to do the work
☐ Just haven't gotten around it
☐ Other (explain) : ____
☐ Don't know/Unsure

16. Overall, do you consider the rooms to be safe?

☐ Yes
☐ No
☐ Don't know/Unsure

Comments : ____
____
____
____

The following questions ask about costs for the facility (facilities) in your community. The information requested in these questions can be used to estimate overall costs for facility care and to make comparisons across similar First Nations and Inuit communities.

17a. What were the annual operating expenditures for Facility 1 for the 2004/2005 fiscal year? How much funding do you think you need?

Expenditure	**Cost for 2004/2005 fiscal year**	**Cost for 2004/2005 fiscal year is**		**Estimated Amount of Funding Needed for One Fiscal Year**
		Estimated	**Actual**	
Capital costs (e.g., rent or mortgage)				
Salaries and benefits for care related staff				
Salaries and benefits for administrative and other staff				
Staff training				
Traditional ceremonies				
Other (please specify)				
Total overall annual expenditures				

17b. What were the annual operating expenditures for Facility 2 for the 2004/2005 fiscal year? How much funding do you think you need?

☐ Not applicable

Expenditure	**Cost for 2004/2005 fiscal year**	**Cost for 2004/2005 fiscal year is**		**Estimated Amount of Funding Needed for One Fiscal Year**
		Estimated	**Actual**	
Capital costs (e.g., rent or mortgage)				
Salaries and benefits for care related staff				
Salaries and benefits for administrative and other staff				
Staff training				
Traditional ceremonies				
Other (please specify)				
Total overall annual expenditures				

18a. How many full time and part time **positions** are there in Facility 1? These are positions, not necessarily the number of staff actually available in the facility.

	Staff	**Full Time Positions**	**Part Time Positions**
Care Services	Nurses (RN)		
	Nursing Assistants		
	Other Care Staff (for example, Physiotherapists, Occupational Therapists, Social Workers)		
	Traditional Healers		
	Other (please specify)		
Non-Care Services	Dietary		
	Housekeeping		
	Administration		
	Other (please specify)		

18b. How many full time and part time **positions** are there in Facility 2? These are positions, not necessarily the number of staff actually available in the facility.

☐ Not applicable

	Staff	**Full Time Positions**	**Part Time Positions**
Care Services	Nurses (RN)		
	Nursing Assistants		
	Other Care Staff (for example, Physiotherapists, Occupational Therapists, Social Workers)		
	Traditional Healers		
	Other (please specify)		
Non-Care Services	Dietary		
	Housekeeping		
	Administration		
	Other (please specify)		

19a. On average, how many care hours do you think each type of staff member provided to each client in Facility 1 in the last year? For example, what is the average number of hours RNs spent with each client? How much funding do you believe you need to provide the number of hours of service required by clients in your facility?

Type of Staff	**Number of**		**Number is**		**Estimated Amount of Funding Needed for One Fiscal Year**
	Hours	**Visits**	**Estimated**	**Actual**	
Nurse (RN)					
Nursing Assistant					
Other Care Staff (for example, Physiotherapists, Occupational Therapists, Social Workers)					
Traditional Healers					
Other care staff (please specify)					
Total, across all staff					

19b. On average, how many care hours do you think each type of staff member provided to each client in Facility 2 in the last year? For example, what is the average number of hours RNs spent with each client? How much funding do you believe you need to provide the number of hours of service required by clients in your facility?

☐ Not applicable

Type of Staff	**Number of**		**Number is**		**Estimated Amount of Funding Needed for One Fiscal Year**
	Hours	**Visits**	**Estimated**	**Actual**	
Nurse (RN)					
Nursing Assistant					
Other Care Staff (for example, Physiotherapists, Occupational Therapists, Social Workers)					
Traditional Healers					
Other care staff (please specify)					
Total, across all staff					

Part D. General Information Regarding Care Services Provided by Family Caregivers in Your Community

In addition to the formal care system, family members, close friends and other individuals may provide assistance to individuals requiring continuing care services.

1. Overall, how familiar would you say you are with the provision of care services by family caregivers in your community?

   ☐ Not familiar
   ☐ Slightly familiar
   ☐ Somewhat familiar
   ☐ Very familiar

2. In your community, approximately what percentage of clients have family caregivers (e.g., family members, close friends, or others) who are involved in their care?

   _________ percentage of clients who have family caregivers involved in their care

3. In your community, who tends to be involved in the provision of care services by family caregivers (e.g., children, spouse, etc.)? Please try to be as specific as possible.

4. What types of assistance do family caregivers provide to the individual(s) needing assistance?

5. How do family caregivers support the provision of formal continuing care services?

____
____
____
____
____
____

6. Over the next 10 years, would you expect that the role of family caregivers will change in your community? If yes, how?

____
____
____
____
____
____

Part E. Other Comments

1. Do you have any other comments regarding the provision of continuing care services, either by the formal care system or by family caregivers, in your community?

____
____
____
____
____
____
____
____
____
____
____

We thank you very much for your patience and effort in completing this survey. Please return the completed document to:

Nancy Gros-Louis McHugh
CSSSPNQL / FNQLHSSC
250 Place Chef Michel Laveau
Suite 101
Wendake (Québec)
G0A 4V0
Téléphone : (418) 842-1540
Télécopieur : (418) 842-7045

Courriel : nancygl@cssspnql.com

Appendix 10. Assessment of the Interviewer's Experience Form

Training Evaluation Form for the *Assessing Continuing Care Requirements in First Nations and Inuit Communities* Pilot Survey

1. Training

1.1 Did the interviewer training that you received before your work allow you to carry out your tasks easily?
(length of training, content, positive or negative points, additions, withdrawals, etc.)

1.2 Did the material given helped you, did you use it?

1.3 Was this your first experience in the community-based research field?

2. Technical Support

2.1 What do you think about the availability of assistance from the Commission during your work?

2.2 Do you have any comments on administrative issues?
(pay, weekly reports, sending questionnaire, etc.)

3. Consent Forms and Questionnaires

3.1 Were the consent forms clear? Culturally adapted?

3.2 Were the questionnaires clear, easy to administer and to complete? Culturally adapted?

4. Personal Experience

4.1 What were your expectations about this project? Have they been fulfiled?

4.2 What did you learn from this community-based research pilot project?
(positive and negative points, difficulties, solutions, etc.)

5. Respondant Participation

5.1 Generally speaking, what were clients and caregivers reasons for refusing to participate?

Clients ____

Caregivers ____

6. Impacts

6.1 Do you think this home care research project will be relevant to your First Nation?

6.2 Would you like to conduct interviews or other research again?