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An Assessment of Continuing Care Requirements in First Nations and Inuit Communities

An Examination of Continuing Care Requirements in Inuit Communities



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EXECUTIVE SUMMARY

1. Introduction

The term “continuing care” refers to a complex system of service delivery that includes all of the services provided by case management, home care, home support, long term care and chronic care. As used 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 may be provided in the home, in supportive living environments, or in facility settings.¹ Although it is recognized that palliative care is part of the continuum of continuing care services, it was not a major focus of this study.

Continuing care services are available to Inuit communities through a Home and Community Care Program funded by the First Nations and Inuit Health Branch.² The program provides funding for basic home and community care services, including case management, nursing care, in-home respite care and personal care. The program does not duplicate services that already exist in communities, but coordinates and links with existing programs and services at the community and/or provincial/territorial level. In theory, the Home and Community Care Program is available to individuals of all ages who have an assessed need.³ However, due to funding constraints, communities may need to decide if some services will be available to all client groups, or whether one or more client groups will receive priority. Each community is able to determine who is eligible to receive services.

The current project, the Continuing Care Research and Costing Project, was intended to provide a better understanding of the gaps in the continuing care services available in both First Nations and Inuit communities. The purposes of the project were: to gain an understanding of the continuing care needs of individuals living in First Nations and Inuit communities; to identify what continuing care services are currently provided in First Nations and Inuit communities; and to develop and cost options for the provision of continuing care services in First Nations and Inuit communities.

The project primarily focused on First Nations living on reserves or Inuit living in communities south of 60° L.⁴ The findings from the study will feed into the development of continuing care policy options for First Nations and Inuit in Canada.

¹ 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, group homes and personal care homes.

² This program is also available for First Nations. First Nations are also able to receive continuing care services through the Assisted Living Program funded by the Social Policy and Programs Branch of Indian and Northern Affairs Canada (INAC). The Assisted Living Program is not available to Inuit communities.

³ The provision of continuing care services depends, in part, on the risk to the client and caregiver. The services need to be provided within established standards, policies and regulations for service practice (Government of Canada, 2004).

⁴ Health Canada and INAC are involved in the delivery of continuing care services for First Nations living on reserve and in Inuit communities south of 60° L. Continuing care services are delivered by First Nations governments in the Yukon and by the governments of Nunavut and the Northwest Territories.

This document presents the findings from the interviews with Inuit individuals who are receiving continuing care services and their caregivers in the Nunavik Region. The findings from other components of the Continuing Care Research and Costing Project are presented in separate documents.

2. The Nunavik Region

The Nunavik Region covers one third of Québec and is located between 55° L and 62° L. The total area is 660,000 sq. km (according to the Inuit; Makivik Corporation, no date) or 429,456 sq. km (according to the government; Institut de la statistique du Québec, 2005). It is bordered on the west by Hudson Bay, on the north by Hudson Strait and on the east by Ungava Bay and Labrador. Although Nunavik is a large region, it is sparsely populated. It is estimated that there are 10,240 people in the region, and that approximately 90% of the permanent residents are Inuit.

Health services in the region are covered under the James Bay and Northern Québec Agreement. Under the Agreement, the Québec government is responsible for providing funding for health services provided through provincial programs as well as for health services that are not included in provincial programs but which are provided to Inuit by Health Canada or other organizations. The Nunavik Regional Board of Health and Social Services is responsible for improving the well-being of the entire Nunavik population by organizing health and social service programs in the region, evaluating the efficiency of the programs and ensuring users receive good quality services that are appropriate for their needs.

Implementation of the James Bay and Northern Québec Agreement involves recognizing the unique difficulties of operating facilities and providing services in the north. Working conditions and benefits are to be sufficiently attractive to recruit and retain staff; health and social services employment opportunities are to be made available to Inuit individuals; and budgets for the development and operation of health and social services and facilities are to take into account the impact of northern costs. Per capita health care costs are, on average, higher in Nunavik than elsewhere in Québec (Duhaime, 2004).⁵ It is estimated (based on 2004 figures) that public spending on health per capita is \$5,940 for Nunavik and \$2,376 for Québec (Duhaime, 2004).

There are 14 communities in Nunavik, 7 on the Hudson coast and 7 on the Ungava coast. The three largest communities are Kuujuaq, Inukjuak and Puvirnituk (all of these communities were included in the current study). The communities are located 1,000 to 1,900 km north of Montreal (Mativik Corporation, no date). There are no road links to Nunavik from the south or between communities within the region. Air service provides links between the communities and elsewhere year round.

Continuing care services in the region include home care, a day program and facility care. Home care services have been in place in the region since 2002. The number of recipients doubled between 2002/2003 and 2003/2004, but remained relatively constant between 2003/2004 and 2004/2005 (Nunavik Regional Board of Health and Social Services, 2004, 2005).

⁵ This is true even when Nunavik is compared to other remote regions of the province.

In 2004/2005, approximately 14% of home care users were between 0 and 17 years of age, 43% were between 18 and 64 years of age, and 44% were 65 years of age or older. A day centre opened in Kuujjuaq in April 2004. The centre provides seniors with transportation services, hot lunches, organized activities and socialization activities five days a week. There are 10 long term care beds in Kuujjuaq, 8 long term care beds in Puvirnituq and 8 beds for individuals with mental health problems and/or intellectual impairment in Inukjuak.

3. Methodology

3.1 Client and Caregivers Samples

The focus of the Continuing Care Research and Costing Project was on individuals who do not have, or who have lost, some capacity to care for themselves. As noted previously, these individuals included: seniors; adults with chronic diseases or conditions; adults with mental health needs; and children with special needs.

The client target sample was 90 individuals, 30 from each of three study communities. The sample consisted of individuals who were receiving continuing care services at home or in the community and individuals who were receiving services in a facility. The sample size was affected by the amount of funding available for the study, but was double what had initially been envisioned. Individuals receiving continuing care services at home as well as those receiving services in a facility were included. All of the facility clients who were considered capable of participating were included in the study. Home care clients were randomly selected from lists of individuals who were receiving continuing care services at the time of the study. A total of 79 individuals participated, 57 who were receiving services at home and 22 who were receiving services in a facility.

One of the questions of interest in this study was the extent to which family caregivers were providing care and support to individuals requiring continuing care services, regardless of whether they were receiving the services at home or in a facility. Caregivers were identified for clients who participated in the study. Where possible, clients were asked to identify a family caregiver who provided him/her with care and/or support. Of the 57 clients living at home, 20 (35.1%) indicated they had a family caregiver. Of the 22 clients living in a facility, 1 (4.5%) indicated he/she had a family caregiver. In some cases, paid health care workers were identified as being the caregiver. Ultimately, 38 caregivers participated in the study. All of the family caregivers (14) provided care to clients receiving services at home. All but two of the 24 paid health care workers provided care to clients receiving services in a facility.

3.2 Research Tools

Several research tools were created for the project. These included consent forms for both clients and caregivers, a measure of functional status, a Client Interview, and a Caregiver Interview. With the exception of the functional status measure (which is a standardized tool), all of the materials were developed in collaboration with First Nations and Inuit representatives.

Three client consent forms were created: one for adults who were capable of providing consent on their own behalf; one for proxies to complete on behalf of adults who were not capable of providing consent; and one for parents/guardians to complete on behalf of children. The general content of each of these consent forms was the same and included: information regarding the purpose of the study; what the study involved; anticipated risks, discomforts, benefits and costs; confidentiality issues regarding the information collected; the right to withdraw from the study without penalty; and contact information for individuals who had questions. A consent form was also created for use with caregivers. This form was similar to the consent forms used for clients, but also indicated that they were being asked to participate *because* it was understood they provided care and/or support to someone who had participated in the study.

In studies focusing on the provision of continuing care, it is more important to assess an individual's functional status than to determine his/her diagnoses as individuals with the same health condition (such as lung cancer) may require different continuing care services because of their different functional status. In this study, clients' functional status was assessed using the *Système de mesure de l'autonomie fonctionnelle* (Functional Autonomy Measurement System or SMAF) developed by Hébert, Carrier and Bilodeau (1988). The tool consists of 29 items that measure functional abilities in five areas: activities of daily living; mobility; communication; mental functions; and instrumental activities of daily living. Higher scores are indicative of poorer functioning.

The Client Interview tool was used to gather information regarding clients who were receiving continuing care services either at home or in a facility. The same interview tool was used for both groups of clients. The Client Interview consisted of several sections which addressed: client demographics; housing; use of health related services; satisfaction with health related services; preferences for where services should be provided; and perceptions of one's health and quality of life.

The Caregiver Interview tool was used to gather information from individuals who provided care and support to the client. Although intended to be used primarily with family caregivers, this tool was used with both family caregivers and paid health care personnel. The same tool was used with caregivers of clients who were receiving services at home and with caregivers of clients who were receiving services in a facility. The Caregiver Interview consisted of several sections which addressed: the caregiver's relationship to the client; the type of care provided; costs associated with the client's care; the caregiver's satisfaction with the services the client was receiving; the caregiver's preferences for where the client should receive services; the impact of caregiving on the caregiver; and caregiver demographics.

3.3 Research Approach

Once clients were identified, they were assigned a study number and contact information was provided to an interviewer who lived in the same community. The list of clients assigned to an interviewer was reviewed by knowledgeable individuals within the community to determine if they were well enough to participate, were currently in the community, and so on. Potential participants were then phoned or visited in person regarding their participation in the study. If a

potential participant agreed to participate, the interviewer then made arrangements to conduct the interview, generally in the client's home.

The interviewer began the client interview by reviewing the consent form and obtaining the client's written agreement to participate. The functional status measure was generally administered first (when appropriate), followed by the Client Interview. Permission to contact a (family) caregiver was requested when clients indicated that they had one. If a client indicated that he/she had a caregiver, the interviewer contacted the caregiver to see if he/she was interested in participating. If the caregiver was willing to participate, the interview was set up for a mutually convenient time. The interviewer began the caregiver interview by reviewing the consent form and obtaining the caregiver's written agreement to participate. Only the Caregiver Interview was administered to the caregivers. Multiple interviews were conducted with the caregiver, if required. Individuals who served as a proxy for the client (because the client did not have the ability to understand the questions, either because of a mental health/cognitive condition or because of age (for example, in the case of a child)) and as a caregiver for the client, were first asked the questions on the Client Interview then the questions on the Caregiver Interview.

As noted, individuals who lived in the same community as the clients were hired to conduct the interviews. A brief job description was developed to assist with the recruitment and selection of interviewers. An emphasis was placed on experienced interviewers who were familiar with the study communities and who were able to communicate in both Inuktitut and English. It was felt that there would be very few individuals who would meet the requirements. Thus, key personnel at the health centres, at the hospitals, at the CLSCs and with the Persons Lacking Autonomy program in the three study communities (as appropriate) were asked to recommend potential interviewers. The names of potential interviewers were submitted to the Local Project Coordinator. The Local Project Coordinator contacted each potential interviewer by phone, described the study and the roles and responsibilities of the interviewers in more detail and ascertained whether the individual was interested in working on the study. Interested individuals were then invited to attend a one day training session in their own community. They were also told that they would need to obtain a police security check prior to the training session. During the course of the study, the Local Project Coordinator maintained regular contact with the interviewers in each of the study communities (regardless of where he was physically located) to ensure that the work was progressing and any problems were identified and addressed. The Local Project Coordinator also spoke with the nurses in the various study communities to ensure that no issues had arisen from their perspective.

3.4 Data Coding and Entry

Comprehensive data coding manuals were developed for each of the three data collection tools (the SMAF, the Client Interview, and the Caregiver Interview). This was done to ensure that the coding of information was consistent: across individuals for the same tool; across different tools for the same questions (for example, across the Client and Caregiver Interviews); and across interviewers. The coders discussed any issues that arose as a group and a consensus was reached. Open-ended questions were coded verbatim. In some cases, responses were regrouped into a smaller number of categories.

4. Findings

4.1 Clients

The findings from the interviews with clients indicated that the majority of home care clients had low to moderate care needs and that facility clients had moderate to high care needs (as measured by the SMAF). While the home care clients covered the full age range (from 0 to 80 years and older), approximately half of the facility clients were under the age of 35.

Both home and facility clients received assistance with case management like activities, namely assistance with obtaining medical equipment, medical supplies and medications, assistance with coordinating and arranging medical appointments and health services, and assistance with identifying professionals who can provide services and/or medical equipment. Less than half of the clients indicated that they received assistance from family caregivers. In general, clients were satisfied with the continuing care services they were receiving. It is cautioned, however, that this finding should not be interpreted as indicating that no additional services are required.

Overall, half of the clients rated their health as “Very Good” or “Good”. The three things most frequently reported as affecting an individual’s health were: physical, emotional, mental and spiritual balance; stress/worry related to medications; and emotional well-being. Spiritual beliefs and/or values were identified most frequently as having a major effect on people’s health and/or lives. Clients were asked what things made them happy and what things made them unhappy. The things that make people the happiest are: outdoor activities; being with other individuals; and leisure activities, such as playing bingo. The things that make people the saddest are: drug and/or alcohol use; negative family issues; and noise.

Over 96% of clients indicated that they would prefer to receive continuing care services in their own community. Over 60% of clients indicated they would prefer to receive services in their own home and 43% indicated they would prefer to receive services in the home of a family member.⁶ Over 75% of clients indicated they would prefer to receive care from a family member. Another 51% indicated they would prefer to receive care from the formal care system.⁷ Over 60% of clients indicated that there was a need for other housing options. Some respondents noted that there was need for additional housing in general in the communities. Other respondents commented on the need for appropriate housing. When asked where they would prefer to receive care and services in the future, approximately 70% of the clients indicated that they would prefer to receive services in a home or community setting. Approximately 25% of the clients indicated that they would prefer to receive services in a hospital.⁸

⁶ Some clients provided more than one response to this question.

⁷ Again, some clients provided more than one response to this question.

⁸ Some clients provided more than one response to this question.

4.2 Caregivers

A total of 38 caregivers, 14 family caregivers and 24 formal caregivers, participated in the study. Over 90% of the caregivers were women. While 93% of family caregivers were able to communicate in the client's preferred language, only half of the formal caregivers were able to do so.

Both family caregivers and formal caregivers provided assistance with coordinating and arranging medical appointments and services and obtaining medical equipment, medical supplies and medications. Family caregivers were more likely than formal caregivers to assist with financial tasks, light housekeeping and home maintenance, and house maintenance inside. Family caregivers are generally satisfied with the services clients receive through the formal care system.

In general, family caregivers' living and employment situation did not appear to be negatively impacted because of providing care. The majority of family caregivers did not respond to questions regarding the positive and negative impacts of providing care. The majority of formal caregivers indicated that providing care had no positive or negative impacts because it was part of their job.

Caregivers were asked for suggestions to improve the care and quality of life for clients. A substantial proportion of family caregivers indicated that they had no suggestions. However, formal caregivers commented on the need for clients to be in more appropriate care settings, to have more services, and to have more family contact.

When asked where clients should receive services, all of the caregivers indicated that the client should receive them in his/her own community. Over 85% of family caregivers felt that clients should receive services in his/her own home or in the home of a family member. The findings from the formal caregivers were more mixed, consistent with the perspective that clients should receive services in appropriate care settings. Since the needs of clients vary, it is not unreasonable to expect that what constitutes an "appropriate care setting" may also vary. Approximately 43% of family caregivers and 71% of formal caregivers felt that clients should receive services from both family caregivers and the formal care system.

Over 57% of family caregivers and 70% of formal caregivers indicated that there is a need for additional housing options in the community. Many of the family caregivers and the formal caregivers did not respond to questions regarding where clients should receive services in the future if their health deteriorates.

4.3 Costs of Receiving and Providing Care

In order to gain an understanding of the costs associated with the provision of continuing care services to Inuit, clients were asked several questions regarding their out-of-pocket expenditures over the last year. While 73% of clients indicated that they had received supplies (primarily medications), they indicated that the costs were covered under the James Bay and

Northern Québec Agreement and thus, they were not aware of what the supplies and services cost. Similar findings were obtained from the caregivers.

Clients appeared to receive little assistance from family members. This finding is consistent with the finding that relatively few clients indicated they had a family caregiver. The majority of clients received assistance from health care professionals (that is, nurses and physicians) when required, particularly when they lived in a facility. It was not possible to cost services based on the available data.

Neither clients nor caregivers were able to provide information regarding the continuing care services they accessed. The Nunavik Regional Health and Social Services Board was therefore asked for information regarding the costs of providing both home and community care and facility care. As funding for health and social services in the region is integrated, the region was unable to provide costing information the way it was requested. However, several factors that affect the provision of home care services were identified. These included benefits and salaries for health professionals (including nurses and home care workers), the need to have interpreters assist with the provision of care, and transportation costs related to both people and resources. The region also noted that funding for the provision of continuing care services comes from multiple sources. Each of the sources has different requirements with respect to access and reporting.

5. Discussion

5.1 Introduction

Several research questions were addressed by the Continuing Care Research and Costing Project. These were:

- What is the number of individuals assessed as having continuing care needs (by type of care) in First Nations/Inuit communities?
- Have clients been appropriately placed in home care and facility care, respectively?
- What are the type and magnitude of services required at each care level in home and facility care?
- What is clients' existing level of satisfaction with the continuing care services they receive?
- What is clients' quality of life?
- What are the clients' preferences for care settings?
- What are the contributions of informal caregivers?
- What are the differences in service provision by community isolation?
- What are the costs of providing services?

The interviews with Inuit continuing care clients and their caregivers provide some answers to each of these questions.

5.2 Individuals Requiring Continuing Care Services in Inuit Communities

The target sample of 90 individuals was determined by available funds. The obtained sample represents 87.8% of the target, which resulted in small numbers in several instances where the sample was divided (for example, into home and facility clients). This would likely have been the case had the full sample been realized. It is important to note that the facility sample represented 85% of the number of available beds. Overall, the home sample represented 19.3% of clients receiving continuing care services at home. Approximately equal numbers of males and females require continuing care services, even for individuals living in a facility.⁹ One of the key findings is the number of younger individuals who are receiving continuing care services, particularly in a facility; 22.8% of clients receiving services at home and 45.5% of clients receiving services in a facility were under the age of 35. In many continuing care studies, the majority of clients are seniors (generally defined as individuals 65 and older). For the Inuit, 43.9% of those receiving services at home and 22.7% of those receiving services in a facility were 65 years of age and older. As a population, Inuit tend to be younger and may experience age related conditions at a younger age. Thus, if one considers seniors to be those aged 55 and older, the proportions increase to 66.7% and 31.8% for individuals receiving services at home and in a facility, respectively.

5.3 Location of Clients Based on Their Current Care Needs

The findings from the SMAF suggest that clients receiving continuing care services at home generally have low to moderate care needs. Clients receiving continuing care services in a facility generally have moderate to high care needs. While this suggests a potential overlap in the mid-range, it also suggests that clients at the upper and lower care levels are located in appropriate care settings. A closer examination of individuals in the mid-range indicated that individuals living in facilities have more difficulties with mental functions than those living at home.

5.4 Types of Services Required for Individuals Living at Home and in Facilities

Despite the fact that clients may be located in appropriate care settings, there are several indications that they are not receiving sufficient services, or a broad enough range of services. While many clients receive care-related services (that is, clinical necessities), few clients living at home receive housekeeping, meal preparation or house maintenance services. Very few clients appeared to receive opportunities for psychological/social activities, respite services, or companionship time. In fact, one of the areas for improvement highlighted for individuals living in facilities was the need for more activities.

5.5 Clients' and Caregivers' Satisfaction with Current Continuing Care Services

In general, clients appeared to be satisfied with the services they receive from both family caregivers and the formal care system with respect to: services being provided when they are needed; how long services are provided for; and the characteristics of the individuals who are providing the services. Clients receiving services from formal caregivers noted, however, that

⁹ Continuing care studies involving non-Aboriginal clients generally find that females outnumber males.

they have little say in who will provide services and when services will be provided. These findings likely reflect the fact that there are a limited number of formal caregivers available. Family caregivers also indicated that they were satisfied with the formal care services clients received. Approximately 9% of clients indicated that they had refused treatments or services in the past year. In all cases, the refusals were related to clients' preferences rather than their perceptions of the quality of care they were receiving. In general, clients appeared to be satisfied with the care they received outside of their communities.

5.6 Clients' Perceived Health and Quality of Life

About half of the clients considered their health to be "Good" or "Very Good", despite the fact that they were experiencing functional difficulties, sometimes in several areas. Clients indicated that their health was affected by physical, emotional, mental and spiritual balance as well as concerns regarding medications. Spiritual beliefs and/or values were frequently identified as having a major influence on people's health and/or lives. The things that make clients the happiest are outdoor activities, being with other individuals, and leisure activities. The things that make clients the saddest are drug and/or alcohol use, negative family issues and noise.

5.7 Clients' and Caregivers' Preferences for Where Services are Received

Both clients and caregivers indicated a preference for clients to receive continuing care services in their own community. Clients generally indicated a preference to receive services at home (either in their own home or in the home of a family member). This perspective was supported by family caregivers, all of whom were providing care to individuals living at home. Formal caregivers, most of whom were providing care to individuals living in a facility, provided mixed responses. It was felt that about a third of the clients should be living either in their own home or in the home of a family member. It was also felt that approximately one-half of clients would benefit from living in a personal care home or an elders/seniors home. The findings from the formal caregivers suggest that not all clients were living in an appropriate location with respect to the type of care they required and/or the type of care that was available to them. The findings from both clients and formal caregivers suggest that additional *appropriate* housing and services are required.

Clients and caregivers were also asked who should provide services to clients. The majority of clients living at home indicated that they would prefer to receive services from family members, although about half of the clients also indicated that they would prefer to receive services from the formal care system.¹⁰ Formal caregivers indicated that over 70% of clients currently living in a facility should receive care from both family caregivers and the formal care system. However, it would appear that individuals living in a facility currently have little contact with their families.

Both clients and caregivers were asked where clients should receive services in the future should their health deteriorate and/or should they require palliative/end-of-life care. About 70% of clients indicated that they would prefer to receive care at home in both cases; approximately

¹⁰ Clients could indicate a preference for assistance from more than one source.

25% indicated that they would prefer to receive care in a hospital setting in both cases. The majority of caregivers did not provide responses to these questions.

5.8 The Contributions of Family Caregivers

Few family caregivers were identified, even for those clients receiving services at home. Of the clients living at home, 35.1% indicated that they had a family caregiver; 4.5% of clients living in a facility indicated they had a family caregiver. This finding may reflect clients' understanding of what a caregiver is. The majority of family caregivers may not have been seen as caregivers *per se* as they were either parents or spouses.

Over 70% of family caregivers work. Of these, half work more than 20 hours a week. Half of the family caregivers also indicated that they provided care to someone in addition to the client. Thus, family caregivers may be unable to provide a lot of assistance to the client on an ongoing basis. While some family caregivers provide assistance with housekeeping, personal care, and nursing or medical care, they also assist with: identifying professionals who can provide medical services and/or equipment; coordinating and arranging medical appointments; and obtaining medical equipment, supplies and medications. These findings suggest that family caregivers work with the formal care system to ensure that clients' basic health care needs are met.

5.9 The Effects of Community Location

As with other Inuit communities in Canada, the communities included in this study are located in northern, remote locations. While the study communities are large compared to other Inuit communities, they are relatively small compared to "large" First Nations communities and are substantially smaller than many southern communities. Both the size and the location of the communities have a substantial impact on the provision of continuing care services for Inuit. For example, funding based on a per capita formula is likely to be insufficient to meet the needs, given some of the costs associated with the location of the communities. This is highlighted by the fact that funding for home care comes from nine different sources. Many health professionals come from southern communities as it is difficult to recruit and retain health care workers within the region. There are substantial costs associated with their salaries and benefits, and the provision of interpreter services to assist them in providing care. Many specialist services are only available in the region two or three times a year. At other times, clients may not be able to access the services, may be able to access limited services, or may need to leave the region and travel to southern communities to obtain the services. Transportation costs have a substantial impact on the provision of continuing care services in the region as much of the transportation of people (both health professionals and clients) and medical supplies and equipment must be done by air.

5.10 Cost of Providing Services

The findings from this study do not enable conclusions to be made regarding the cost of providing continuing care services to home and facility clients by level of care. Nevertheless, it is clear that "hidden" costs associated with the provision of such services are substantial. As

noted previously, salaries, benefits and transportation costs all have substantial impacts on the provision of services.

6. Future Directions

The findings from this phase of the Continuing Care Research and Costing Project indicated that there are several areas in which improvements can be made. These include the following:

- Additional funding is required to hire, train, and retain individuals who are specifically responsible for the collection, analysis and reporting of utilization data.
- There is a need for additional general and specialized housing in the region. Many of the home care clients live in over crowded homes. For individuals who require continuing care services in a facility setting, there is a need for assisted living settings, for elders' lodges, homes for the physically challenged and homes for the mentally challenged.
- Additional services could be added to improve care for current continuing care clients. Key areas to consider include physiotherapy, social and recreational activities, and specialized education for children with special needs.
- Individuals living in facilities need more appropriate care settings, activities that are designed to both meet their needs and ensure they remain an important part of the community, and more involvement with family members.
- There is considerable need to increase local capacity. Interested individuals need to be identified and trained. Steps need to be taken to ensure that training and support can be ongoing and that motivation incentives are available in order to facilitate the retention of trained individuals. "Pools" of trained individuals should be developed for high need occupations such as medical interpreters, home support workers, nurses, etc., so that the necessary resources are available at the community level when they are required. Additional funding is required to both maintain and build on existing capacity.

Developing and implementing these changes would likely entail enhanced collaboration among several levels of government and several departments within each level. Inuit are generally happy with what they have and are unlikely to make requests for additional services. That does not mean, however, that existing services are sufficient. To the extent that it is possible to do so, from both a practical and a financial perspective, the improvements should be made at the community level. Where that cannot be done, attempts should be made to improve services at the sub-regional and regional levels.

7. Conclusion

The Nunavik Region has established a number of resources for individuals who require continuing care services. It is hoped that the findings from this phase of the Continuing Care Research Project will enable the region to improve these resources for current clients and their families as well as for individuals who may require the services in the future.

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1. INTRODUCTION

1.1 Defining Continuing Care

The term “continuing care” refers to a complex system of service delivery rather than to a type of service, such as physician services or hospital services (Federal/Provincial/Territorial Subcommittee on Continuing Care, 1992). The system has a number of components and is integrated conceptually, as well as in practice, through a “continuum of care”. The term reflects two complementary concepts: that care may “continue” over a long period of time, and that an integrated program of care “continues” across service components (that is, that there is a continuum of care).

Continuing care is generally used to describe a system of service delivery that includes all of the services provided by case management, home care, home support, long term care and chronic care. The efficiency and effectiveness of the system depends not only on the efficiency and effectiveness of each component, but also on the way that the service delivery system is structured (Federal/Provincial/Territorial Subcommittee on Continuing Care, 1992).

As used 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 may be provided in the home, in supportive living environments, or in facility settings.¹ Although it is recognized that palliative care is part of the continuum of continuing care services, it was not a major focus of this study.

1.2 Continuing Care Services in First Nations and Inuit Communities

Continuing care services are available to First Nations and Inuit communities through an Assisted Living Program funded by the Social Policy and Programs Branch of Indian and Northern Affairs Canada (INAC) and through a Home and Community Care program funded by the First Nations and Inuit Health Branch (FNIHB) of Health Canada.

The Assisted Living Program is delivered by First Nations organizations (the program is not available in Inuit communities). The Assisted Living Program consists of three components: in-home care, which includes meal preparation, light housekeeping, short-term respite care, and minor home maintenance; foster care, which provides funding for supervision and care in a family setting to individuals who are unable to live on their own because of physical or psychological limitations but who do not need constant medical attention; and facility

¹ 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, group homes and personal care homes.

(institutional) care, which reimburses expenses for Type I and Type II² social care in facilities (Government of Canada, 2004).

The Assisted Living Program is available to individuals normally living on-reserve who have been formally assessed by designated health and/or social service personnel as requiring care because they have functional limitations due to age, health problems or disability. The program is not intended for individuals who have the means to obtain services for themselves.

The Home and Community Care Program is provided primarily by First Nations and Inuit organizations (the program is available in over 600 communities across the country).³ The program provides funding for basic home and community care services, including case management, nursing care, in-home respite care and personal care. The program does not duplicate services that already exist in communities, but coordinates and links with existing programs and services at the community and/or provincial/territorial level.

In theory, the Home and Community Care Program is available to individuals of all ages who have an assessed need.⁴ However, due to funding constraints, communities may need to decide if some services will be available to all client groups, or whether one or more client groups will receive priority. Each community is able to determine who is eligible to receive services.

Few other programs (regardless of whether they are provided by the federal government, by a provincial/territorial government, by a First Nation or Inuit organization, or by another agency) contribute to the provision of continuing care services in First Nations and Inuit communities.

1.3 The Continuing Care Research and Costing Project

Despite the availability of the Assisted Living and Home and Community Care Programs, there appear to be substantial gaps in the continuum of services being provided to First Nations and Inuit individuals. Currently, neither INAC nor Health Canada have all the necessary authorities to provide a full range of continuing care services in First Nations and Inuit communities.⁵

² These care levels refer to federal care levels. Type I is residential care for individuals requiring limited supervision and assistance with activities of daily living. Type II is extended care for individuals requiring some personal care on a 24 hour basis. Individuals requiring more extensive care (that is, Type III, IV, or V care) are considered the responsibility of provincial/territorial health authorities and are generally cared for off reserve (INAC, 2003).

³ The program is available to individuals living on a First Nations reserve, in a First Nations community (if north of 60° L) or in an Inuit settlement.

⁴ The provision of continuing care services depends, in part, on the risk to the client and caregiver. The services need to be provided within established standards, policies and regulations for service practice (Government of Canada, 2004).

⁵ There are contradictory views about constitutional responsibilities for Aboriginal health care. The federal government holds that there is no constitutional obligation or treaty that requires the Canadian government to offer health programs or services to Aboriginal peoples. In contrast, Aboriginal peoples link federal health programs to treaty obligations and the broader trustee role of the federal government (for example, Boyer, 2003, 2004a, 2004b; Inuit Tapiriit Kanatami, 2004a, 2004c; Romanow, 2002).

The current project, the Continuing Care Research and Costing Project, was intended to provide a better understanding of the gaps in the continuing care services available in First Nations and Inuit communities. The purposes of the project were:

- To gain an understanding of the continuing care needs of individuals living in First Nations and Inuit communities;
- To identify what continuing care services are currently provided in First Nations and Inuit communities: and
- To develop and cost options for the provision of continuing care services in First Nations and Inuit communities.

The project primarily focused on First Nations living on reserves or Inuit living in communities south of 60° L.⁶ The findings from the study will feed into the development of continuing care policy options for First Nations and Inuit in Canada.

Several research questions were addressed by the project. These are:

- What is the number of individuals assessed as having continuing care needs (by type of care) in First Nations/Inuit communities?
- What are the type and magnitude of services required at each care level in home and facility care?
- What are the contributions of informal caregivers?
- What are the differences in service provision by community isolation?
- What are the clients' preferences for care settings?
- What is their existing level of satisfaction with the continuing care services they receive?
- What is their quality of life?
- Have clients been appropriately placed in home care and facility care, respectively?
- What are the costs of providing services?

The Continuing Care Research and Costing Project involved several components including:

- A review of published and unpublished literature regarding continuing care in Aboriginal populations in Canada, Indigenous populations internationally and non-Aboriginal populations in Canada;⁷

⁶ Health Canada and INAC are involved in the delivery of continuing care services for First Nations living on reserve and in Inuit communities south of 60° L. Continuing care services are delivered by First Nations governments in the Yukon and by the governments of Nunavut and the Northwest Territories.

⁷ Consistent with the Terminology Guidelines developed by the National Aboriginal Health Organization (2003), the term "Aboriginal" is used to refer collectively to First Nations, Inuit and Métis. The term "Indigenous" is used to refer to aboriginal people internationally.

- A review of national surveys and databases containing information regarding continuing care needs in Aboriginal populations in Canada;
- Interviews with key informants, including representatives of First Nations and Inuit communities and regional and national organizations, and representatives from Health Canada and INAC at both the regional and national levels; and
- Interviews with First Nations and Inuit individuals who are receiving continuing care services and their caregivers (for example, family members and close friends).

1.4 From One Study to Three Studies

Initially, Hollander Analytical Services Ltd., a health services and policy research company, was contracted by Health Canada to conduct the interviews with First Nations and Inuit individuals and their caregivers in eight communities (four First Nations communities in Manitoba, three First Nations communities in Québec, and one Inuit community in Nunavik). Three advisory groups, one at the national level, one at the regional level in Manitoba and one at the regional level in Québec, were to assist with the development and implementation of this component of the Continuing Care Research and Costing Project. A representative from Nunavik sat on the Québec regional advisory group.

As a result of discussions with the regional advisory groups and the funder, it was decided that the First Nations of Québec and Labrador Health and Social Services Commission (FNQLHSSC; Commission de la santé et des services sociaux des Premières Nations du Québec et du Labrador, CSSSPNQL) would be responsible for conducting the study in the First Nations communities in Québec, the Assembly of Manitoba Chiefs (AMC) would be responsible for conducting the study in the First Nations communities in Manitoba, and Hollander Analytical Services would be responsible for conducting the study in the Inuit community. Hollander Analytical Services served in an advisory capacity for both the FNQLHSSC and the AMC.

These decisions had several consequences with respect to Inuit involvement in the study. First, two more Inuit study communities in Nunavik were added (for a total of three communities) in order to increase the size and breadth of the study sample. Second, the study sample was doubled (from 45 individuals to 90 individuals) in order to obtain a better picture of the needs of Inuit continuing care clients and their caregivers. Third, the Nunavik representative on the Québec regional advisory group became the primary contact for the Inuit study sites, a role which was in addition to her other responsibilities. Fourth, it was necessary for Hollander Analytical Services to hire a Local Project Coordinator to implement this component of project in the Nunavik region. This individual did not live in the region, but was familiar with one of the study communities. Hollander Analytical Services was responsible for the coding and analysis of the Inuit data and for developing the report on the findings from the Inuit study communities.

1.5 Organization of this Report

This document presents the findings from the interviews with Inuit individuals who are receiving continuing care services and their caregivers. As the Nunavik representative and the Local Project Coordinator were actively involved in the implementation of this component of the

project, their experiences have been incorporated into the document. The findings from other components of the Continuing Care Research and Costing Project are presented in separate documents.

In the next chapter (Chapter 2), several issues regarding the Inuit research and policy environment are examined. The methods used for the interviews with Inuit individuals and their caregivers are presented in Chapter 3. Processes related to the hiring and training of interviewers are discussed in Chapter 4. Both Chapters 3 and 4 provide commentary on lessons learned as part of the current study. Chapters 5, 6 and 7 present the findings from the Inuit continuing care clients and their caregivers. The final chapter, Chapter 8, discusses the findings and identifies areas for future development.

2. RESEARCH AND POLICY ENVIRONMENT

2.1 Introduction

There are four Inuit regions in Canada: Inuvialuit (Northwest Territories); Nunavut; Nunavik (Northern Québec); and Nunatsiavut (Labrador). Half of the Inuit population lives in regions outside of Nunavut (Inuit Tapiriit Kanatami, 2004c). Inuvialuit, Nunavut and Nunatsiavut are briefly described below. Because the current research project focused on Nunavik, this region is described in more detail in Section 2.4.

Inuvialuit covers approximately 1.2 million sq. km. The economy is traditionally based, with an emphasis on trapping, hunting and fishing. It is estimated that there are more than 42,083 people in Inuvialuit. Approximately half of the population is Aboriginal. The region includes the communities of Inuvik, Tuktuujaqtuuq (Tukoyaktuk) and Aklaavik (Aklavik) (Solutions North, 2002).

Nunavut became Canada's newest territory in April, 1999. The territory consists of almost 2 million sq. km (approximately 20% of Canada); about 45% percent of the territory lies on the northern part of Canada's mainland. Many Inuit still live off the land, following traditional Inuit practices of trapping, hunting, and fishing. Carving, jewellery making and printmaking are contributing substantially to the economy. The region has a population of about 28,410. Communities include Iqaluit, Panniqtuuq (Pangnirtung) and Iglulik (Igloodik) (Solutions North, 2002)

Nunatsiavut covers approximately 72,520 sq. km. Economic opportunities focus on traditional skills and training and skills transfer opportunities. An important contributor to economic development is the Voisey's Bay Project; Voisey's Bay has one of the richest nickel-copper-cobalt deposits in the world. It is estimated that the population of Nunatsiavut is approximately 5,300. The region includes the communities of Happy Valley-Goose Bay, Nunainguk (Nain), and Aqvituq (Hopedale) (Labrador Inuit Association, 2005).

2.2 The Cultural Context of the Research Environment

Inuit Tapiriit Kanatami, the national association mandated to advocate on behalf of Inuit, has stated, that increasingly, the federal government has been moving toward policies that focus on First Nations on reserve (Inuit Tapiriit Kanatami, 2004c). Many federal programs designed for the benefit of Inuit have often been "ineffective, poorly coordinated, and inadequately targeted" (Inuit Tapiriit Kanatami, 2004c, p. 2). The problems are exacerbated by program under funding, and the lack of an accountability framework. Integrated Inuit specific policies and programs need to be developed and comprehensive Land Claim Agreements need to be implemented (Inuit Tapiriit Kanatami, 2004c).

All of the Inuit regions have signed land claims agreements. These agreements deal with land, natural resources, environment, economic development and some aspects of self-government. They do not, however, cover the full range of social, cultural and economic issues affecting Inuit. In developing the various regions, Inuit have often focused on "public

government”. This is reflected to varying degrees in the four Inuit regions. This decision means that Inuit are “taxpaying Canadians who see themselves as ‘more than First Canadians, but also Canadians First’” (Inuit Tapiriit Kanatami, 2004c, p. 3). Nevertheless, it is felt that the federal government continues to have fiduciary responsibility for the Inuit with respect to Aboriginal rights, economic development, education, environmental issues, health and housing and that an integrated policy approach for Inuit specific issues needs to be developed to address complex social and economic problems. These problems include short life expectancy, high unemployment rates, low incomes, poor housing conditions and high rates of communicable diseases.

2.3 The James Bay and Northern Quebec Agreement

The James Bay and Northern Québec Agreement, which was signed in November 1975, is considered to be the first modern land claims settlement in Canada. Signatories to the Agreement included the Government of Québec, the James Bay Energy Corporation, the James Bay Development Corporation, The Québec Hydro-Electric Commission, the Grand Council of the Crees (of Québec), the Northern Québec Inuit Association, and the Government of Canada. The Agreement addressed several issues including: land issues; hunting, fishing and trapping rights; local government; and health and social services (INAC, 2004).

Under the James Bay and Northern Québec Agreement (and an amendment, the Northeastern Québec Agreement, which was signed in January 1978), the territory was divided into three types of lands. Category I lands are designated for the exclusive use and benefit of Aboriginal people. Category II lands belong to the province, but Aboriginal people have exclusive hunting, fishing and trapping rights. Category III lands also belong to the province, and both Aboriginal and non-Aboriginal people may hunt and fish on them. However, Aboriginal people have exclusive rights to harvest certain aquatic species and fur-bearing mammals (INAC, 2004).

With regard to governmental powers, Inuit communities are incorporated as municipalities and have specific powers under Québec legislation (INAC, 2004). Regional government structures created under the Agreement include the Kativik Regional Government and the Kativik School Board. An Inuit corporation, the Makivik Corporation, was also created under the Agreement in June 1978. This corporation is responsible for receiving and administering compensation moneys, overseeing the implementation of the Agreement and ensuring the integrity of the Agreement (Makivik Corporation, no date). The James Bay and Northern Québec Agreement substantially affected federal involvement in Northern Québec. The federal government now subsidizes many services it previously provided, and the services are now administered by the local governments and the province of Québec.

For example, under the Agreement, the Québec government is responsible for providing funding for health services provided through provincial programs as well as for health services that are not included in provincial programs but which are provided to Inuit by Health Canada or other organizations. As part of implementing the Agreement, the unique difficulties of operating facilities and providing services in the north are to be recognized by Québec. Working conditions and benefits are to be sufficiently attractive to recruit and retain staff; health and social services

employment opportunities are to be made available to Inuit individuals; and budgets for the development and operation of health and social services and facilities are to take into account the impact of northern costs.

2.4 The Nunavik Region⁸

The Nunavik Region covers one third of Québec and is located between 55° L and 62° L. The total area is 660,000 sq. km (according to the Inuit; Makivik Corporation, no date) or 429,456 sq. km (according to the government; Institut de la statistique du Québec, 2005). It is bordered on the west by Hudson Bay, on the north by Hudson Strait and on the east by Ungava Bay and Labrador. Although Nunavik is a large region, it is sparsely populated. Provincial statistics for 2004 estimate that there are 10,240 people in the region (Institut de la statistique du Québec, 2005). Approximately 90% of its permanent residents are Inuit.

Inuit have inhabited the Nunavik region for more than 4,000 years. Over the past 300 years, the most substantial and long-standing contact between Inuit and Europeans was with Anglican Missionaries, traders, and the Hudson's Bay Company (Mativik Corporation, no date).

Inuit society is undergoing major change. Although Inuit were nomadic, in the early 1950s they established residence in permanent villages. Inuit are Canadian citizens, and pay all federal and provincial sales taxes as well as income tax. Currently, Inuit in this region are actively working on developing an autonomous government that will allow them to establish their own priorities. Nunavik's economy is heavily influenced by government; government operations represent more than 50% of the region's domestic product (Duhaime, 2004).

As shown in Figure 2-1, there are 14 communities in Nunavik, 7 on the Hudson coast and 7 on the Ungava coast. As shown in Table 2-1, the communities vary in size. The three largest communities are Kuujjuaq, Inukjuak and Puvirnituk. The communities are located 1,000 to 1,900 km north of Montreal (Mativik Corporation, no date). There are no road links to Nunavik from the south or between communities within the region. Air service provides links between the communities and elsewhere year round. The Makivik Corporation currently owns two airlines, First Air and Air Inuit. First Air provides passenger and cargo services between 24 northern communities with connections to Edmonton, Winnipeg, Ottawa and Montreal (First Air, 2005). Air Inuit provides scheduled, charter, cargo and emergency transportation for the region, 24 hours a day, 365 days a year (Air Inuit, 2005). Maritime service is also available in the summer and fall. However, the lack of proper port facilities affects the cost of shipping to the region (Mativik Corporation, no date).

⁸ Much of the information in this section is based on documents produced by the Nunavik Regional Board of Health and Social Services (2003; no date).

Figure 2-1: The Nunavik Region



From Makivik Corporation. (no date). *Media Centre*.

The Nunavik region has the highest population growth in Canada. The population is growing at a rate that is six times higher than that in the rest of Québec (Duhaime, 2004). It is estimated that the population in the region will increase by 26.6% over the 25 year period from 2001 to 2026 (Institut de la statistique du Québec, 2005). This is approximately 1.1% growth per year. However, between 1996 and 2001, the region grew by 2.1%, with some communities (such as Akulivik, Salluit, Quaqaq, and Tasiujaq) growing by 14% or more (George, 2002).

The Inuit population tends to be young; over 60% is under the age of 30, twice that of southern Québec (Makivik Corporation, no date). Approximately 50% of individuals are under 20 years of age; about 3% are over the age of 65 (Nunavik Regional Board of Health and Social Services, 2003). The young population can be explained, in part, by a birth rate that is two times higher than in the rest of the province (Duhaime, 2004). Life expectancy has increased considerably since the 1950s, from an average of 48 years to the current life expectancy of 62 years (Makivik Corporation, no date). However, life expectancy is lower in Nunavik than in the rest of the province. Infant mortality is high; in 1997, the infant mortality rate in the region was three times higher than in the rest of the province. Life expectancy of elderly individuals is four times less than in the rest of Québec (Duhaime, 2004).

Table 2-1: Total Population of Nunavik by Age Group (2001 Figures)⁹

Community	0 –14	15-24	25-44	45-54	55-64	65+	Total
Akulivik	190	90	100	35	15	10	440
Aupaluk ¹⁰	70	25	50	5	10	0	160
Inukjuak	470	240	325	60	55	50	1200
Ivujivik	125	45	75	25	10	10	290
Kangiqsualujuaq	300	95	185	50	15	25	670
Kangisujuaq	210	100	135	35	10	0	490
Kangirsuk	175	60	115	30	20	10	410
Kuujuuaq	660	275	425	110	35	40	1565
Kuujuarapik	180	90	150	40	20	20	500
Puvirnituq	475	240	300	95	35	35	1180
Qaqaq	135	55	65	10	0	10	275
Salluit	415	205	255	60	35	35	1005
Tasiujaq ¹¹	80	40	45	5	5	5	180
Umiujaq ¹²	130	55	80	30	10	5	310
Total	3615	1615	2305	590	275	255	8675

Many Inuit have low education levels, but this is changing. The federal government initially established schools in the 1950s and 1960s and the provincial government established schools in the 1960s and 1970s.¹³ Since 1978, the education system has been operated by the Kativik School Board. The level of education is lower in Nunavik than in the rest of the province (Duhaime, 2004). Approximately 53% of individuals between 20 and 34 years of age in Nunavik do not have a secondary school diploma. Provincially, only 16% of individuals in this age range do not have a secondary school diploma (Duhaime, 2004).

Students are taught in Inuktitut until Grade 3 at which time they choose a second language. The Inuit language and culture are taught through primary and secondary school (Mativik Corporation, no date). Inuktitut is the most commonly spoken language (over 95% of Inuit can communicate in Inuktitut). English is used in practice most often primarily because of the federal government's long involvement in administrative matters.

A large number of residents in the region are part of the labour market (Duhaime, 2004). This is, in part, due to the fact that the population is relatively young. It is estimated that approximately 73% of individuals 25 to 64 years are employed (Institut de la statistique du Québec, 2005; 2002 figures). Despite efforts to earn a living, individuals in Nunavik earn less than other Québécois. The level of personal income per capita is also lower in Nunavik than it is

⁹ The 2001 figures are from Statistics Canada (2003). Provincial statistics for 2004 estimate that the population is distributed as follows: 3,783 individuals 0 to 14 years of age; 1,945 individuals 15 to 24 years of age; 2,919 individuals 25 to 44 years of age; 1,286 individuals 45 to 64 years of age; and 307 individuals 65 years of age and older (Institut de la statistique du Québec, 2005). It is believed that these figures represent both Inuit and non-Inuit individuals.

¹⁰ Based on 1996 figures. However, there was zero growth rate between 1996 and 2001 (George, 2002).

¹¹ Based on 1996 figures. There appears to have been a 19.4% increase in population between 1996 and 2001 (George, 2002). However, since the total population is still less than 250, Statistics Canada does not provide more detailed information.

¹² Based on 1996 figures. No additional information is available regarding any changes between 1996 and 2001.

¹³ Provincial and federal schools operated at the same time in the same communities (Kativik School Board, no date).

in the Yukon, the Northwest Territories or Nunavut (Duhaime, 2004). Working individuals tend to support a high number of dependents; on average, families in Nunavik are larger than families elsewhere in Québec (Duhaime, 2004). In addition, the cost of home and personal care products, food, gasoline, vehicles and hunting and fishing equipment are higher in Nunavik than in the rest of Québec (Duhaime, 2004). This is due, at least in part, to limited transportation options.

Day-to-day expenses of home owners in Nunavik are higher than those of home owners in other parts of Québec. It is estimated that average monthly payments for owner-occupied dwellings is approximately \$1,295 in Nunavik, and \$706 in the rest of Québec. Over 97% of the dwellings in the region are rented. Although social housing is less expensive in Nunavik than in the rest of the province (average gross monthly payments for rented dwellings are \$255 and \$529, for Nunavik and Québec, respectively), dwellings are overcrowded. The region does not have a private housing market that can help relieve the shortage (Duhaime, 2004).

Per capita health care costs are, on average, higher in Nunavik than elsewhere in Québec (Duhaime, 2004).¹⁴ It is estimated (based on 2004 figures) that public spending on health in Nunavik is approximately \$57 million compared to approximately \$17 billion for Québec as a whole. Public spending on health per capita is estimated to be \$5,940 for Nunavik and \$2,376 for Québec (Duhaime, 2004). As discussed in more detail below, the Nunavik Region has two health centres and a nursing station in every community. The higher costs and the number of health care facilities does not, however, mean that health levels are better than in other regions in Québec (Duhaime, 2004).

2.5 The Nunavik Regional Board of Health and Social Services¹⁵

Created in 1995, the Nunavik Regional Board of Health and Social Services is part of Québec's network of organizations and institutions responsible for population health and well-being. Its primary role is to improve the well-being of the entire Nunavik population by organizing health and social service programs in the region, evaluating the efficiency of the programs and ensuring users receive good quality services that are appropriate for their needs. In addition, the Board is responsible for allocating budgets to institutions in the region. The Board's major partners are the ministère de la Santé et des Services sociaux, the other regional boards of health and social services in the province, the region's two health centres, the Kativik Regional Government, the Kativik School Board and the Makivik Corporation.

The Nunavik Regional Board of Health and Social Services is administered by a board of directors which consists of representatives from each of the 14 communities in the region, as well as representatives from both health centres, the users, and the regional government. The head office of the Nunavik Regional Board of Health and Social Services is in Kuujjuaq.

The Nunavik Regional Board manages several federal programs including: Brighter Futures; Mental Health; Prenatal Nutrition; Family Violence; Home and Community Care; Diabetes Prevention and Management; and Contaminants, Nutrition and Health.

¹⁴ This is true even when Nunavik is compared to other remote regions of the province.

¹⁵ Much of the information in this section is based on documents produced by the Nunavik Regional Board of Health and Social Services (2003; no date).

2.6 The Study Communities

2.6.1 Kuujjuaq

Kuujjuaq means “the great river”. The community developed at its present site between 1941 and 1945. Since the signing of the James Bay and Northern Québec Agreement, Kuujjuaq has been the administrative centre of Nunavik. The Inuit population was estimated to be 1,687 as of December 31, 2004 (INAC, 2005).

The community has two schools – an elementary school and a high school. Community services include a church, a youth centre, a community centre, an outdoor skating rink, a fire station, a police station and a community radio station (INAC, 2005). In addition, there is a 500 seat conference centre, two three-star hotels, several restaurants, a bar with a dance floor and several stores and shops (Northern Village of Kuujjuaq, no date).

Electricity is supplied to the community via diesel generators. The water supply consists of household supply, a reservoir and water treatment. Sewers collect waste water. Municipal garbage collection is available. There are approximately 317 housing units (INAC, 2005).

The Ungava Tulattavik Health Centre is located in Kuujjuaq. The health centre serves several roles and offers services normally provided by local community service centres (CLSCs),¹⁶ child and youth protection centres (CPEJs),¹⁷ short-term hospital centres (CHs),¹⁸ extended care residential hospital centres (CHSLDs)¹⁹ and rehabilitation centres for youths with adjustment difficulties (CRJDAs).²⁰ The centre serves approximately 4,444 people in Kuujjuaq and on the Ungava coast. The centre has 15 short term (acute care) beds and 10 long term (extended care) beds.

The primary services offered by the centre include: general medicine (consultation, emergency and hospitalization); maternity; outpatient surgery; community services (including home care, social services and mental health); physiotherapy/occupational therapy; dentistry; laboratory; radiology; electrocardiography; electroencephalography; pharmacy; a group home; residential services; child and youth protection; and archives. Professional resources include: 7 general practitioners; 12 nurses; 1 internist; 2 psychiatrists (1 for adults and 1 for children); 2 physiotherapy technicians; 3 medical technologists; 2 radiology technicians; 1 pharmacist; 1 dentist; and 1 dental technician (Nunavik Regional Board of Health and Social Services, 2003).

¹⁶ The CLSCs offer current, front-line health and social services, physical rehabilitation and social reintegration. The centres assess individuals' needs and offer required services. The CLSCs also provide public health services. There is a CLSC point of service in each of the 14 communities.

¹⁷ Child and youth protection centres offer services to youths under the Youth Protection Act and the Young Offenders Act, as well as child placement and adoption services.

¹⁸ Short-term hospital centres provide diagnostic services as well as general and specialized medical and psychosocial care.

¹⁹ Extended care residential hospital centres provide alternative living environments on a temporary or permanent basis as well as residential assistance and support services to adults who, because of a functional loss of autonomy, cannot remain in their normal living environment.

²⁰ Rehabilitation centres for youths with adjustment difficulties provide social rehabilitation and integration services to youths experiencing behavioural, psychosocial or family difficulties. Group homes are located in Kuujjuaq, Puvirnituk and Salluit.

Visiting specialists include: anaesthesists; cardiologists (for adults and children); plastic surgeons; gastro-enterologists; gynaecologists; ear/nose/throat specialists; pediatricians; psychiatrists (for both children and adults); physiotherapists and technicians; occupational therapists and technicians; audiologists; ophthalmologists; orthodontists; and prosthetist-orthotists. Services provided by visiting resources include: audiology; denture therapy; electroencephalography; optometry; orthodontics, and hearing aids.

Both the professionals from the health centre and the visiting specialists travel to the various communities on the Ungava coast.

2.6.2 Puvirnituk

Puvirnituk means “smell of rotten meat”. The community was developed in 1952 and incorporated in 1989. Originally, the community refused to sign the James Bay and Northern Québec Agreement. The Inuit population was estimated to be 1,410 as of December 31, 2004 (INAC, 2005).

The community has one school that provides preschool, elementary and secondary level activities. Community services include a library, two churches, a youth centre, a community centre, an outdoor skating rink, a fire station, a police station and a community radio station (INAC, 2005). In addition, there is a hotel, a museum and two stores. Traditional activities, such as seal hunting, fishing, and the hunting of migratory birds remain important. (Northern Village Corporation of Puvirnituk, no date).

Electricity is supplied to the community via diesel generators. The water supply consists of household supply, a reservoir and water treatment. Sewers collect waste water. Municipal garbage collection is available. There are approximately 233 housing units (INAC, 2005).

The Inuulitsivik Health Centre is located in Puvirnituk. Like the Ungava Tulattavik Health Centre in Kuujuaq, the Inuulitsivik Health Centre serves multiple roles. The centre serves approximately 5,593 people on the Hudson coast. The centre has 17 short term (acute care) beds and 8 long term (extended care) beds.

The primary services include: general medicine (consultation, emergency and hospitalization); maternity; community services (including home care, social services and mental health); physiotherapy/occupational therapy; dentistry; laboratory; radiology; electrocardiography; pharmacy; child and youth protection; archives; and patient services in Montreal. Professional resources include: 2 general practitioners; 12 nurses; 1 community health worker; 7 midwives; 5 maternity workers; 7 health care workers; 1 audiologist; 2 psychologists; 1 dental hygienist; 3 laboratory technicians; 1 radiology technician; 1 pharmacist; and 1 archivist (Nunavik Regional Board of Health and Social Services, 2003).

Visiting specialists include: anaesthetists; cardiologists (for adults and children); plastic surgeons; gynaecologists; internists; ophthalmologists; prosthetist-orthotists (for adults and children); ear/nose/throat specialists; pediatricians; and psychiatrists.

Both the professionals from the health centre and the visiting specialists travel to the various communities on the Hudson coast.

The Inuulitsivik Health Centre also manages a patient services unit in Montreal, the Module du Nord Québécois (Northern Québec module). The unit assumes responsibility for Inuit patients, from anywhere in Nunavik, who are transferred to the south for care and services not available in the region. The unit is responsible for all aspects of patient transfer including: transportation, escort, interpretation services, appointments and all types of support. Approximately 1,500 individuals are transferred south each year; 20% of these involve emergencies. The majority of individuals are sent to the McGill University Health Centre. Data from 2001-2002 indicated that 1,466 individuals were transferred to Montreal (61% were from the Hudson coast, 39% were from the Ungava coast). Of these, 783 individuals received care in a clinic setting and 683 were admitted to hospital. The average stay in Montreal was 15.9 days. The average stay in hospital was 10 days. Only 67% of the individuals who were transferred had an escort. Of the 1,466 individuals who were transferred to Montreal, 41% were male and 59% were female. The majority of individuals (63%) were between 18 and 64 years of age. An additional 26% were between 0 and 17 years of age and 11% were 65 years of age or older.

2.6.3 Inukjuak

Inukjuak means “the giant”. Previously known as Port Harrison, the community was established about 1909. The Inuit population was estimated to be 1,375 as of December 31, 2004 (INAC, 2005).

Inukjuak has one school which provides preschool, elementary and secondary level activities. Community services include a library, a church, a youth centre, a community centre, an outdoor skating rink, a fire station, a police station and a community radio station (INAC, 2005). Inukjuak has a major arts centre. The community has several dog teams. Following a period when only snowmobiles were used, the Inuit have gone back to the traditional way (Northern Village Corporation of Inukjuak, no date).²¹

Electricity is supplied to the community via diesel generators. The water supply consists of household supply, a reservoir and water treatment. Sewers collect waste water. Municipal garbage collection is available. There are approximately 262 housing units (INAC, 2005).

A Reintegration Centre offers residential care 24 hours a day as well as external services to men and women 18 years of age or older who have been diagnosed with severe and persistent mental health problems and/or intellectual impairment. Examples of the types of mental health problems addressed include: mood disorder; anxiety disorder; schizophrenia and other psychotic disorders; and dual diagnoses (such as mental illness and substance abuse) (Asante, 2000). Entry into the program is voluntary; clients are not forced or coerced to join or follow the program. Residential services include short term placement (3 to 6 months), long term placement (1 to 2 years), short term crisis intervention (up to 1 week) and short term respite care (up to 3 months). External services include a day program and community follow-up and support.

²¹ The price of snowmobiles ranges from \$7,000 to \$10,000 and is going up as is the price of gas (Northern Village Corporation of Inukjuak, no date).

The centre is a regional resource and is the only one of its kind in Nunavik. The goal of the centre is to enable clients to develop the necessary skills to be successfully integrated into their communities. Staff at the centre work with both clients and their families to help identify, understand and resolve problems. Services include: behavioural management; vocational training; training in activities of daily living; and enhancing the knowledge and practice of traditional skills (Asante, 2000). The centre has two full time psycho-educators, four part time educators, six on-call educators, two night guards and a coordinator (fiscal 2000 staffing levels; Asante, 2000). The psycho-educators conduct psychosocial needs assessments, arrange for periodic evaluations of client medication and assist in the development and implementation of client treatment plans. The educators encourage clients to learn various skills and support clients in complying with their medication. The night guards ensure that clients and the facility are safe and secure overnight. The coordinator is responsible for the overall functioning of the centre (Asante, 2000).

2.7 Continuing Care in Nunavik

2.7.1 Home Care

Home care services have been in place in the region since 2002. The number of recipients doubled between 2002/2003 and 2003/2004 (Nunavik Regional Board of Health and Social Services, 2004). Table 2-2 presents the distribution of home care users by gender and age group for 2003/2004 for each of the communities in the region. As shown in the table, across the region, 43.8% of those receiving home care services are male and 56.2% are female. Overall, approximately 9.3% of home care users are children (0 - 17 years of age), 46.2% are adults (18 - 64 years of age), and 44.5% are seniors (65 years of age and older). Approximately 37% of those using home care services live in the three study communities. For these three communities, 47.2% of those using home care services are male and 54.9% are female. In the three study communities, approximately 11% of home care users are children, 33.3% are adults and 57.7% are seniors. It is noted that of the 78 individuals who were enrolled and eligible for services did not receive services in 2003/2004. Thus, 587 individuals received home support services in 2003/2004 (Nunavik Regional Board of Health and Social Services, 2004).

In 2004/2005, a total of 603 individuals received home support services. The clients were distributed as follows: 82 children (0 to 17 years of age; 13.6%); 256 individuals 18 to 64 years of age (42.5%); and 265 individuals 65 years of age and older (43.9%) (Nunavik Regional Board of Health and Social Services, 2005). While the total number of clients was approximately the same in 2003/2004 and 2004/2005, the number of children aged 0 to 5 years receiving home care services doubled in 2004/2005.

Table 2-2: Home Support Service Users by Gender and Age Group (2003/2004)

Community	Male	Female	0-5	6-17	18-64	65-69	70-79	80+	Total
Akulivik	14	13	2	1	14	5	3	2	27
Aupaluk	1	2	0	0	3	0	0	0	3
Inukjuaq	34	63	2	9	26	27	29	4	97
Ivujivik	4	13	0	0	7	5	5	0	17
Kangiqsualujuaq	36	31	0	5	46	6	9	3	69
Kangiqsujuaq	8	22	0	1	18	2	6	3	30
Kangirsuk	30	38	0	6	41	8	9	2	66
Kuujuuaq	40	40	4	4	38	12	14	8	80
Kuujuaraapik	24	37	1	3	28	13	15	1	61
Puvirnituq	42	32	4	4	18	15	28	5	74
Quaqtaq	13	29	2	3	22	7	8	0	42
Salluit	27	24	3	1	14	15	17	1	51
Tasiujaq	13	22	4	3	24	2	1	1	35
Umiujaq	5	8	0	0	8	0	3	2	13
Total	291	374	22	40	307	117	147	32	665

Nunavik Regional Board of Health and Social Services, 2004

Table 2-3 presents the distribution of home care users by diagnostic category for the region as a whole and for the three study communities for 2003/2004. In the region overall, the most commonly occurring conditions were cardiac conditions (24.1%), nutritional conditions (10.8%), diabetes and diabetes related conditions (10.4%) and mental health conditions (10.3%). In the three study communities, the most commonly occurring conditions were cardiac conditions (21.3%), mental health conditions (12.2%), respiratory conditions (10.9%) and nutritional conditions (10.0%).

Table 2-3: Home Support Service Users by Diagnostic Category (2003/2004)²²

Diagnostic Category	Nunavik Region		Three Study Communities	
	Total	Percentage	Total	Percentage
Cardiac condition ²³	148	24.1	49	21.3
Respiratory conditions	53	8.6	25	10.9
Diabetes and diabetes-related conditions ²⁴	64	10.4	9	3.9
Nutritional conditions ²⁵	66	10.8	23	10.0
Cerebrovascular conditions ²⁶	25	4.1	11	4.8
Sensory conditions ²⁷	10	1.6	9	3.9
Nervous system disorders	14	2.3	6	2.6
Other physical conditions ²⁸	73	11.9	36	15.7
Accident victim	9	1.5	2	0.9
Cancer	24	3.9	10	4.3
Autoimmune disorders ²⁹	6	1.0	0	0.0
Mental health conditions ³⁰	63	10.3	28	12.2
Other ³¹	58	9.5	22	9.7
Total	613	100	230	100

Nunavik Regional Board of Health and Social Services, 2004

Table 2-4 presents the number of hours of service by community. As shown in the table, a total of 45,949 hours of service and 6,085 visits were provided in 2003/2004. It was estimated that a further 6,125 hours of service were not provided in 2003/2004 primarily because of a lack of financial and human resources (Nunavik Regional Board of Health and Social Services, 2004). The total hours of service provided in 2003/2004 were 2.75 times higher than the total hours of service provided in 2002/2003 (in 2002/2003, 16,573 hours of service were provided). A total of 18,016 hours of service, representing 39.2% of the total, were provided in the three study communities in 2003/2004. In 2004/2005, a total of 39,325 hours of home care services were provided (Nunavik Regional Board of Health and Social Services, 2005). Of these, 8,794 hours were provided by home care workers, an additional 28,470 hours were provided by nurses (Nunavik Regional Board of Health and Social Services, 2005).³²

²² It is not clear why the totals in the table do not match those presented in the previous table. It is assumed that diagnostic information was not available for all individuals.

²³ This category includes individuals with cardiovascular disease, and cardiac or circulatory disorders.

²⁴ This category includes individuals with diabetes, diabetes associated renal disorder and diabetes associated cardiovascular disorder.

²⁵ This category includes individuals with nutritional disorders and impaired fasting blood sugar or glucose tolerance.

²⁶ This category includes individuals with cerebrovascular disease or accidents.

²⁷ This category includes individuals with severe blindness and/or deafness.

²⁸ This category includes individuals with musculoskeletal diseases and disorders (e.g., arthritis, fractures, amputations).

²⁹ This category includes individuals with lupus.

³⁰ This category includes individuals with severe and persistent mental disorders, transient mental disorders, and dementia.

³¹ This category includes individuals with endocrine, hepatic/biliary/pancreatic, genitourinary, renal, gastrointestinal, and acute cutaneous or subcutaneous conditions, as well as older individuals with a physical or cognitive dependency.

³² It is thought that the remaining hours were provided by other health care workers, such as rehabilitation technicians.

Table 2-4: Home Support Service Hours by Community (2003/2004)

Community	Home Support Service Hours
Akulivik	1,050
Aupaluk	460
Inukjuaq	8,178
Ivujivik	903
Kangisualujjuaq	5,398
Kangisujuaq	2,226
Kangirsuk	3,217
Kuujjuaq	3,151
Kuujjuaraapik	921
Puvirnituq	6,687
Quaqtaq	1,650
Salluit	9,858
Tasiujaq	1,495
Umiujaq	755
Total	45,949

Nunavik Regional Board of Health and Social Services, 2004

In 2003/2004, 34 individuals (14 males, 20 females) received more than 300 hours of service. These individuals were distributed as follows: 5 children, 12 adults, and 17 seniors. Together, these individuals received 20,563 hours of service. Palliative care services were provided to 22 individuals, for a total of 2,525 hours of service (1,872 hours were provided to 3 people; Nunavik Regional Board of Health and Social Services, 2004). In 2004/2005, six individuals received a total of 3,567 hours; five individuals received a total of 2,322 hours and one individual received a total of 1,245 hours.

Health Canada, through the Home and Community Care Program, provides funding for two home care coordinators, six nurses and three rehabilitation technicians. It also covers medical and technical aids and 40% of the cost of the home care workers' training (additional funding for the home care workers' training is provided by the Kativik Regional Government; Nunavik Regional Board of Health and Social Services, 2005). Complementary services and essential policy components, such as support for activities of daily living, respite care, rehabilitation services, psychosocial services, and interpretation services, are funded by the Québec Ministry of Health and Social Services. In order to offer essential services, the health centres have operated in a deficit situation (Nunavik Regional Board of Health and Social Services, 2004).³³

2.7.2 Day Centre

A day centre opened in Kuujjuaq in April 2004. The centre, which involves a partnership between the Nunavik Regional Board of Health and Social Services, the Ungava Tulattavik Health Centre and the municipality of Kuujjuaq, provides seniors with transportation services, hot lunches, organized activities and socialization activities five days a week. Celebrations for special occasions are also organized (Nunavik Board of Health and Social Services, 2005).

³³ The budget deficit for the health centres is approximately \$1.5 million. Budget amounts have not been revised since the mid-1980s (Nunavik Regional Board of Health and Social Services, 2004).

2.7.3 Facility Care

As noted above, 10 long term care beds are available in Kuujjuaq, 8 long term care beds are available in Puvirnituk and 8 beds for individuals with mental health problems and/or intellectual impairment are available in Inukjuak.

3. METHODOLOGY

3.1 Selection of the Study Communities

As noted above, the study was conducted in three Inuit communities in Nunavik: Kuujjuaq, Purvirnituk, and Inukjuak. Initially, Kuujjuaq was chosen as the Inuit study community for the Continuing Care Research and Costing Project. When the study was changed from one study with eight sites to three studies with three to four sites each, Purvirnituk was added as it offered continuing care services that were similar to those available in Kuujjuaq. Inukjuak was added as it has several children with special needs as well as adults with mental health needs.

The study representative from the Nunavik Regional Board of Health and Social Services discussed the study with the executive directors of the health centres in Kuujjuaq and Purvirnituk and with the director of the Reintegration Centre in Inukjuak prior to presenting it to the Executive of the Nunavik Regional Health and Social Services Board. The presentations to the directors of the three facilities included discussions regarding: the importance of the study; the anticipated timing for data collection; what assistance might be required from the organizations with respect to access to clients and identification of potential interviewers; other assistance the organizations could provide; and any concerns the organizations had regarding participation. The study was well received by each of the centres.

The study representative from the Nunavik Regional Board of Health and Social Services presented the study to the Executive of the Regional Health and Social Services Board in June 2005.³⁴ As a result, the Board passed a resolution indicating support for the study; a copy of the resolution is provided in Appendix A.³⁵ It was felt by the study representative that this was sufficient. Therefore, permission was not sought from each of the study communities individually. In addition, while an Information and Data Sharing Agreement had been drafted for use in the region, this was not taken to the Board for feedback and approval. The draft Information and Data Sharing Agreement is presented in Appendix B.

3.2 Sample

3.2.1 Introduction

The focus of the Continuing Care Research and Costing Project was on individuals who do not have, or who have lost, some capacity to care for themselves. These individuals included: seniors; adults with chronic diseases or conditions; adults with mental health needs; and children with special needs. For the purposes of this study, seniors were defined as being individuals 55 years of age and older who are unable to care for themselves because of a physical disease or

³⁴ Representatives from the research team and from the First Nations and Inuit Branch of Health Canada offered to go to Nunavik on several occasions to present the study and address any questions that were raised. The study representative from the region did not feel that a visit was necessary and offered to present the study to the Executive on behalf of the research team. It is noted that the representative from the national Inuit organization, Inuit Tapiriit Kanatami, encouraged a visit to the region.

³⁵ As noted above, the Nunavik Regional Board of Health and Social Services includes representatives from each of the communities in the region (including the three study communities).

condition or because of a mental health condition. Adults with chronic diseases or conditions were defined as being individuals between 18 and 54 years of age who were unable to care for themselves completely because of a chronic disease or condition which affects their ability to function physically. Adults with mental health needs were defined as being individuals between 18 and 54 years of age who were unable to care for themselves completely because of a chronic condition that affects their ability to function mentally and/or cognitively. Children with special needs were defined as being individuals between 0 and 17 years of age who should chronologically be able to care for themselves, but who are unable to do so completely because of a chronic disease or condition that has affected their ability to function physically, mentally, and/or cognitively. A more complete definition of each of the study groups is included in Appendix C.

3.2.2 Identification of the Inuit Client Sample

For the Inuit study sites, the client target sample was 90 individuals, 30 from each of the three study communities; the sample size was affected by the amount of funding available for the study, but was double what had initially been envisioned. Individuals receiving continuing care services at home as well as those receiving services in a facility were to be included.

For the potential facility sample, an attempt was made to include all of the individuals living in the facilities in the study communities. In Kuujjuaq, the facilities included the elders home as well as the chronic care wing of the hospital; a total of 10 individuals were identified. The facility in Puvirnituq was the chronic care wing of the hospital; a total of 8 individuals were identified. In Inukjuak, the facility was the Reintegration Centre; a total of 8 individuals were identified.

For the potential home sample, individuals who were identified as receiving continuing care services within each of the study communities were randomly selected.³⁶ Initially, a random sample of 50 individuals was drawn for each community.³⁷ Individuals who appeared more than once on the list were removed.

Once the potential home and facility samples were identified, the lists were reviewed by knowledgeable individuals within each of the study communities (generally, individuals working with the Persons Lacking Autonomy program or the head nurse at the hospital) to ensure that

³⁶ Lists of individuals identified as continuing care clients are maintained within each of the study communities; 113 individuals were identified for Kuujjuaq, 72 individuals were identified for Puvirnituq and 111 individuals were identified for Inukjuak. The lists should be reviewed on an annual basis (R. Ferguson, personal communication, November 2005). The files in Kuujjuaq may be more up-to-date on an ongoing basis than those in the other two communities. However, the lists in Puvirnituq and Inukjuak had been revised for the year before the sample was drawn; the list for the Kuujjuaq had not been reviewed at the time of the study. The random sample of clients receiving services at home was drawn by a representative of the Nunavik Regional Board of Health and Social Services. The sample of clients receiving services in a facility were identified by a representative from each of the health centres and the Reintegration Centre.

³⁷ Although only 20 to 22 individuals who were receiving services at home were required, the researchers over sampled to allow for individuals who could not be located, who had died, and who refused.

clients were alive, living in the community, and physically and psychologically well enough to participate in the study.³⁸

After the lists were reviewed, the potential sample consisted of 114 individuals who were receiving continuing care services at home and 22 individuals who were receiving continuing care services in a facility. The potential home sample represented 38.5% of the individuals in the three study communities who were receiving continuing care services at home. The potential facility sample represented 84.6% of the individuals in the three study communities who were receiving continuing care services in a facility.

As noted above, the goal was to interview 30 individuals per community. Within each study community, the number of home care clients contacted depended on the number of facility clients who participated. Individuals who were receiving services at home and who refused to participate in the study were usually replaced. All of the facility clients participated; that is, 22 individuals comprised the facility sample (9, 8, and 5 from Kuujjuaq, Puvirnituk and Inukjuak, respectively). The number of identified home care clients were 21, 22, and 25 for Kuujjuaq, Puvirnituk and Inukjuak, respectively. However, due to a large number of refusals in Kuujjuaq near the end of the study, as well as a desire on the part of the interviewers in Kuujjuaq to be finished with the study only 10 of the 21 individuals from Kuujjuaq participated in the study (all of the individuals from Puvirnituk and Inukjuak participated). The final home sample consisted of 57 individuals.

3.2.3 Identification of the Inuit Caregiver Sample

One of the questions of interest in this study was the extent to which informal caregivers were providing care and support to individuals requiring continuing care services, regardless of whether they were receiving the services at home or in a facility. It was noted relatively early in the research project by the members of the various project advisory groups that the term “informal caregiver”, which is commonly used in the non-Aboriginal literature to refer to unpaid family members, friends, and others who provide care and assistance, was not appropriate. In Inuit and First Nations communities, family members as well as other members of the community may provide assistance to someone needing care and/or support. The term “unpaid caregiver” was also not considered appropriate as, at least in some First Nation communities, family members may be paid to provide care to an individual requiring assistance.³⁹ After some discussion, it was decided that the term “family caregiver” would be used to identify family, friends, and volunteers who provided assistance to individuals requiring continuing care services.

Caregivers were identified for clients who participated in the study. Where possible, clients were asked to identify a family caregiver who provided him/her with care and/or support. The majority of the clients did not identify a family caregiver. Of the 57 clients living at home, 20 (35.1%) indicated they had a family caregiver. Of the 22 clients living in a facility, 1 (4.5%) indicated he/she had a family caregiver. In some cases, paid health care workers were identified as being the caregiver. Ultimately, 38 caregivers participated in the study. All of the family

³⁸ The lists were reviewed by knowledgeable individuals as the researchers did not want the clients to be unduly harmed by the requirements of the study.

³⁹ This does not seem to be the case in Inuit communities.

caregivers (14) provided care to clients receiving services at home. All but two of the 24 paid health care workers provided care to clients receiving services in a facility. Thus, of the 57 clients who were receiving services at home, 16 (28.1%) had either a family or a formal caregiver.⁴⁰ Of the 22 clients who were receiving services in a facility, all had a formal caregiver.

3.3 Research Tools

3.3.1 Introduction

Several research tools were created for the project. These included consent forms for both clients and caregivers, a Client Interview, and a Caregiver Interview. In addition, a measure of functional status was adapted for use in the study. All of the materials, with the exception of the functional status measure, were drafted by Hollander Analytical Services using materials from the literature, from other work done by Hollander Analytical Services, and from discussions with the regional advisory groups for the project. The draft materials were reviewed and discussed by representatives from the three study regions (Manitoba, Québec and Nunavik). Based on these discussions, a core set of questions, which was used by all three study regions, was identified. In some cases, the wording of the core questions was modified to meet the needs of a specific region. The question was still considered core if the concept was the same, regardless of the exact wording that was used.⁴¹ In addition, the study regions were able to add region specific questions to the tools.

The tools used in the Inuit study region are described in more detail below. Both core and region specific questions are identified. A copy of all of the tools used in the Inuit study region are presented in Appendix D.

3.3.2 Consent Forms Used in the Inuit Study Sites

As noted earlier, the study included several groups of clients: children, individuals with physical conditions, and individuals with mental health conditions or cognitive impairments. As a result, three client consent forms were created: one for adults who were capable of providing consent on their own behalf (the Adult Participant Consent Form); one for proxies to complete on behalf of adults who were not capable of providing consent (the Proxy Participant Consent Form); and one for parents/guardians to complete on behalf of children (the Child Participant Consent Form).

The general content of each of these consent forms was the same and included: information regarding the purpose of the study; what the study involved; anticipated risks, discomforts, benefits and costs; confidentiality issues regarding the information collected; the right to withdraw from the study without penalty; and contact information for individuals who

⁴⁰ Although 20 home care clients indicated they had a family caregiver, only 14 family caregivers participated in the study. Formal caregivers participated for two more home care clients. Thus, a total of 16 home care clients had a caregiver who participated in the study.

⁴¹ It was necessary to take this approach as the three study regions could often agree on the concept, but could not always agree on the wording of the various questions. For example, the term “assisted living” did not have the same meaning in the different study regions.

had questions. These consent forms were only available in English. Therefore, the interviewer generally had to translate and present the content verbally in Inuktitut.

Once a client, proxy or parent had agreed to have the identified individual participate in the study, he/she was asked to sign a General Consent form indicating what he/she was granting permission for (for example, to participate in the study only, or to have the interviewer contact a family caregiver). The General Consent form was available in both English and Inuktitut. The interviewer also signed this form indicating that he/she felt the client, proxy or parent understood what the study involved. A copy of the appropriate consent form and the General Consent form were left with the client/proxy/parent if he/she wished.⁴²

A consent form was also created for use with caregivers. This form was similar to the consent forms used for clients, but also indicated that they were being asked to participate *because* it was understood they provided care and/or support to someone who had participated in the study. Again, this form was only available in English. It was translated by the interviewer, as required. Once a caregiver had agreed to participate in the study, he/she was asked to sign the Caregiver Consent Form. The Caregiver Consent Form was available in both English and Inuktitut. The interviewer also signed this form indicating that he/she felt the caregiver understood what the study involved. A copy of the consent form was left with the caregiver if he/she wished.⁴³

3.3.3 Client Interview Tool Used in the Inuit Study Sites

The Client Interview tool was used to gather information regarding clients who were receiving continuing care services either at home or in a facility. The same interview tool was used for both groups of clients. Instructions were included throughout the tool to assist the interviewer with gathering relevant information.

The first page of the interview tool was used to identify the community the client was from, the client, the interviewer, and the language(s) used to conduct the interview. This page also allowed the interviewer to comment on the interview and/or the client's situation. The second page of the interview tool asked who provided the information on the tool; this was used to determine if someone other than the client (that is, a proxy) was used to answer some of the questions. This page also requested information regarding where the client was living (that is, at home or in a facility). The main part of the Client Interview consisted of several sections which addressed: client demographics; housing; use of health related services; satisfaction with health related services; preferences for where services should be provided; and perceptions of one's health and quality of life. The content of each of these sections is described in more detail below.

⁴² Initially, it had been intended that a copy of the consent form would be provided automatically. Discussions with the Inuit representatives for the study, however, indicated that because of language and education issues, most individuals would likely not want to have a copy, and that leaving a copy in the household could be problematic.

⁴³ As with the client consent forms, it had initially been intended that a copy of the consent form would automatically be provided to the caregiver. After discussions with the Inuit representatives, it was decided that a copy of the form would only be provided if the caregiver wished to have it.

Section A: Demographics. The demographics section requested information regarding: the client's gender; his/her age; the language(s) the client can speak; the language(s) the client can understand; the language the client uses most often in daily life; the client's education level; whether the client is currently working for pay and if so, how many hours a week he/she works; the client's sources of income over the past year; and the number of people living in the household. No information was gathered regarding the client's marital status as this was not considered appropriate for First Nations and Inuit clients. All of the demographic questions were used in all three study regions, although some of them (for example, the questions on language) were modified to be appropriate for the specific study region.

In order to assist with protecting the identity of study participants, age categories, rather than age, or date of birth, were used.⁴⁴ The age groupings were as follows: 0 to 17 (to identify children with special needs); 18 to 24, 25 to 34, 35 to 44, and 45 to 54 (to identify adults with physical and mental health conditions); and 55 to 64, 65 to 74 and 75 and up (to identify seniors). These groups were similar to those used on the First Nations and Inuit Regional Longitudinal Health Survey (2002).

For the three language questions, the choices on the Client Interview used in the Inuit study communities were: English, French, Inuktitut and Other.

For the question regarding the client's educational level, the choices were: No formal schooling; Kindergarten to Grade 3; Grades 4 to 7; Some High School (defined as Grades 8 to 12); High School Graduate (defined as having completed Grade 12); Some technical school, trade school, college or university; Completed bachelor's degree or equivalent (including a diploma or certificate from a technical or trade school); Completed graduate degree or equivalent (including a Master's degree, PhD, or MD); and Other. For the Inuit, it was recognized that some individuals may not have received any formal schooling, but may have been self-taught; interviewers were instructed to include this information under Other.

The choices for the question on sources of income were identical to those on the First Nations and Inuit Regional Longitudinal Health Survey (2002). In order to obtain as complete a picture of sources of income as possible, interviewers were instructed to ask a general question regarding sources of income over the past year and then to read out any choices that the respondent did not identify.

Section B: Housing for Those at Home. This section contained several questions designed to address the housing situation for clients receiving services at home (the housing situation for clients receiving services in a facility were addressed in Section C). Information was requested regarding: ownership of the home; the age of the home; the number of rooms in the home; resources available in the home; the need for repairs; the need for and types of modifications made because of the client's physical condition or health problem; the presence of mold and mildew; and the safety of the main water supply in the home. Although all of the questions in

⁴⁴ Given the size of the study communities in all three study communities, there was a concern that if some of the data, especially the demographic information, were collected in a particular manner it would be relatively easy to identify the client. Therefore, steps were taken to try to minimize this as much as possible.

this section were used in all three study regions, some of them (for example, ownership of the home) were modified to be appropriate for the specific study region.

For the Inuit, the choices for ownership of the home included: rented by the client or another member of his/her household; owned by the client or another member of his/her household; owned by the Kativik Municipal Housing Corporation; and Other.

The question regarding the number of rooms in the home was similar to one included on the First Nations and Inuit Regional Longitudinal Health Survey (2002).

The question on the resources available in the home was similar to one included on the First Nations and Inuit Regional Longitudinal Health Survey (2002). The question asked about the availability of: a fridge; a stove for cooking; electricity; water delivery; cold and hot running water; a flush toilet; a septic/sewage system; garbage collection service; a heating system; a telephone; and an external sidewalk. It was noted by the Inuit representatives that most communities in the Nunavik region have water delivery and few have external sidewalks.

The question regarding the need for repairs was taken from the First Nations and Inuit Regional Longitudinal Health Survey (2002). Repairs were defined as “fixing what is already present”. Clients were asked about the need for major and minor repairs and regular maintenance. Major repairs included defective plumbing or electrical wiring and structural repairs to walls, floors and ceilings. Minor repairs included missing or loose floor tiles, bricks or shingles and defective steps, railings and sidings. Regular maintenance included painting and furnace cleaning.

Three questions were asked regarding the need for modifications to the home because of the client’s physical condition or health problem: are or were modifications required; what modifications were made (if required); and, if modifications are required but have not been made, why have they not been made. Modifications were defined as “changes to what is already present because of a physical condition or health problem.” For the Inuit study sites, the choices for the last question were: Cost; No one to do the work; Just haven’t gotten around to it; (Modifications) refused by the Kativik Municipal Housing Corporation; and Other.

The questions regarding mold and mildew and the safety of the main water supply were adapted from the First Nations and Inuit Regional Longitudinal Health Survey (2002).

Section C: Housing for Those in a Facility. This section contained several questions designed to address the housing situation for clients receiving services in a facility (the housing situation for clients receiving services in a home were addressed in Section B; see above). Information was requested regarding: whether the client shared his/her room with another individual and if so, what his/her relationship is to that person; whether the client’s spouse or another relative also lived in the facility; whether the client’s room was in need of repairs, improvements and/or modifications; whether the client’s room and the facility were considered to be safe; the client’s perceptions of different aspects of the facility; and whether the client would recommend the facility to others. The majority of the questions in this section, particularly those regarding different aspects of the facility, were developed specifically for this study by

members of the Manitoba Regional Advisory Group. Some of the questions were similar to those asked in Section B. The majority of the questions in this section were used by all three study regions although some were modified for the specific study region.

The question regarding the need for repairs was identical to that used for clients receiving services at home. The question regarding the need for improvements was developed specifically for this study. For the Inuit study sites, the question asked about the need for improvement in, and the type of improvement required (if needed), with regard to: air circulation; lighting; mirrors; taps; temperature control; room size; noise level; and floors. For the Inuit study sites, the question regarding the need for modifications asked about the need for modifications, and the type of improvement required (if needed), with regard to: width of doorways; size of bathroom; handrails; toilet height or location; bathtub type, size or location; room size; and more space generally. Modifications were defined as in Section B. As in Section B, if modifications had been made, clients were asked what these were. If modifications were required, but had not been made, clients were asked why the modifications had not been made. The choices for this question were the same as in Section B.

Five items addressed client's perceptions of different aspects of the facility. These questions were developed specifically for this study. For the Inuit study sites, one question asked clients to rate the different departments in the facility (that is, nursing, dietary, housekeeping, laundry, maintenance, social activities and administration) using a four point scale (Poor, Fair, Good, Excellent). A second question asked clients to rate the staff in the facility with regard to courtesy, friendliness, helpfulness and professionalism using the same four point scale. A third question asked clients to rate various resources (food, facilities, services, activities, safety, external sidewalks, staff and visitors) using the four point scale. The fourth question asked clients about their understanding of the resident contribution/rent. The final question asked clients whether the facility should offer more services, and if so, what these should be.

Section D: Use of Health Related Services. This section included several questions regarding the type of assistance the client receives from both family caregivers and the formal care system. As noted earlier, a family caregiver was defined as a family member, a friend, a neighbour, or any other individual who provided care and/or support to the client. Individuals who provide care arranged through the formal care system are not considered family caregivers. The questions in this section addressed: whether the client had a family caregiver and if so, what his/her relationship was to that caregiver; how long the client had been receiving help/support from the family caregiver (if applicable); whether the client had recently lost someone who used to provide him/her with care and/or support and if so, who is helping the client now; how far away the family caregiver lived from the client (if applicable); the type of assistance the client receives because of his/her physical condition or health problem; and who provides assistance. Many of the questions in this section were adapted from Hollander, Chappell, Havens, McWilliam, and Miller (2002). Some questions were developed specifically for the current study. The majority of the questions in this section were used by all three study regions, although some (such as who provided assistance) were modified for the specific study region.

The questions regarding whether the client had a family caregiver, and if so, what the relationship of the family caregiver was were adapted from the Hollander et al. (2002) study. The

questions on whether the client had recently lost someone who used to provide him/her with care and support and if so, who was helping the client now were also adapted from the Hollander et al. (2002) study.

The questions regarding the length of time the client had been receiving help/support from a family caregiver and how far away the family caregiver lived from the client were developed specifically for this study. For the question regarding the length of time the client had been receiving help/support from a family caregiver, the choices were: less than one year; one to two years; more than two years but less than five years; and more than five years. For the question regarding how far away the family caregiver lives from the client, the choices were: (in) the same house; very close; (in) the same community; and far away (with estimates of time and/or distance requested).

Three questions were designed to provide information regarding the type of assistance/support the client currently receives. Together, the questions examined: what types of assistance the client receives; who provides the assistance (for example, family caregivers or formal care providers); how much assistance is provided by family caregivers because of the client's increased need for care; and how much time is provided on a weekly basis by both family caregivers and the formal care system. All of these questions were adapted from the Hollander et al. (2002) study.⁴⁵ Some of the choices in the questions (for example, the provision of traditional healers and/or traditional medicines) were developed specifically for the study. One question asked whether clients received help with several activities (including eating, personal care, communication, financial activities, housekeeping, house maintenance, mobility, nursing care, obtaining medical services and equipment, and obtaining a traditional healer and/or traditional medicines). Many of these items were similar to areas addressed in the functional status measure (see Section 3.3.4 below). Clients who indicated that they received help with one or more of the activities, were asked who provided the assistance (a family caregiver, a formal care provider, or both). If a family caregiver provided assistance, the client was asked how much assistance was provided *because of* the client's increased need for care.⁴⁶ A second question asked what kinds of assistance various types of family caregivers⁴⁷ provided, and how much assistance was provided in a given week. The third question asked what types of assistance various types of formal care providers offered and how much assistance was provided in a given week.⁴⁸

⁴⁵ Information on who provided help, what help was provided and how much help was provided in a given week were collected via Informal and Formal Caregiver Diaries in the Hollander et al. (2002) study. The discussions with the First Nations and Inuit representatives from each of the study regions strongly suggested that the diary format would not work in the present study. Because the information gathered through the diaries in the Hollander et al. study were critical for the costing component (as it is in the current study), the diaries were adapted and included as part of the Client Interview.

⁴⁶ It is recognized that family members may provide assistance to one another because of their relationship rather than because an individual requires assistance. It is important in continuing care studies, therefore, to distinguish between activities that would normally be performed and activities that are performed *because* the client is not able to perform them by him/her self.

⁴⁷ For the Inuit study sites, the family caregivers included: family members; other relatives; friends; volunteers; volunteer spiritual care; and others.

⁴⁸ For the Inuit study sites, the formal care providers included: homemakers/home support workers; maintenance workers; home care aides; home care nurses; foot care nurses; public health nurses; wellness coordinators;

Section E: Other Health Related Services. The questions in this section focused on expenditures related to supplies and equipment needed by the client because of his/her physical condition(s) or health problem(s). The questions addressed: whether supplies and equipment had been obtained, and if so, how much they had cost; whether the client had been referred to a service within and/or outside his/her community; and whether the client was satisfied with the care he/she received outside of the community (if applicable). The questions regarding supplies and equipment were adapted from Hollander et al. (2002) and Browne, Gafni, Roberts and Hoxby (1992). The questions on services were developed specifically for the study. All three study regions used the same questions, although some were modified for the specific study region.

Three questions addressed whether clients had received supplies and equipment. For the Inuit study sites, clients were asked whether they had *received* a number of items in the last *month*. These items included: wheelchair; walker; cane; dressings; syringes; pillows; ostomy supplies; diabetic foods; drugs/medications; traditional medicines; and vision care. Clients who indicated that they had received one or more of these items were asked who had covered the purchase and/or rental cost, and what the approximate cost was. The Inuit participants were asked if they (or someone else on their behalf) had *purchased* any supplies, aids or devices that cost less than \$100 in the last *month*. The Inuit participants were also asked if they (or someone else on their behalf) had *purchased* or *rented* any supplies, aids or devices that cost more than \$100 in the last *year*. If supplies and/or equipment had been purchased (or rented), participants were asked to identify the item and the approximate cost.⁴⁹

Two questions examined whether clients had been referred to a service within the last *month*; one question asked about services within the community and one asked about services outside of the community. Clients who indicated that they had been referred to a service were asked how much the service had cost (regardless of whether they or a family member had paid for the service). Clients who indicated that they had been referred to a service outside of the community were asked how satisfied they were with the care they had received.

Section F: Satisfaction with Health Related Services. This section asked clients several questions regarding: the services they had received both from their family caregivers and the formal care system; their satisfaction with the services they had received from the formal care system; whether they had experienced any difficulties receiving care in the last year; and whether treatments or services had been refused (either by or on behalf of the client or by someone else). Many of the questions in this section were adapted for this study. The majority of questions were used by all three study regions. Proxies were not asked these questions.

Clients were asked several questions about the care and services they received from family caregivers. For example: “Do you receive the care/service you need often enough?” and

physicians; occupational therapists and technicians; physiotherapists and technicians; massage therapists; welfare workers; traditional healers; paid spiritual care; and other.

⁴⁹ Information regarding expenditures was collected via Expenditure Diaries and the Client Interview in the Hollander et al. (2002) study. As noted earlier, discussions with First Nations and Inuit representatives from each of the study regions suggested that the diary format would not work in the present study. Because the information was critical for the costing component of the current study, the Expenditure Diaries were adapted for this study and included as part of the Client Interview.

“Do you receive care from someone you feel comfortable with?” Clients were asked a similar set of questions regarding the care and services they received from the formal care system. All of questions were developed for this study. Clients were asked to use a three point scale (Never, Sometimes, Always or Almost Always) in responding to each question.

Clients were also asked how satisfied they were with services provided through the formal care system. Satisfaction was assessed using questions that addressed clients’ satisfaction with services received, worker characteristics, and care concerns. The majority of the questions were adapted from Penning and Chappell (1996).⁵⁰ Two questions were developed specifically for this study: “How often would you say that workers respect you, understand you and listen to you?” and “How often would you say that workers speak the language(s) with which you are most comfortable?” Clients were asked to use a three point scale (Never, Sometimes, Always).

Clients were asked whether they had experienced difficulties in receiving care in several areas (including transportation, access to care, medical supplies and equipment) during the past year, and if so, how often they had experienced difficulties. This question was adapted from the First Nations and Inuit Regional Longitudinal Health Survey (2002).

Clients were asked if they had refused any treatment or service in the last year. They were also asked if they had been refused any treatment or service in the last year (by someone else). If clients said “Yes” to either one or both questions, they were asked to provide a reason. These questions were developed for the current study.

Section G: (Preference for) Location of Services. This section of the Client Interview consisted of several questions regarding: clients’ awareness of housing options; where clients would prefer to receive services, and who they would prefer to receive services from, if they had a choice; and what they would want to do about future needs and services. The majority of the questions were developed for the current study and were used by the three study regions. Proxies were not asked these questions.

Clients were asked if they were aware of other housing options (that is, other than the housing options available in their community). They were also asked if they felt there was a need for other housing options in their community, and if so, what these should be.

Clients were asked what kind of housing situation they would prefer, where they would like the housing to be available and who they would prefer to receive care and support from. These questions were based on a study conducted by Chapleski, Sobeck and Fisher (2003). The choices of living situation included: living in the client’s own home with appropriate care and support services; living in the home of a family member; living in an assisted living situation (such as a personal care home, elders/seniors home, or group home) and living in a facility or institutional setting. Clients were asked if they prefer that the housing be available: in their own community; where services can be accessed easily (even if that meant living outside their community); and another location. Clients were also asked who they would prefer to receive care/support from: family members; friends; neighbours; the formal care system; or someone else. Clients could select more than one response for this question.

⁵⁰ This tool was also used by Hollander et al. (2002).

Section H: Health and Quality of Life. The questions in this section examined the client's perceptions of his/her own health and quality of life. Some of the questions in this section were developed for this study. The majority of the questions were used by all three regions. Proxies were not asked these questions.

Clients were asked what things affected their health. The choices included: diet; stress/worry; social supports; lack of proper sleep/rest; emotional well-being; lack of exercise/activity; physical, emotional, mental, and spiritual balance; and other. Clients could provide more than one response. Clients were also asked to rate their overall health using a five point scale (Excellent, Very Good, Good, Fair and Poor). These questions were adapted from the First Nations and Inuit Regional Longitudinal Health Survey (2002).

To assess perceptions of quality of life, clients were asked: "What things make you happy?", "What things make you unhappy?" and, "In general, would you say you are happy with your life?"⁵¹ Clients in the Inuit study sites were also asked how their personal, cultural and spiritual beliefs and values influenced their health and life. This question was based on information gathered as part of the Multiclientele Assessment Tool used by the Québec Ministry of Health and Social Services.

Section I: Additional Comments. This section was included to allow clients to make any other comments about the care or services they felt they needed or received. Interviewers were instructed to follow-up on any issues that may have been raised during the interview.

3.3.4 Functional Status

In studies focusing on the provision of continuing care, it is more important to assess an individual's functional status than to determine his/her diagnoses as individuals with the same health condition (such as lung cancer) may require different continuing care services because of their different functional status. Clients' functional status was assessed using the *Système de mesure de l'autonomie fonctionnelle* (Functional Autonomy Measurement System or SMAF) developed by Hébert, Carrier and Bilodeau (1988). The SMAF is based on the World Health Organization's (1980) classification of disabilities. The SMAF was used by the three study regions.

The SMAF consists of 29 items that measure functional abilities in five areas: activities of daily living; mobility; communication; mental functions; and instrumental activities of daily living (see Table 3-1). Each item is scored on a four to six point scale which ranges from 0 (independent) to -3 (dependent) for a maximum total score of -87. For this study, the scoring was reversed (for example, -3 was scored as 3); this did not affect the coding or interpretation. Higher scores are indicative of poorer functioning. Only the functional status component of the SMAF was used in this study; information regarding resource availability was omitted.

⁵¹ A variety of published Quality of Life and Health Related Quality of Life measures were considered for this study. As a result of discussions with representatives from the various advisory groups, all of them were considered inappropriate and/or too complex based on people's priorities (this was particularly an issue for the Inuit study sites).

Information regarding the use of aids and supplies (for example, incontinence pads, wheelchairs, and hearing aids) was also gathered.

Table 3-1: Functional Abilities Addressed by the SMAF

Major Area (Subscale)	Activities Addressed
Activities of Daily Living	Eating Washing Dressing Grooming Urinary function Bowel function Toileting
Mobility	Transfers (bed to chair or wheelchair and vice versa) Walking inside Installing a prosthesis or orthosis Propelling a wheelchair inside Negotiating stairs Getting around outside
Communication	Vision Hearing Speaking
Mental Functions	Memory Orientation Comprehension Judgment Behaviour
Instrumental Activities of Daily Living	Housekeeping Meal preparation Shopping Laundry Telephone Transportation Medication use Budgeting

The SMAF was chosen as a measure of functional status for this study as it has good psychometric properties. For example, Desrosiers, Bravo Hébert and Dubuc (1995) reported test-retest and inter-rater reliabilities of .95 and .96 respectively, for the total SMAF score. Correlation coefficients were over .74 for all five subscale scores (which correspond to the five areas of function) for both types of reliability (Desrosiers et al., 1995). The SMAF total score has also been shown to account for 85% of the variance in required nursing-care time (Hébert, Dubuc, Buteau, Desrosiers, Bravo, Trottier, St-Hilaire, & Roy, 2001). The SMAF was used in other continuing care studies that examined care needs and costs for (non-Aboriginal) elderly clients living in different care settings and in different jurisdictions (see Hébert et al., 2001; Hollander et al., 2002).⁵² The SMAF is part of the Multiclientele Assessment Tools used by the province of Québec to assess continuing care clients (including First Nations and Inuit clients).

⁵² In the Hollander et al. (2002) study, clients receiving continuing care services at home were compared with clients receiving continuing care services in a facility and clients receiving services in Victoria were compared with clients receiving services in Winnipeg. It was felt that the SMAF could be used to compare home and facility clients in the current study, and could be used to compare across clients in the three study regions.

The SMAF can be used with clients or other individuals who know the client well; several individuals can complete the tool. Thus, information was gathered regarding who completed the SMAF (for example, the client, a family member/caregiver, or a paid health care worker). Information was also gathered regarding the language used to administer the tool. Finally, in order to make comparisons across respondents, individuals completing the SMAF on behalf of the client were asked whether the client had refused care or services in the past year, and if so, why.

3.3.5 Caregiver Interview Tool Used in the Inuit Study Sites

The Caregiver Interview tool was used to gather information from individuals who provided care and support to the client. Although intended to be used primarily with family caregivers, this tool was used with both family caregivers and paid health care personnel. The same tool was used with caregivers of clients who were receiving services at home and with caregivers of clients who were receiving services in a facility. As with the Client Interview, instructions were included throughout the tool to assist the interviewer with gathering relevant information. Several of the questions on the Caregiver Interview were similar to questions on the Client Interview to enable comparisons to be made between clients' and caregivers' perceptions of the care and services the client needs and receives.⁵³

The first page of the interview tool was used to identify the community the client was from, the caregiver, the interviewer, and the language(s) used to conduct the interview. This page also allowed the interviewer to comment on the interview and/or the caregiver's situation. The main part of the Caregiver Interview consisted of several sections which addressed: the caregiver's relationship to the client; the type of care provided; costs associated with the client's care; the caregiver's satisfaction with the services the client was receiving; the caregiver's preferences for where the client should receive services; the impact of caregiving on the caregiver; and caregiver demographics. The content of each of these sections is described in more detail below.

Section A: Provision of Assistance. This section consisted of several questions regarding the caregiver's relationship with the client as well as demands on the caregiver's time. The majority of the questions were used in the three study regions (Manitoba, Québec, and Nunavik).

Caregivers were asked how long they had been providing care and support to the client, what their relationship to the client was, and where they lived in relation to the client. The latter question was developed for this study. The other two questions were adapted from Hollander et al. (2002). The choices used in all three questions were identical to those used on the Client Interview.

Caregivers were asked if they considered themselves the client's primary family caregiver and, if not, who the primary caregiver is. The main or primary family caregiver was defined as the person who provides the client with most of the help. Caregivers were asked if anyone helps them provide care and support to the client and, if so, who provides assistance. Caregivers were also asked if they provided care to anyone else, and if so, how many other

⁵³ A similar approach had been used by Chapleski et al. (2003) and Hollander et al. (2002).

people they provided care and support for. All of these questions, except for the question regarding the number of people cared for/supported by the caregiver, were adapted from Hollander et al. (2002). The latter question was developed for this study.

Section B: Type of Care Provided. This section included three questions regarding the type of care and services provided to the client by both family caregivers and the formal care system. Together, the questions examined: what types of assistance the client receives; who provides the assistance (for example, family caregivers or formal care providers); how much assistance is provided by family caregivers because of the client's increased need for care; and how much time is provided on a weekly basis by both family caregivers and the formal care system. All were similar to questions included on the Client Interview (in Section D) and were adapted from Hollander et al. (2002).

Section C: Other Health Related Services. The questions in this section focused on expenditures related to supplies and equipment needed by the client because of his/her physical condition or health problem. The questions addressed: whether supplies and equipment had been obtained, and if so, how much they had cost; whether the client had been referred to a service within and/or outside his/her community; and whether the caregiver was satisfied with the care he/she received outside of the community (if applicable). All were similar to questions included on the Client Interview (in Section E). The questions regarding supplies and equipment were adapted from Hollander et al. (2002) and Browne, Gafni, Roberts and Hoxby (1992). The questions on services were developed specifically for the current study.

Section D: Satisfaction with Health Related Services. The questions in this section examined the caregiver's perceptions of the formal care services the client receives. All of the questions were similar to ones included on the Client Interview (in Section F).

Two questions addressed the caregiver's satisfaction with the formal care services the client receives. One of these questions asked about different aspects of care – for example, “Does the client receive the care/service when he/she needs it?” This question was developed for the current study. The second question examined caregiver's satisfaction with the services the client received, the characteristics of the paid health workers that provided care to the client, and care concerns. The majority of the questions were adapted from Penning and Chappell (1996).⁵⁴ One question addressed caregiver's perceptions of whether the client had experienced any difficulties in receiving care in the past year. This question was adapted from the First Nations and Inuit Regional Longitudinal Health Survey (2002). Two questions examined whether the caregiver had refused any care or services on behalf of the client and whether the client had been refused care or services by someone else. If the caregiver responded “Yes” to either question, he/she was asked to provide an explanation. Both of these questions were developed for the study.

Section E: (Preference for) Location of Services. This section of the Caregiver Interview examined: caregivers' awareness of housing options; where caregivers would prefer clients receive services and from whom; and caregivers' preferences regarding the clients' future care and service needs. The questions in this section were similar to ones included on the Client Interview (in Section G). The questions regarding housing options and future needs were

⁵⁴ This tool was also used by Hollander et al. (2002).

developed for this study. The questions regarding where caregivers would prefer clients receive services and from whom were based on a study by Chapleski et al. (2003).

Section F: Effects of Caregiving. The three questions in this section were intended to assess how providing care and support for the client had impacted the caregiver. One of the questions asked caregivers to identify the positive benefits of providing care to the client. A second question asked for the disadvantages of providing care.⁵⁵ The third question asked caregivers to indicate how the care and quality of life of the client could be improved. All of the questions were open-ended. The three questions were developed for this study and used by two of the study regions (Manitoba and Nunavik; the Québec region used a different set of questions to address this issue).

Section G: Demographic Information (for Caregivers). The demographics section requested information regarding the caregiver's gender; his/her age; the language(s) the caregiver can speak; the language(s) the caregiver can understand; the language the caregiver uses most often in daily life; the caregiver's education level; whether the caregiver is currently working for pay and if so, how many hours a week he/she works; the caregiver's sources of income over the past year; and the effects caregiving have had on the caregiver's living and employment situation. The wording and choices for all except the last question were similar to questions included on the Client Interview (in Section A). Many of the questions were adapted from the First Nations and Inuit Regional Longitudinal Health Survey (2002).

The question on the impact of caregiving on the caregiver's living and employment situation examined several aspects including whether the caregiver had: to change where he/she lived because of providing care to the client; take time off work to help the client receive care; and quit his/her job in order to provide care. The question was adapted from Hollander et al. (2002).

Section H: Additional Comments. This section was included to allow caregivers to make any other comments about the care or services they felt the client needed or received and/or the impact of caregiving on themselves. Interviewers were instructed to follow-up on any issues that may have been raised during the interview.

3.4 Research Approach

Once clients were identified, they were assigned a study number and contact information was provided to an interviewer who lived in the same community. The list of clients assigned to an interviewer was reviewed by knowledgeable individuals within the community (as noted above). Individuals who were considered to be appropriate for the study (for example, in the community) were then phoned or visited in person regarding their participation in the study.

⁵⁵ Several measures of Caregiver Burden/Stress were considered, including one used by John, Hennessy, Dyeson, & Garrett (2001) with Pueblo family caregivers. The measures were considered too complex to be used with the Inuit. In addition, the discussions with the First Nations and Inuit representatives of the three study regions indicated a need to look at both the positive and negative aspects of caregiving. Most existing measures that examine the impact of caregiving emphasize the negative aspects.

Potential participants were told that if they chose to participate, their name would be entered into a draw for \$150.00. Only other participants from the same community were included in the draw, and separate draws were done for clients and caregivers from the same community.⁵⁶ If a potential participant agreed to participate, the interviewer then made arrangements to conduct the interview, generally in the client's home.

Interviews were conducted at a mutually convenient time, and were conducted during the day, in the evening and on weekends. Interviewers were instructed to conduct the interview with the client one-on-one (unless a proxy or parent was required), and to conduct the interview in a quiet location. However, given the housing situation for many of the participants, this was not always achieved. The interviewer began the client interview by reviewing the consent form and obtaining the client's written agreement to participate. The functional status measure was generally administered first (when appropriate), followed by the Client Interview. Permission to contact a (family) caregiver was requested when clients indicated that they had one. Multiple interviews were conducted with the client, if required.

If a client indicated that he/she had a caregiver, the interviewer contacted the caregiver to see if he/she was interested in participating. If the caregiver was willing to participate, the interview was set up for a mutually convenient time. Again, interviewers were instructed to conduct the interview with the caregiver one-on-one and to conduct it in a quiet location. This was not always achieved. The interviewer began the caregiver interview by reviewing the consent form and obtaining the caregiver's written agreement to participate. Only the Caregiver Interview was administered to the caregivers. Multiple interviews were conducted with the caregiver, if required.

Individuals who served as a proxy for the client (because the client did not have the ability to understand the questions, either because of a mental health/cognitive condition or because of age (for example, in the case of a child)) and as a caregiver for the client, were first asked the questions on the Client Interview then the questions on the Caregiver Interview.

3.5 Data Coding and Entry

Comprehensive data coding manuals were developed for each of the three data collection tools (the SMAF, the Client Interview, and the Caregiver Interview). This was done to ensure that the coding of information was consistent: across individuals for the same tool; across different tools for the same questions (for example, across the Client and Caregiver Interviews); and across interviewers. The coders discussed any issues that arose as a group and a consensus was reached. Decisions that affected responses on the original materials were documented (for example, Section C of the Client Interview was not to be completed for individuals who were receiving services at home. If this section was completed, all of the questions were coded as Not

⁵⁶ Thus, there were a total of six draws: three for clients (one for each of the study communities) and three for caregivers (one for each of the study communities). In discussions with the representatives from all three study regions, it was noted that First Nations and Inuit individuals have been, and continue to be, involved in many studies and surveys. It was expected that a monetary incentive for participation would increase response rate, although it was noted that the incentive had to be meaningful for individuals within each of the regions. Discussions with the Inuit study representatives suggested that \$150.00 would be a reasonable amount to offer in the Inuit study communities.

Applicable). Open-ended questions were initially coded verbatim, although for some questions (such as those regarding what makes an individual happy), responses were subsequently regrouped into a smaller number of categories.

For the most part, coding went smoothly. However, one area that was particularly problematic related to the identification of a family caregiver. There was a question on the Client Interview which asked “Do you have a family caregiver, that is, a family member, friend, neighbour, or other individual who provides care and/or support to you outside of the formal care system?” It was found that in some cases, clients answered “Yes” to this question but then indicated on other questions that they did *not* receive help from a family caregiver.⁵⁷ In other cases, clients answered “No” to this question but indicated elsewhere that they *did* receive help from a family caregiver. In both cases, clients were considered to have a family caregiver. As a result of this decision, it appeared that in some cases, a family caregiver should have been interviewed but was not.

As discussed below, several individuals were involved in data collection. To address quality assurance issues at the data coding and entry stages, several steps were taken. These were as follows:

- Three coders/data entry personnel were used for all of the measures.
- Two individuals coded the functional status measure. All of the functional status measures were data entered by a third individual who had not been involved in coding the tool.
- Two individuals coded the Client Interview. Over 75% of the Client Interviews were data entered by someone other than the individual who had coded the tool.
- One individual coded all of the Caregiver Interviews. All of the Caregiver Interviews were entered by someone else.
- For all of the tools, any unusual codes were double checked and any coding errors that were noted at the time of data entry were corrected.
- Logic checks, data entry checks and checks for coding consistency were conducted once all of the data had been entered.
- Frequencies were run for each of the questions on each tool and unusual findings were double checked.

3.6 Data Storage and Security

A draft Information and Data Sharing Agreement was developed for the Nunavik study region. This document specified how the data were to be collected and treated by the interviewers, how it was to be treated by representatives from Hollander Analytical Services

⁵⁷ While this was an unexpected finding, it was recognized that this may have occurred because the interview tool did not include a question that specifically addressed the type of assistance these family caregivers may have provided.

during the study, and how it was to be treated after the study. As noted above, this document was never used within the region. Nevertheless, the concepts contained within it were adhered to.

Interviewers were instructed to keep all documents in a safe location during the course of the study. They were also asked to return completed documents to the Local Project Coordinator in a sealed envelope. The Local Project Coordinator reviewed all completed interview materials for completeness and put them in sealed envelopes. The sealed envelopes were then forwarded to Hollander Analytical Services' main office in Victoria via ExpressPost.⁵⁸

Once the packages were received in Victoria, the data were kept in a secured office. Consent forms were kept separate from completed data forms. Electronic data were stored on computers which were only accessible by personnel from Hollander Analytical Services.

At the present time, both the paper and electronic copies of the data are being maintained by Hollander Analytical Services. The Nunavik Region had initially indicated that they wished to develop a data repository. However, little has been done in this regard. All of the study materials will continue to be stored by Hollander Analytical Services until appropriate, alternative arrangements are made.

3.7 Lessons Learned

3.7.1 Support of the Region

The support of the Nunavik Regional Board of Health and Social Services as well as the support of key individuals within each of the study communities was critical for the success of the project.

A representative from the Nunavik Regional Board of Health and Social Services participated in discussions with the Manitoba and Québec study regions regarding various aspects of the study, including: involvement of the study communities; identification of the study sample; development of the data collection tools; implementation of the study; and steps to be taken as part of completing the study. As noted in Chapter 1, when the Continuing Care Research and Costing Project changed from one study being conducted in three regions to three separate (but similar) studies, the time demands on the Nunavik representative were substantial. In addition, the representative participated in the study *in addition to* her other work demands (this included attendance at several face-to-face meetings outside of the region). Although the representative was always conceptually willing to assist as required, competing priorities did not always make it possible to do so. This sometimes resulted in lengthy delays in providing feedback. It is important to note that a study of this nature requires an awareness of the local situation. It also requires a relatively large amount of time. For future studies, it is therefore important to consider having an individual who is able to devote the required amount of time within his/her normal working day.

⁵⁸ ExpressPost rather than courier was used as it was considered less expensive, delivery was guaranteed within a particular time period, and packages could be tracked. A signature was required upon delivery.

It is stressed that the primary challenge regarding the representative from the Nunavik Regional Board of Health and Social Services was competing time demands rather than a lack of willingness to provide assistance. The representative indicated that while the Public Health department within the Regional Board has participated in several studies, this has not been the case for the Planning and Programming department. The representative noted that the study had been a learning experience for her and indicated that if she were to be involved in another study, she would bring someone into the region sooner, and would be involved at an earlier stage in the development of the research tools.

The representative presented the study to key individuals within each of the study communities and to the Executive of the Nunavik Regional Board of Health and Social Services. These presentations were essential for obtaining regional support for the study, as well as for obtaining cooperation and active participation within each of the study communities. Without the support at both the regional and community levels, it would not have been possible to conduct the study. It is critical that someone who is familiar with the local communities make the initial contacts.

The Nunavik Regional Board of Health and Social Services also made a number of in-kind contributions to the study. For example, the translation of both the General and Caregiver Consent forms were done by an individual within the organization. The packages of interview materials were created by personnel within the Regional Board (this included: copying of consent forms, interview forms and other materials; collation of the materials; provision of envelopes to hold the materials; and stuffing of the envelopes). They assisted with identifying potential interviewers and contact people within each of the study communities. They also arranged transportation, lodging and meal vouchers for the Local Project Coordinator while he was in the region. The Local Project Coordinator was also provided with office space (including access to a phone and filing cabinets) within the Regional Board's building. It is estimated that approximately \$12,500 in in-kind contributions was provided by the Nunavik Regional Board of Health and Social Services.

The Nunavik Regional Board of Health and Social Services also ensured that interviewers were paid in a timely manner. The Board paid the interviewers up-front and then invoiced Hollander Analytical Services for the amount. In addition, the Regional Board also covered the up-front costs associated with the incentive draws for both the clients and the caregivers. Again, Hollander Analytical Services was invoiced.

Feedback from personnel at the Nunavik Regional Board of Health and Social Services and from key organizations within each of the study communities indicated that they were happy the study was conducted and felt it had been a good experience to be involved in the study. They are looking forward to seeing the results from the study.⁵⁹ Some individuals indicated that they were not overly aware that the study was being conducted. While this could be considered a positive comment in that individuals were not negatively impacted by the study, the comment seemed to stem from the fact that the Local Project Coordinator did not always use the office

⁵⁹ R. Ferguson, personal communication, November 2005.

available in the Regional Board's building. Some individuals indicated they would have liked to have been more involved.⁶⁰

3.7.2 Use of a Local Project Coordinator

Because of the competing demands on the representative from the Nunavik Regional Board of Health and Social Services, and because it was felt that there was no one within the region who would be able to implement the study, it was decided that an individual from outside of the Nunavik region should be hired as the Local Project Coordinator to implement the study.⁶¹ This had several consequences.

First, the Local Project Coordinator was hired by Hollander Analytical Services and therefore needed to meet contractual obligations with the funder (for example, receiving security clearance through the federal government). Second, due to study demands and transportation costs, the Local Project Coordinator left his home in southern Québec to live within the Nunavik region for the eight weeks required for data collection. Third, because the Local Project Coordinator did not normally reside within the region, transportation, lodging and meals needed to be arranged on his behalf. Because the communities within the region can only be accessed year round by air, the Local Project Coordinator needed to fly from one study community to another to: hire, train and support interviewers; select the client sample; and ensure that implementation of the study and data collection were proceeding as planned. The Local Project Coordinator also maintained phone contact with the interviewers in the other study communities while he was in the third community. The travel component was expensive. In addition, because of a shortage of housing within the region, lodging is often difficult to obtain and is very expensive. Both the travel and lodging aspects had substantial consequences for the study budget.

Both the Local Project Coordinator and the representative of the Nunavik Regional Board of Health and Social Services felt that the approach used in this study (for example, traveling from one community to another while continuing to support the other study communities) had worked well. A similar approach should be considered for future, multi-community studies in the region. However, study budgets would need to include adequate funding for travel and lodging.

3.7.3 Involvement of Three Study Communities

Although the study was initially intended to be conducted in only one community (Kuujjuaq), at the request of the region, two other communities were included. From a methodology perspective, this enabled the sample size to be increased and broadened, thus increasing generalizeability. It also appeared to have an impact on participation. Because of its size and location, Kuujjuaq is often identified as a study site in the region. As a result, individuals living in the community have been asked to participate in several studies, and may be experiencing "research fatigue". It also seemed that the incentive draws of \$150 were not considered sufficient in Kuujjuaq (although this did not seem to be the case in the other

⁶⁰ Ibid

⁶¹ This is similar to the approach used by the Public Health department when they are involved in research studies.

communities).⁶² In this study, research fatigue probably accounted for at least some of the refusals encountered in Kuujuaq. The two other communities (Puvirnituq and Inukjuak) have not been involved in studies as often, and appeared to be very enthusiastic about participating in the current one. The target sample was obtained in both of these communities. As noted above, the inclusion of the three study communities also had time and cost implications as the Local Project Coordinator needed to travel between the communities.

3.7.4 Identification of the Client and Caregiver Samples

Both the potential and final facility samples were identified with the assistance of key personnel in the facilities (usually a head nurse). No difficulties were encountered with regard to the identification of the samples. Although research team members contacted the individuals living in facility settings, nurses and assistants served as interpreters and proxies for all of these individuals. It was felt that, without this assistance from the paid health care personnel, the facility clients may not have been willing to participate.⁶³ It was noted that paid health care personnel are sensitive to the needs of their clients and are not always willing to allow strangers to collect information regarding them. The fact that the paid health care personnel were willing to serve as proxies for the clients, and as caregivers, suggested that they felt the study was important.⁶⁴ The support of the administrative/management component of the facilities was critical for obtaining the facility sample. These organizations provided approval for the research team to enter the facilities and they provided precious, non-reimbursed staff time to the study. Without the assistance of both the administrative/management levels and the care delivery personnel, it is unlikely that a facility sample would have been obtained. This reinforces the importance of active engagement of the community in a research study of this nature.

The sample of individuals receiving services at home were identified through lists maintained within each of the study communities. While the lists seem to be reviewed regularly, some of the random numbers identified unknown individuals. It was thought that, in some cases, this may have been due to spelling errors in the individuals' names.⁶⁵ It also appeared that the lists may have included individuals who had received continuing care services in the community in the past as well as those who were currently receiving services. The review of the potential community sample appears to have gone well, as only a couple of individuals were identified at the interviewer level as being away from the community.

It is felt that some individuals may not have been identified as being family caregivers either by the clients or by the interviewers. It was noted that some individuals may not have wanted to acknowledge a loss of autonomy as they did not want to feel dependent on others. For some, an acknowledgement of a loss of autonomy may result in feeling a loss of purpose.⁶⁶ Interviewers may have accepted a client's perception of whether he/she had a family caregiver and may not always have noted that clients were receiving assistance on a regular basis.

⁶² Both the Executive Director and the study representative from the Nunavik Regional Board of Health and Social Services felt that the amount was appropriate.

⁶³ R. Murray, personal communication, November 2005.

⁶⁴ R. Ferguson and R. Murray, personal communication, November 2005.

⁶⁵ R. Murray, personal communication, November 2005.

⁶⁶ Ibid

3.7.5 The Research Tools

There did not appear to be any difficulties with the consent forms. Both the Client and Caregiver Interview tools were considered quite lengthy, particularly when they needed to be translated into Inuktitut. It had been estimated, based on the implementation of the study in the Manitoba region, that the Client Interview would take approximately one and a half hours and the Caregiver Interview would take approximately one hour. Both interviews took approximately two hours to complete in English and approximately four hours to complete in Inuktitut (as noted below, most of the Client Interviews were conducted in Inuktitut).

Some of the questions on the Client Interview did not apply that well to the Inuit. It was anticipated that this might be the case based on discussions with the Inuit study representatives prior to the implementation of the study. However, it was felt that it was important to include all of the core questions on the research tools used in each study region in order to enable comparisons across the regions. Some questions, such as the question regarding where individuals would like to receive palliative care/end-of-life services should they require them in the future, were included (even though it was thought that they may not be answered that well) because of national policy implications. It was felt that the Client Interview should have addressed why individuals are currently experiencing a loss of autonomy (that is, their diagnoses).⁶⁷

As noted above, the Caregiver Interview was deliberately created to enable comparisons to be made between clients and caregivers. However, this may not have worked well with the Inuit, as in some cases, caregivers were present while the clients were being interviewed and were reluctant to answer the same questions the client had responded to.

Future studies focusing on the needs of clients and the impact of caregiving on family members will need to seriously consider the issues raised in this study.

⁶⁷ R. Murray, personal communication, November 2005, based on information provided by the interviewers. As noted earlier, information regarding an individual's specific health condition(s) was deliberately not included as it is functional status, rather than diagnosis *per se* that is important for the provision of continuing care services.

4. INTERVIEWING AND ASSESSMENT PROCESS

4.1 Recruitment and Selection of Interviewers

A brief job description was developed to assist with the recruitment and selection of interviewers (see Appendix E.) An emphasis was placed on experienced interviewers who were familiar with the study communities and who were able to communicate in both Inuktitut and English. Because it was felt that there would be very few individuals who would meet the requirements, key personnel at the health centres, at the hospitals, at the CLSCs and with the Persons Lacking Autonomy program in the three study communities (as appropriate) were asked to recommend potential interviewers.

The names of potential interviewers were submitted to the Local Project Coordinator. The Local Project Coordinator contacted each potential interviewer by phone, described the study and the roles and responsibilities of the interviewers in more detail and ascertained whether the individual was interested in working on the study. Interested individuals were then invited to attend a training session in their own community. They were also told that they would need to obtain a police security check prior to the training session.

Eleven interviewers were formally hired at the time of the training session. Interviewers were hired from the three study communities.

4.2 Training of Interviewers

All of the interviewers were required to attend a one day training session in their own community. The training sessions were conducted by the Local Project Coordinator. A training manual was created for use in these sessions (see Appendix E). The training session included discussions regarding: the purpose of the study; how to recruit clients and how to document refusals; issues to consider in conducting the interviews (for example, the importance of having a quiet location); the purpose and content of the various research tools; and what was expected with respect to completed interviews and maintaining confidentiality. Interviewers were asked to sign a contract and an Oath of Confidentiality.

Interviewers were told that they would be paid \$90 per completed interview and that invoices would be paid once all of their interviews had been completed.⁶⁸ Interviewers were also paid the equivalent of one interview for attending the training session.

4.3 Support of Interviewers

The Local Project Coordinator maintained regular contact with the interviewers in each of the study communities (regardless of where he was physically located) to ensure that the work was progressing and any problems were identified and addressed. The Local Project Coordinator

⁶⁸ Consideration had been given to paying the interviewers on an hourly basis. However, it was felt that it was better to pay on the basis of completed interviews. The Nunavik Regional Health and Social Services ensured that interviewers were paid in a timely manner once their work was completed. Hollander Analytical Services reimbursed the Board.

also spoke with the nurses in the various study communities to ensure that no issues had arisen from their perspective.

There were no major problems encountered with the interviewers in either Puvirnituk or Inukjuak. However, some of the individuals who were trained in Kuujuaq either did not complete any interviews or completed only two or three interviews. Given the limited number of individuals available to conduct interviews in this community, this meant that the remaining individuals had to take on additional work. Given the time constraints of the study, and a relatively high client refusal rate, it was not possible to obtain the full target sample in Kuujuaq.

4.4 Challenges Related to Data Collection

With the exception of Kuujuaq, data collection proceeded more or less as anticipated and no major problems were encountered regarding interviewer availability or client recruitment.

It was felt that hiring interviewers from within the study communities was important as they would be familiar with the clients and caregivers, and the clients and caregivers would be more comfortable providing information to a known individual rather than to a stranger. It was noted, however, that some interviewers had a tendency to answer questions on behalf of the clients and/or caregivers (that is, without asking the participants the questions), because they knew the individuals. When this occurred, the Local Project Coordinator reminded the interviewers to ask the participants all of the questions on the interview forms. He also noted that input from the interviewers could be recorded on the front page of the interview forms or on separate sheets of paper.

It was noted at the coding stage that apparent discrepancies in client and caregiver responses were generally not addressed by the interviewers. Although some discrepancies were identified during the review by the Local Project Coordinator, this was not always the case. For example, a client may have indicated that he/she did not have a family caregiver, but may also have provided perceptions regarding the care received from family members. The use of coding manuals and consistent coding rules helped to ensure that the data could be interpreted.

Both the Local Project Coordinator and the representative from the Nunavik Regional Board of Health and Social Services discussed the study experience with the interviewers at the end of the study. A relatively consistent set of topics were discussed, although a formal debriefing form was not used.⁶⁹ Interviewers generally found the study difficult and were glad when it was over. They noted that the interview tools were long and that it was sometimes difficult to interview individuals whom they knew well.

⁶⁹ A set of debriefing questions were developed by the Manitoba study region. It had been intended that these questions would be adapted and used with the Inuit. However, by the time this might have occurred, the interviewers had already participated in an informal debriefing session with the Local Project Coordinator and/or the representative from the Nunavik Regional Board of Health and Social Services.

4.5 Lessons Learned

4.5.1 Police Security Checks

Obtaining police security checks for the interviewers went smoothly. A contact person within the Kativik Regional Police Department was identified for this purpose. The person knew what was required, and the research team received good cooperation and timely responses. This was important as it enabled the study to be conducted within the available time frame.

4.5.2 Use of Local Interviewers

The use of local interviewers had both advantages and disadvantages. The local interviewers knew the community, the residents, the language and culture and likely had a positive impact on participation rates. On the other hand, they sometimes knew the participants, and were reluctant to ask questions when they felt the answers were already known. Although the interviewers were all experienced having worked on other studies, it was noted that in this study, seemingly contradictory responses were not always identified and/or addressed. Finally, although key personnel within the study communities recommended potential interviewers, the behaviour of some individuals was inconsistent with the recommendations. It is recognized that the Nunavik region is still in the process of developing research capacity. As research capacity increases, these issues may become less problematic.

4.5.3 Use of a Formal Debriefing Process

While it is felt that the discussions with the interviewers highlighted all of the major issues, the use of a formal debriefing process and consistent questions may have identified additional issues that could be addressed in future studies.

5. FINDINGS FOR CLIENTS

5.1 Introduction

This chapter presents the findings from the Client Interview. The target sample is described, both in terms of demographic information and functional status. Information is provided regarding proxy data for clients who were unable to complete the interview on their own. Information is also provided on: the clients' housing situation; the availability of caregivers; clients' use of health services; clients' satisfaction with the services they currently receive; clients' perceptions of their health and quality of life; and where clients would like to receive services in the future.

5.2 Demographic Information

The target sample for each of the three study communities was 30 individuals, for a total sample size of 90. While the target was reached in both Puvirnituq and Inukjuak, only 19 interviews were completed in Kuujuaq. Thus, the total sample size was 79. The majority of the clients (57) lived at home and comprise the "Home" sample. The remaining 22 individuals live in a facility and comprise the "Facility" sample.

As shown in Table 5-1, the majority (64.6%) of the Client Interviews were conducted in Inuktitut; most of these involved individuals living at home. An additional 16.5% of the interviews were conducted in English and 11.4% were conducted in French; most of these involved individuals living in a facility. A further 7.6% of the Client Interviews were conducted in Inuktitut *and* either English (83.3%) *or* French. In all but one case, the interviewers were able to provide any necessary translation. Approximately 66.7% of Client Interviews were completed by clients themselves; the majority of these were completed by individuals living at home. An additional 21.8% of Client Interviews were completed by paid health care personnel; all of these were completed on behalf of individuals living in a facility. Family caregivers completed 7.7% of the Client Interviews on behalf of the clients, and 3.8% of Client Interviews were completed by more than one individual. Individuals who completed the Client Interview on behalf of a client are referred to as proxies. The effect of having so many proxies is discussed in more detail below (see Section 5-4).

Table 5-1: Individuals Completing the Client Interview

		Home		Facility		Total	
		#	%*	#	%	#	%
Language used	English	2	3.5	11	50.0	13	16.5
	French	0	0.0	9	40.9	9	11.4
	Inuktitut	50	87.7	1	4.5	51	64.6
	More than one language	5	8.8	1	4.5	6	7.6
	Total	57	100	22	100	79	100
Client Interview completed by	Clients	51	89.4	1	4.8	52	66.7
	Family caregivers	5	8.8	1	4.8	6	7.7
	Paid health care personnel	0	0.0	17	81.0	17	21.8
	More than one individual	1	1.8	2	9.5	3	3.8
	Total	57	100	21	100	78	100

Table 5-2 provides demographic information regarding the clients. Overall, 45.6% of the sample was male; 54.4% was female. For clients receiving services at home, 43.9% were male and 56.1% were female. This is similar to what is observed for the Nunavik region as a whole. For clients receiving services in a facility setting, half were male and half were female. Figure 5-1 provides the same information in graphic form. Clients living at home were similar to clients living in a facility with respect to gender ($\chi^2(1) = .24, ns$).^{70, 71}

Overall, 9.0% of the sample was between 0 and 17 years of age, 20.5% was between 18 and 34 years of age, 12.8% was between 35 and 54 years of age, 15.4% was between 55 and 64 years of age, 24.4% was between 65 and 74 years of age, and 17.9% was 75 years of age or older (see Table 5-2 and Figure 5-2). The relative proportions for the different ages groups are similar to what is observed for the Nunavik region as a whole. Approximately 50% of the individuals living in a facility setting were under the age of 35. Of the 10 individuals in this group, 3 lived in the Reintegration Centre, and 7 lived in a hospital or elders/seniors home; 2 of the individuals were children. For both of the children living in the facility, it was noted that, while their basic needs were met, they could benefit from physiotherapy, specialized education, and age-appropriate activities. It was also noted that several of the younger individuals had lived in the facility for a long time: “This person has lived in the hospital since childhood” (25 to 34 year old); “(The client) has been living in the hospital for many years as (his/her) family were unable to provide care at home” (18 to 24 year old); and “(The client) had an accident when (he/she) was nine and has lived in the hospital ever since” (18 to 24 year old). Clients living at home were similar to clients living in a facility with respect to age when children were included in the analysis ($U = 435.00, ns$).⁷² When children were not included, the analysis indicated that clients living in a facility tended to be younger than clients living at home ($U = 335.00, p < .05$).

Clients were asked what languages they could speak; clients could indicate that they spoke more than one language. Overall, 88.6% of the sample could speak Inuktitut, 27.8% could speak English, 2.5% could speak French, and 2.5% could speak some other language. All but one of the individuals who spoke a language other than Inuktitut could also speak Inuktitut (for example, all of the individuals who spoke English could also speak Inuktitut). Some 10.1% of the clients were mute. Clients were also asked what languages they could understand; again, clients could indicate that they understood more than one language. Overall, 96.2% of the sample could understand Inuktitut, 36.7% could understand English, 2.5% could understand French, 2.5% could understand some other language and 2.5% were unable to understand at all. All but one of the individuals who understood a language other than Inuktitut also understood Inuktitut. The majority (86.1%) of the clients used Inuktitut most often in their daily life. These findings

⁷⁰ The chi-squared statistic (symbolized as χ^2) is used to determine if observed and expected frequencies are statistically different. In this case, the χ^2 was not significant, indicating that the distribution of males and females was similar for the home and facility samples, and suggesting that males and females use the services equally. A significant χ^2 would have indicated that males and females did not use the services equally. In the non-Aboriginal literature, females generally use facility services more frequently than males.

⁷¹ Similar findings were observed when the analysis was conducted without the children.

⁷² The Mann Whitney U statistic (symbolized as U) can be used to determine if two groups of individuals differ from one another. The significant U when children were not included in the analysis indicates that the home and facility samples differ from one another with respect to age. An examination of Table 5-2 indicates that 66.7% of the home sample is over the age of 55, while 66.7% of the facility sample is under the age of 54.

are consistent with information presented elsewhere (for example, Nunavik Regional Board of Health and Social Services, 2005).

Table 5-2: Description of the Client Sample

Characteristic		Home		Facility		Total	
		#	%	#	%	#	%
Gender	Male	25	43.9	11	50.0	36	45.6
	Female	32	56.1	11	50.0	43	54.4
	Total	57	100	22	100	79	100
Age	0-17	5	8.8	2	9.5	7	9.0
	18-34	8	14.0	8	38.0	16	20.5
	35-54	6	10.5	4	19.0	10	12.8
	55-64	10	17.5	2	9.5	12	15.4
	65-74	18	31.6	1	4.8	19	24.4
	75 and older	10	17.5	4	19.0	14	17.9
	Total	57	100	21	100	78⁷³	100
Language Spoken ⁷⁴	English	15	26.3	7	31.8	22	27.8
	French	1	1.8	1	4.5	2	2.5
	Inuktitut	55	96.5	15	68.2	70	88.6
	Other language	2	3.5	0	0.0	2	2.5
	Unable to speak	0	0.0	8	36.4	8	10.1
Language Understood ⁷⁵	English	18	31.5	11	50.0	29	36.7
	French	1	1.8	1	4.5	2	2.5
	Inuktitut	56	98.2	20	90.9	76	96.2
	Other	2	3.5	0	0.0	2	2.5
	Unable to understand	0	0.0	2	9.1	2	2.5
Language Used Most Often on a Daily Basis	English	2	3.5	0	0.0	2	2.5
	French	0	0.0	0	0.0	0	0
	Inuktitut	53	93.0	15	68.2	68	86.1
	Use both English and Inuktitut	1	1.8	0	0.0	1	1.3
	Other language	1	1.8	0	0.0	1	1.3
	Unable to communicate	0	0.0	7	31.8	7	8.9
	Total	57	100	22	100	79	100
Education Level	No formal schooling	31	54.4	13	61.9	44	56.4
	Kindergarten to Grade 3	7	12.3	4	19.0	11	14.1
	Grades 4 to 7	6	10.5	3	14.3	9	11.5
	Some High School	7	12.3	1	4.8	8	10.3
	High School Graduate	3	5.3	0	0.0	3	3.8
	Some technical/trade school, college or university	2	3.5	0	0.0	2	2.6
	University degree or equivalent ⁷⁶	1	1.8	0	0.0	1	1.3
	Total	57	100	21	100	78	100
Currently Working for Pay	Yes	5	8.8	0	0.0	5	6.3
	No	52	91.2	22	100	74	93.7
	Total	57	100	22	100	79	100

⁷³ Age information was not available for one of the individuals living in a facility.

⁷⁴ Participants were asked what languages they spoke. Individuals could indicate that they spoke more than one language. Percentages are based on the total number of individuals in each group (that is, 57clients receiving services at home and 22 clients receiving services in a facility).

⁷⁵ Participants were asked what languages they understood. Individuals could indicate that they understood more than one language. Percentages are based on the total number of individuals in each group (that is, 57clients receiving services at home and 22 clients receiving services in a facility).

⁷⁶ Includes individuals who have received a degree/diploma/certificate from a trade or technical school, individuals who have a Bachelor's degree, Master's degree, PhD, MD or similar certification.

Figure 5-1: Home and Facility Clients by Gender

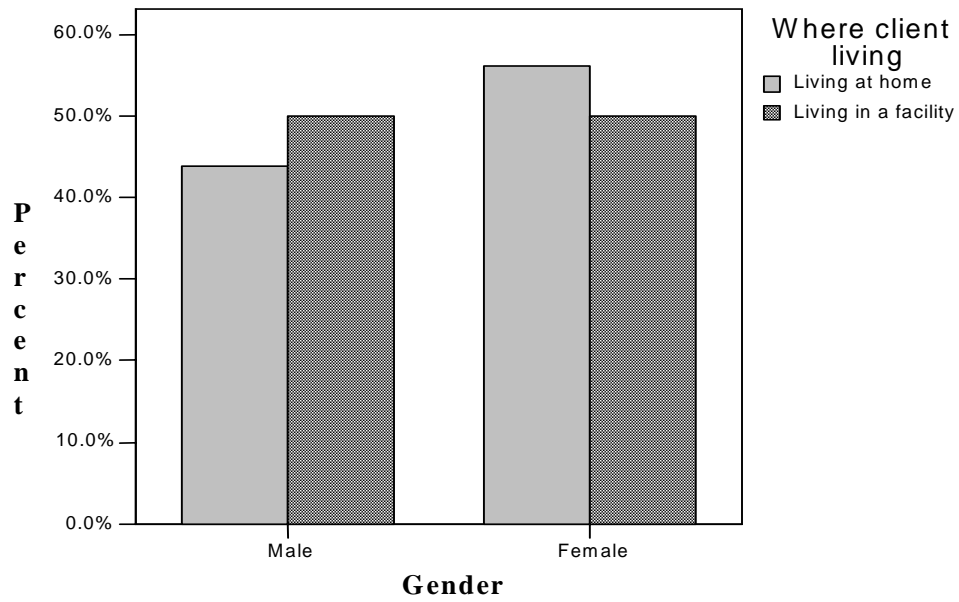
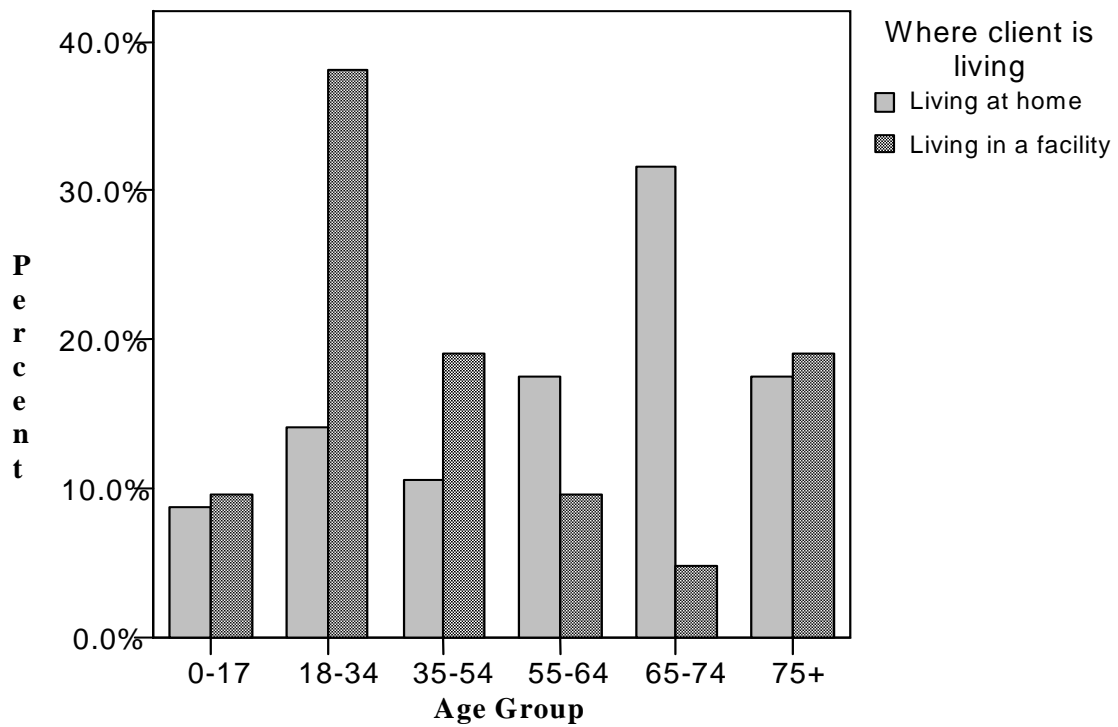


Figure 5-2: Home and Facility Clients by Age



Overall, 56.4% of the clients had no formal schooling, 25.6% had some elementary school (Kindergarten to Grade 7), and 10.3% had some high school (Grades 8 to 12). Only 3.8% had graduated from high school and 3.9% had some post-secondary education. These findings are consistent with what has been reported for the Nunavik region as a whole.

The majority (93.7%) of clients indicated that they were not currently working for pay. While it may be expected that individuals living in a facility setting would not be working, and that individuals over the age of 65 may not be working, only 5 of the 24 individuals under the age of 65 living at home indicated that they were working. Of these, two individuals indicated that they worked less than 5 hours per week, one individual worked 20 hours per week and two individuals worked 35 to 40 hours per week.

Clients were asked about their sources of income over the past year; clients could indicate that they received income from more than one source. As indicated in Table 5-3, the majority of clients received income from Old Age Pensions, Guaranteed Income Supplements and Social Assistance. The Other sources of income indicated in the table included Youth Protection, Widower Pension and Co-op Membership funds.

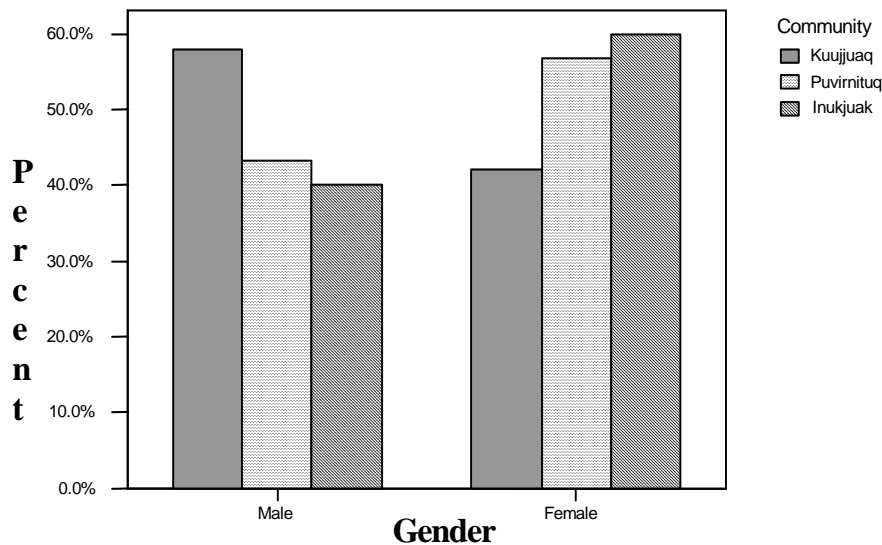
Table 5-3: Sources of Income

Source of Income	Home		Facility		Total	
	#	%	#	%	#	%
Employment (including paid employment and self-employment)	5	8.9	0	0.0	5	6.4
Employment Insurance	4	7.1	0	0.0	4	5.1
Social Assistance	6	10.7	12	54.5	18	23.1
Old Age Pension	31	55.4	6	27.3	38	48.7
Canada or Québec Pension Plan Benefits	7	12.5	3	13.6	10	12.8
Guaranteed Income Supplement or Spouse's Allowance	14	25.0	6	27.3	20	25.6
Retirement, Pensions, Superannuation, Annuities	3	5.4	0	0.0	3	3.8
Child Tax Benefit	12	21.4	2	9.1	14	17.9
Child Support and/or Alimony	1	1.8	0	0.0	1	1.3
Workers' Compensation	5	8.9	0	0.0	5	6.4
Disability Allowance	7	12.5	1	4.5	8	10.3
Other	6	10.7	1	4.5	7	9.0
Total number of individuals	56	N/A	22	N/A	78	N/A

Note: Percentages are based on the number of individuals in each group who provided information regarding their income. Individuals could provide multiple responses.

As noted previously, the study was conducted in three communities. Because of the small sample size, the fact that many of the individuals in Kuujjuaq were living in a facility, and the three communities were not expected to differ from one another, the findings reported above are based on the entire sample. In order to obtain a complete picture, however, analyses were conducted to determine if the three communities differed with respect to gender, age and education level.⁷⁷ The findings are shown in Figures 5-3, 5-4 and 5-5; all figures include the children. The findings indicated that the proportion of males and females did not differ statistically across communities ($\chi^2 (2) = 1.60$, ns).⁷⁸ The findings also indicated that the clients did not differ across communities with respect to age when children were included ($H (2) = 5.73$, ns).⁷⁹ When children were excluded from the analysis, it was noted that the age of clients significantly differed across communities ($H (2) = 7.67$, $p < .05$); the sample in Inukjuak tended to be younger and the sample in Kuujjuaq tended to be older. Finally, the findings indicated that education levels differ across communities ($H (2) = 10.16$, $p < .01$);⁸⁰ clients in Inukjuak tend to be better educated than clients in the other two communities. This finding is consistent with the fact that younger individuals tend to be better educated.

Figure 5-3: Gender of Clients by Community



⁷⁷ Given the large proportion of the sample that spoke, understood and used Inuktitut on a daily basis, language use among the three communities was not analyzed. Given the large proportion of the sample that was not currently working for pay, income was also not analyzed.

⁷⁸ Similar findings were obtained when the children were excluded from the analysis.

⁷⁹ The Kruskal Wallis statistic (symbolized as H) is similar to the Mann Whitney U but is used with more than two groups. A non-significant finding would have indicated that the groups did not differ statistically from one another.

⁸⁰ Similar findings were observed when the analysis was conducted without the children.

Figure 5-4: Age of Clients by Community

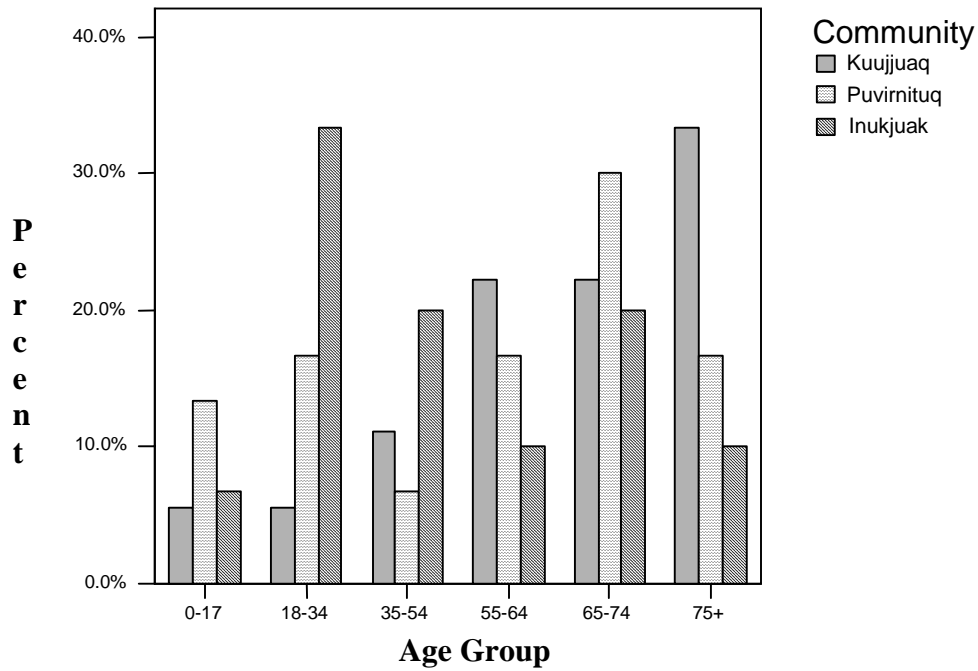
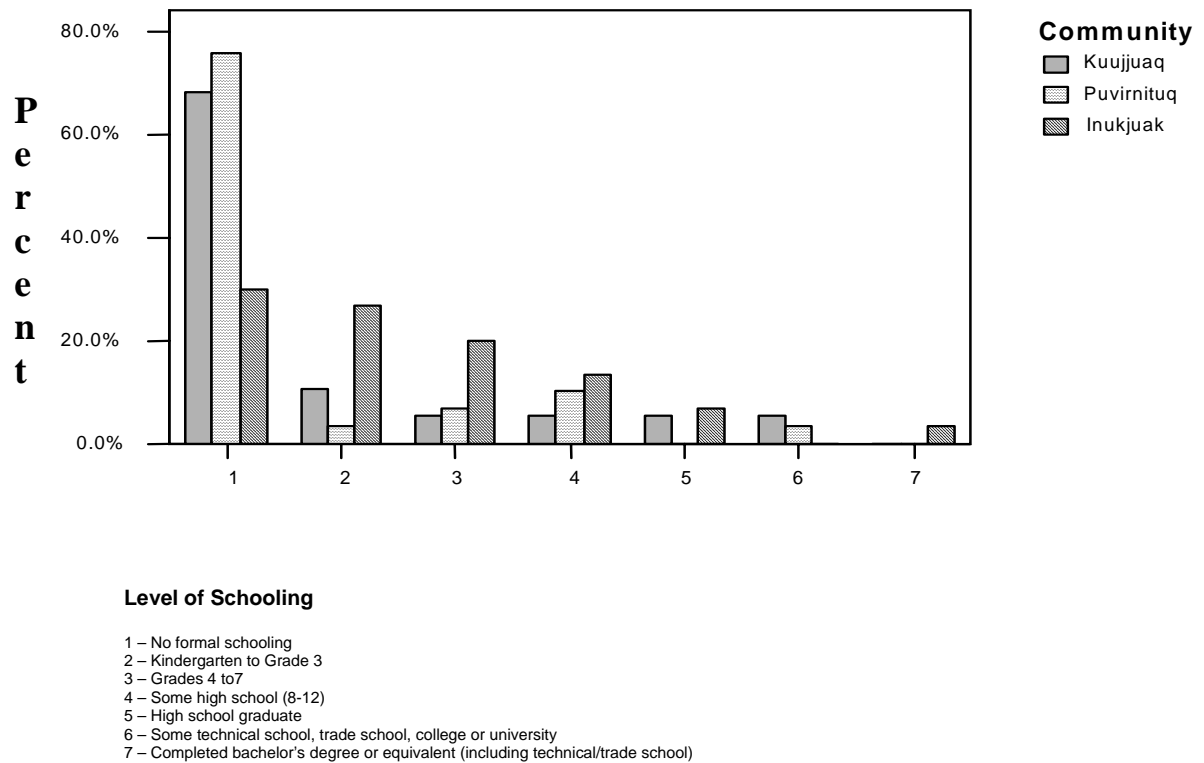


Figure 5-5: Educational Level of Clients by Community



5.3 Functional Status and Determination of Care Levels

5.3.1 Introduction

In continuing care, an individual's functional ability is generally more important than his/her health condition(s) in determining resource requirements. As the focus of the current study was on continuing care requirements, a measure of functional status, the SMAF, was included as one of the study instruments. The SMAF provides information about functional status in five areas (ADLs, Mobility, Communication, Mental Functions, and IADLs). It also provides information about the utilization of several assistive devices, such as incontinence products, canes, and hearing aids. Findings related to the use of various assistive devices are discussed in Section 5.3.2. Findings related to clients' functional status are discussed in more detail in Section 5.3.3.

Functional status information was obtained for all but one client. As shown in Table 5-4, the majority (61.5%) of functional status interviews were conducted in Inuktitut. An additional 16.7% were conducted in English, 14.1% were conducted in French, and 7.7% were conducted in both English and Inuktitut. In all but one case, the interviewers were able to provide any necessary translation. The majority (64.1%) of functional status interviews were completed by clients; 7.7% were completed by family caregivers, 24.4% were completed by paid health care personnel, and 2.6% were completed by both the client and a paid health care member.

Table 5-4: Individuals Completing the Functional Status Measure

		Home		Facility		Total	
		#	%	#	%	#	%
Language used	English	2	3.6	11	50.0	13	16.7
	French	1	1.8	10	45.5	11	14.1
	Inuktitut	47	83.9	1	4.5	48	61.5
	More than one language	6	10.7	0	0.0	6	7.7
	Total	56	100	22	100	78	100
Functional measure completed by	Clients	49	87.5	1	4.8	50	64.9
	Family caregivers	5	8.9	1	4.8	6	7.8
	Paid health care personnel	1	1.8	18	85.7	19	24.7
	More than one individual	1	1.8	1	4.8	2	2.6
	Total	56	100	21	100	77	100

5.3.2 Use of Assistive Devices

Table 5-5 presents findings related to the use of various assistive devices. Findings are provided only for those individuals who indicated they used one or more devices. As shown in the table, 19 individuals had glasses or used a magnifying glass. All of these individuals lived at home. Although only seven individuals used a walker, approximately 22.7% of the individuals living in a facility had one. Fourteen individuals used a wheelchair. The majority of these individuals lived in a facility, and it appears that over 45% of the individuals in a facility have a wheelchair. Note that 14% of clients living at home used a cane, walker, or wheelchair. Given that external sidewalks are generally not available in the study communities, the ability of these clients to move outside of the home may be affected, particularly during certain times of the

year. Twelve clients (15.4% of the sample) experienced both bladder and bowel incontinence and incontinence both during the day and at night.⁸¹ Three of these individuals lived at home; the remainder lived in a facility. Two clients (2.6%) were bedridden and required assistance with positioning. As shown in Table 5-5, 5.1% of clients were bedridden and required a lift to be transferred; none of the clients required a transfer board.

Table 5-5: Use of Various Assistive Devices by Location of Client

Type of Assistive Device	Home		Facility		Total	
	#	%	#	%	#	%
Nasogastric tube	0	0.0	0	0.0	0	0.0
Gastrostomy	0	0.0	2	9.0	2	2.6
Incontinence pad	1	1.8	10	45.5	11	14.1
Urinary condom or indwelling catheter	0	0.0	0	0.0	0	0.0
Ostomy	1	1.8	0	0.0	1	1.3
Commode, bedpan or urinal	0	0.0	0	0.0	0	0.0
Lift	0	0.0	4	18.2	4	5.1
Transfer board	0	0.0	0	0.0	0	0.0
Cane (including tripod and quadripod cane)	2	3.6	1	4.5	3	3.8
Walker	2	3.6	5	22.7	7	9.0
Prosthesis or orthosis	2	3.6	2	9.0	4	5.1
Wheelchair	4	7.1	10	45.5	14	17.9
Glasses or magnifying glass	19	33.9	0	0.0	19	24.4
Hearing aid	2	3.6	0	0.0	2	2.6
Computer or communication board	0	0.0	0	0.0	0	0.0
Medication dispenser aid	2	3.6	1	4.5	3	3.8
Total number of individuals	56	N/A	22	N/A	78	N/A

Note: Percentages are based on the number of individuals in each group who provided information regarding their income. Individuals could provide multiple responses.

5.3.3 Creation of Care Levels

As previously noted, the SMAF consists of five subscales. Using scores on the five subscales and the total score, individuals can be categorized using a 14 category classification system (Dubuc, Hébert, Desrosiers, Buteau, & Trottier, 1999). The categories are related to the amount of assistance the client requires; clients in Category 1 require the least amount of assistance, while those in Category 14 require the most. Thus, each of the categories can be considered a “level of care”.

The Dubuc et al. (1999) classification system was not used in this study, primarily because of the sample size. Instead, the approach used by Hollander et al. (2002) was used.⁸² The

⁸¹ The majority of these individuals also used incontinence pads and are included in the table. However, two individuals used incontinence pads possibly as protection, as they did not appear to be incontinent and three individuals experienced incontinence, but did not wear pads.

⁸² In the Hollander et al. study, which involved a substantially larger sample, it was found that clients were captured in each of the 14 categories in the Dubuc et al. (1999) classification system, with approximately 23.6% of clients falling into the four lowest care levels. In addition, the proportion of home and facility clients varied by care level. These findings would have made it difficult to make outcome and cost comparisons between the two groups of clients. In order to address this issue, Hollander et al. (2002) used total SMAF scores, rather than the Dubuc et al. (1999) classification system, to determine “care level” categories. A Pearson correlation conducted between

distribution of total SMAF scores for the Inuit data was examined and possible cut points for care level categories were identified. The distributions of total SMAF scores for both the Québec and Manitoba First Nations data were also examined to determine the best cut points for all three sets of data (using the same cut points for all three sets of data enables comparisons to be made among the three study regions).

Ultimately, seven “care level” categories were created. The first category included total scores between 0 and 4.5. The second category included total scores between 5.0 and 14.5. The third category included total scores between 15.0 and 24.5. The fourth category included total scores between 25.0 and 39.5. The fifth category included total scores between 40.0 and 52.5. The sixth category included total scores between 53.0 and 64.5. The seventh category included total scores between 65.0 and 87.0.⁸³ The means and standard deviations for all care levels are presented in Table 5-6. Using total functional status scores as a dependent variable, a 2 (location of care; home versus facility) by 7 (care levels) analysis of variance (ANOVA) was conducted.⁸⁴

Table 5-6: Means and Standard Deviations for Total Functional Status Scores by Care Levels

Care Level*		Home	Facility	Total
Level 1 (0 to 4.5)	Mean	1.4	-	1.4
	Standard Deviation	1.5	-	1.5
	Number	27	0	27
Level 2 (5.0-14.5)	Mean	7.6	13.0	7.9
	Standard Deviation	2.1	-	2.4
	Number	17	1	18
Level 3 (15.0-24.5)	Mean	18.2	21.3	19.4
	Standard Deviation	2.8	3.8	3.4
	Number	6	4	10
Level 4 (25.0-39.5)	Mean	29.4	28.4	28.9
	Standard Deviation	2.8	4.5	3.5
	Number	4	4	8
Level 5 (40.0-52.5)	Mean	-	46.0	46.0
	Standard Deviation	-	8.5	8.5
	Number	0	2	2
Level 6 (53.0-64.5)	Mean	55.5	57.0	56.4
	Standard Deviation	0.7	6.1	4.4
	Number	2	3	5
Level 7 (65.0-87.0)	Mean	-	74.8	74.8
	Standard Deviation	-	6.1	6.1
	Number	0	8	8

* Numbers in parentheses refer to total SMAF scores.

category allocations using the Dubuc et al. classification system and total scores indicated that the two scales were closely related.

⁸³ These categories are similar to those created by Hollander et al. (2002).

⁸⁴ An ANOVA enables comparisons among the means or averages of more than two groups. The ANOVA statistic is symbolized as F.

Because the care levels were created so that home and facility clients within a care level would be comparable, but clients within different care levels would differ, it was expected that the analysis would show a significant main effect for care levels indicating that the care level groups were statistically different from one another. It was also expected that the main effect of location of care would not be significant; a significant finding would indicate that clients living at home were different from clients living in a facility. Further, it was expected that the interaction between the location of care and care levels would not be significant; a significant interaction would indicate that clients living at home differed from clients living in a facility, but only for one or more of the care levels. The results were as expected. The ANOVA revealed a significant main effect of care levels ($F(6,67) = 283.27, p < .001$). Neither the main effect of location of care, nor the interaction were significant.⁸⁵

5.3.4 Demographic Characteristics and Functional Status

One of the questions of interest was whether the distribution of males and females differed across care levels. A second question was whether the number of individuals in each age group differed across care levels. Table 5-7 presents gender by care level. Table 5-8 presents age by care level. Given the large number of empty cells, no analyses were conducted.

Table 5-7: Gender by Care Level

		Male		Female		Total	
		#	%	#	%	#	%
Home	Level 1 (0-4.5)	10	40.0	17	54.8	27	48.2
	Level 2 (5.0-14.5)	9	36.0	8	25.8	17	30.4
	Level 3 (15.0-24.5)	3	12.0	3	9.7	6	10.7
	Level 4 (25.0-39.5)	2	8.0	2	6.5	4	7.1
	Level 5 (40.0-52.5)					0	0.0
	Level 6 (53.0-64.5)	1	4.0	1	3.2	2	3.6
	Level 7 (65.0-87.0)					0	0.0
	Total	25	100	31	100	56	100
Facility	Level 1 (0-4.5)					0	0.0
	Level 2 (5.0-14.5)	1	10.0			1	4.8
	Level 3 (15.0-24.5)	3	30.0	1	9.1	4	19.0
	Level 4 (25.0-39.5)	3	30.0	1	9.1	4	19.0
	Level 5 (40.0-52.5)			2	18.2	2	9.5
	Level 6 (53.0-64.5)	1	10.0	1	9.1	2	9.5
	Level 7 (65.0-87.0)	2	20.0	6	54.5	8	38.1
	Total	10	100	11	100	21	100

Note: Empty cells have been left blank (except for Totals) to assist with illustrating which cells contain figures.

⁸⁵ Similar findings were observed when the children were eliminated from the analyses.

Table 5-8: Age by Care Level

	Care Levels	Age													
		0-17		18-34		35-54		55-64		65-74		75+		Total	
		#	%	#	%	#	%	#	%	#	%	#	%	#	%
Home	Level 1 (0-4.5)			4	57.1	4	66.7	7	70.0	9	50.0	3	30.0	27	48.2
	Level 2 (5.0-14.5)			3	42.9	2	33.3	2	20.0	6	33.3	4	40.0	17	30.4
	Level 3 (15.0-24.5)	3	60.0							2	11.1	1	10.0	6	10.7
	Level 4 (25.0-39.5)	1	40.0					1	10.0	1	5.6	1	10.0	4	7.1
	Level 5 (40.0-52.5)													0	0.0
	Level 6 (53.0-64.5)	1	40.0									1	10.0	2	3.6
	Level 7 (65.0-87.0)													0	0.0
	Total	5	100	7	100	6	100	10	100	18	100	10	100	56	100
Facility	Level 1 (0-4.5)													0	0.0
	Level 2 (5.0-14.5)					1	25.0							1	4.8
	Level 3 (15.0-24.5)			2	25.0	1	25.0	1	50.0					4	19.0
	Level 4 (25.0-39.5)			1	12.5	1	25.0			1	100	1	25.0	4	19.0
	Level 5 (40.0-52.5)											2	50.0	2	9.5
	Level 6 (53.0-64.5)			1	12.5							1	25.0	2	9.5
	Level 7 (65.0-87.0)	2	100	4	50.0	1	25.0	1	50.0					8	38.1
	Total	2	100	8	100	4	100	2	100	1	100	4	100	21	100

Note: Empty cells have been left blank (except for Totals) to assist with illustrating which cells contain figures.

Another question of interest was whether individuals at the various care levels differed with regard to the functional difficulties they experienced. Table 5-9 presents means and standard deviations for each subscale and the total score by care level. Figures 5-6 and 5-7 present the information in graphic form. As shown in both Table 5-9 and Figure 5-6, clients receiving services at home have little difficulty with all of the areas at Level 1. At Level 2, they have some difficulty with IADLs. At Level 3, they have more difficulty with IADLs and some difficulty with ADLs. At Level 4, they have more difficulty with IADLs and ADLs and some difficulty with mobility. At Level 6, they have difficulty in all areas except mental functions (there were no clients in this group at Levels 5 and 7).

As shown in both Table 5-9 and Figure 5-7, clients receiving services in a facility have difficulty with mental functions at all levels. With the exception of mental functions, clients receiving services in a facility show a pattern of losses that is similar to that observed with clients receiving services at home. That is, IADLs are affected first, followed by ADLs, followed by mobility, and followed by communication. At the highest level (Level 7), all areas are affected. The findings are consistent with patterns of functional loss that are observed in non-Aboriginal populations.

It was thought that some of the subscales (e.g., Communication and IADLs) may be more sensitive than others to the developmental abilities of children. Therefore, a logistic regression was conducted to determine if location of care could be predicted using any of the subscale scores from individuals 18 years of age and older only (that is, children were excluded from the analysis). Only the Mental Functions subscale was significant, indicating that clients that had difficulties with mental functioning (particularly judgment; see Table 5-10) were more likely to be living in a facility than at home. This is consistent with the findings presented in Table 5-9 and Figure 5-7.

Table 5-9: Means and Standard Deviations for Each Subscale on the Functional Status Measure

Care Level			Activities of Daily Living	Mobility	Communication	Mental Functions	Instrumental Activities of Daily Living	Total SMAF Score
Level 1 (0-4.5)	Home	Mean	0.0	.13	.37	.07	.81	1.39
		SD	0.0	.36	.74	.27	1.29	1.53
		Number	27	27	27	27	27	27
	Facility	Mean	-	-	-	-	-	-
		SD	-	-	-	-	-	-
		Number	0	0	0	0	0	0
Level 2 (5.0-14.5)	Home	Mean	.50	.47	1.44	.35	4.79	7.56
		SD	1.00	.87	1.20	.61	2.70	2.14
		Number	17	17	17	17	17	17
	Facility	Mean	0.0	0.0	0.0	7.00	6.00	13.00
		SD	-	-	-	-	-	-
		Number	1	1	1	1	1	1
Level 3 (15.0-24.5)	Home	Mean	1.00	.83	1.50	.50	14.33	18.17
		SD	1.55	1.21	1.76	.55	2.25	2.84
		Number	6	6	6	6	6	6
	Facility	Mean	.50	.13	0.0	5.75	14.88	21.25
		SD	1.00	.25	0.0	3.86	3.84	3.77
		Number	4	4	4	4	4	4
Level 4 (25.0-39.5)	Home	Mean	6.25	3.38	.50	1.50	17.75	29.38
		SD	4.57	2.93	.58	3.00	2.63	2.81
		Number	4	4	4	4	4	4
	Facility	Mean	3.63	.13	.25	5.50	18.88	28.38
		SD	2.93	.25	.50	3.42	3.71	4.50
		Number	4	4	4	4	4	4
Level 5 (40.0-52.5)	Home	Mean	-	-	-	-	-	-
		SD	-	-	-	-	-	-
		Number	0	0	0	0	0	0
	Facility	Mean	9.75	3.25	2.00	7.50	23.50	46.00
		SD	3.18	2.47	1.41	3.54	.71	8.49
		Number	2	2	2	2	2	2
Level 6 (53.0-64.5)	Home	Mean	17.50	11.00	2.00	2.50	22.50	55.50
		SD	.71	1.41	1.41	3.54	.71	.71
		Number	2	2	2	2	2	2
	Facility	Mean	15.83	9.50	1.67	7.67	22.33	57.00
		SD	3.69	3.50	1.15	4.73	.58	6.08
		Number	3	3	3	3	3	3
Level 7 (65.0-87.0)	Home	Mean	-	-	-	-	-	-
		SD	-	-	-	-	-	-
		Number	0	0	0	0	0	0
	Facility	Mean	20.56	13.69	5.25	12.63	22.63	74.75
		SD	.90	1.58	2.66	1.69	.74	6.14
		Number	8	8	8	8	8	8

Note: Maximum possible scores are: Activities of Daily Living, 21; Mobility, 18; Communication, 9; Mental Functions, 15; Instrumental Activities of Daily Living, 24; Total, 87.

Figure 5-6: Distribution of SMAF Subscale Scores by Care Level for Clients Receiving Services at Home

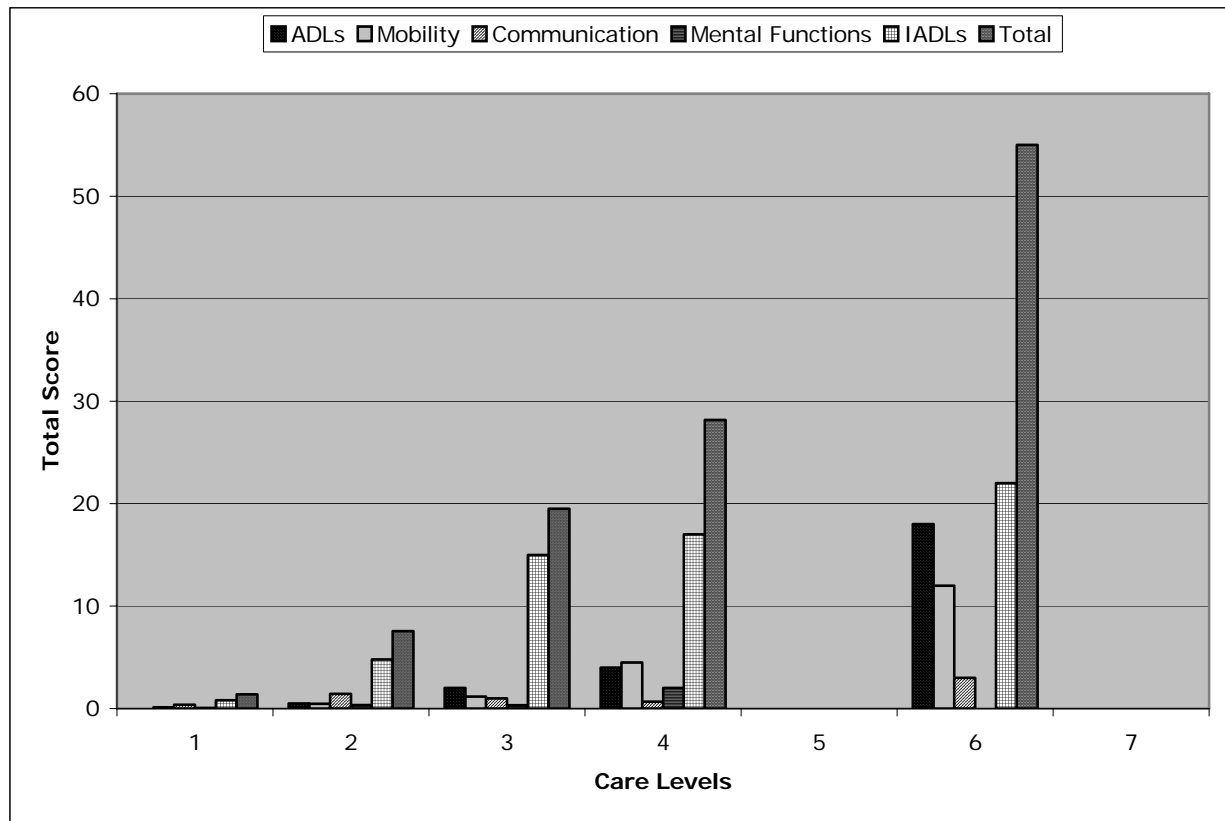


Figure 5-7: Distribution of SMAF Subscale Scores by Care Level for Clients Receiving Services in a Facility

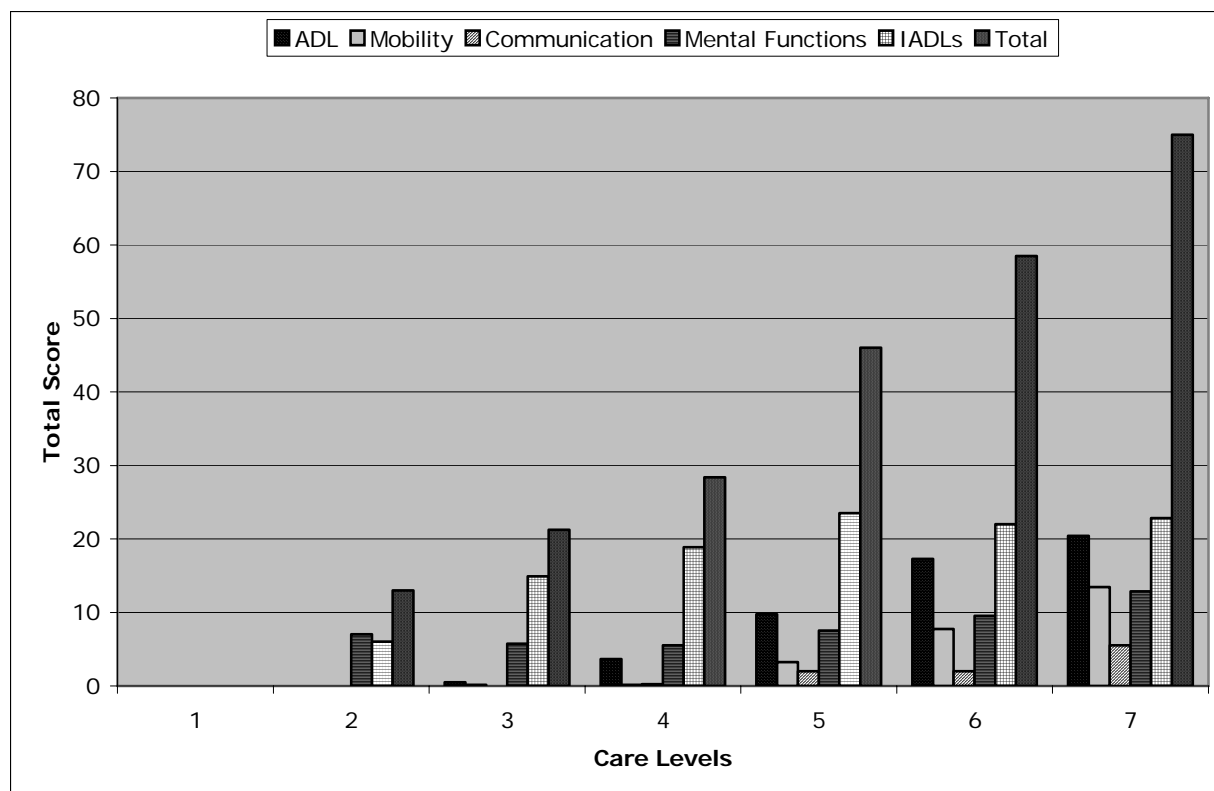


Table 5-10: Means and Standard Deviations for the Mental Functioning Items by Location of Clients

Item		Home	Facility
Memory	Mean	0.14	1.79
	Standard Deviation	0.40	0.92
Orientation	Mean	0.04	1.47
	Standard Deviation	0.20	1.22
Comprehension	Mean	0.02	1.58
	Standard Deviation	0.14	1.17
Judgment	Mean	0.04	2.32
	Standard Deviation	0.20	0.89
Behaviour	Mean	0.06	1.42
	Standard Deviation	0.24	1.07

Note: Total score possible on each item is 3. The higher the score, the poorer one's functional ability is. The findings are based on 51 clients living at home and 19 clients living in a facility.

5.4 Involvement of Proxies

As shown in Table 5-1 above, approximately 33% of the Client Interviews were completed by someone who served as a proxy for the client. Proxies were used for all but one of the clients receiving services in a facility, but for only a few of the individuals receiving services at home. In some cases, both a client and a proxy completed different sections of the Client Interview. However, in the majority of cases, one or more proxies answered the questionnaire on behalf of the client.

Proxies were asked to provide only factual information regarding the client.⁸⁶ When only proxies were used, data were not obtained for some of the questions on the Client Interview (for example, those related to satisfaction with current care services, or where one would like to obtain continuing care services in the future). Thus, data regarding some areas on the Client Interview are not available for individuals receiving services in a facility.

5.5 Housing

5.5.1 Individuals Living at Home

Clients living at home were asked a number of questions regarding their living situation. For example, clients were asked whether they rented or owned their own home. All but one client indicated that the home was owned by the Kativik Municipal Housing Corporation and that they rented the home (that is, 98.2% of clients lived in rental accommodation). As shown in Table 5-11, 24.6% of clients lived in homes that were less than five years old; another 31.6% lived in homes that were more than 15 years old. Approximately 17.5% of the clients did not know how old their home was.

The homes appeared to be in relatively good condition; 55.4% of clients indicated that only regular maintenance was required (for example, paint). An additional 32.1% indicated that minor repairs were required (for example, fixing holes in walls, fixing a broken bathtub). However, 12.5% of clients indicated that major repairs were needed (for example, fixing broken windows, fixing spots that leak when it rains). Several individuals commented that the rooms were small. Others commented that one or more rooms in the house were cold because of poor heating. Mold or mildew was present in 19.3% of the homes. The majority (83.6%) of clients felt that the main water supply in their home was safe for drinking.⁸⁷

Of the 12 individuals who indicated that modifications to their home were required because of their physical or health condition, only half indicated that the modifications had been made (usually grab bars in the bathroom and wheelchair ramps; others commented that these types of modifications were required). There appeared to be two major reasons why required repairs and modifications were not made: either people had asked for the repairs or modifications

⁸⁶ Proxies for individuals living in a facility were (mistakenly) asked to comment on various aspects of the facility. This information is discussed in more detail in the following section. Because almost all of the Client Interviews for individuals living in a facility were completed by proxies, the description of the findings does not confound information provided by clients with information provided by proxies.

⁸⁷ The houses in the study communities are in relatively good condition compared to houses in other Inuit regions.

to be made and the housing corporation had not come, or, people had not asked for the repairs/modifications.

Table 5-11: Characteristics of Home

Characteristic of Home		# of Clients	%
Age of home	Less than 1 year	1	1.8
	1 to 5 years old	13	22.8
	6 to 10 years old	3	5.3
	11 to 15 years old	12	21.1
	16 to 20 years old	11	19.3
	21 to 25 years old	2	3.5
	More than 25 years old	5	8.8
	Age unknown	10	17.5
	Total	57	100
Home in need of repairs	Yes, major repairs	7	12.5
	Yes, minor repairs	18	32.1
	No, only regular maintenance	31	55.4
	Total	56	100
Home has mold or mildew	Yes	11	19.3
	No	46	80.7
	Total	57	100
Main water supply is safe for drinking	Yes	46	83.6
	No	9	16.4
	Total	55	100

Clients were asked what resources they had available in their homes. All of the clients indicated that they had a fridge, an electric stove, electricity, home water delivery, cold running water, hot running water, a flush toilet, a septic tank or sewage system, and home garbage collection service. All but one client (1.8%) indicated they had a heating system (usually oil) and all but five clients (8.8%) indicated they had a telephone. However, external sidewalks appeared to be uncommon; only five clients (8.8%) indicated that their home had a sidewalk outside.

As shown in Table 5-12, individuals living at home generally lived in large households;⁸⁸ 38.5% of clients living at home lived with five or more other individuals (that is, in households having six or more individuals). The mean number of people living in a household was 5.2 (standard deviation = 2.3). Clients were also asked how many rooms were in their home, including the kitchen, living room, bedrooms and finished basement rooms, but not including bathrooms, halls, laundry rooms or attached sheds. Some 22.8% of clients indicated that they lived in homes that had six or more rooms. The mean number of rooms in a home was 4.9 (standard deviation = 1.0).

⁸⁸ This question was not applicable for individuals living in a facility setting.

Table 5-12: Number of People Living in Home and Number of Rooms in Home

		# of Clients	%
Number of People Living in Home	1	1	1.8
	2	6	10.5
	3	5	8.8
	4	13	22.8
	5	10	17.5
	6	6	10.5
	7	6	10.5
	8	6	10.5
	9	0	0.0
	10	4	7.0
	Total	57	100
Number of Rooms in Home	1	0	0
	2	0	0
	3	1	1.8
	4	20	35.1
	5	23	40.4
	6	8	14.0
	7	5	8.8
	Total	57	100

Table 5-13 shows the number of people living in a household as a function of the number of rooms in the house. Basavarajappa (1998, p. 13) defined overcrowding as “more than one person per room”. Using this definition, 31.6% of the clients receiving services at home lived in overcrowded homes.

Table 5-13: Number of People Living in Home by Number of Rooms in the Home

Number of People Living in Home	Number of Rooms in Home					Total	
	3	4	5	6	7		
1			1			1	1.8
2		6				6	10.5
3		5				5	8.8
4	1	5	7			13	22.8
5		2	6	1	1	10	17.5
6		2	2	1	1	6	10.5
7			4	2		6	10.5
8			1	3	2	6	10.5
10			2	1	1	4	7.0
Total	1	20	23	8	5	57	100

Note: Empty cells have been left blank (except for Totals) to assist with illustrating which cells contain figures.

5.5.2 Individuals Living in a Facility

Clients living in a facility setting were asked several questions regarding their living situation. As noted earlier, proxies generally completed the Client Interview for individuals living in a facility. As a result, *clients'* perceptions regarding some areas (such as: whether the room was safe; whether the facility was safe; ratings of the different departments; ratings of the staff; ratings of the facility; and whether the facility should be recommended) were not available. The findings from several other questions are presented below. While some of these questions relate to relatively factual information, others border on a grey area between fact and perception.

Of the 22 clients living in a facility, 54.5% shared a room with someone. In all cases, the person was not related to the client. None of the clients had a spouse or relative in an adjoining room in the facility.

In general, the facilities appeared to be in good condition; 71.4% of respondents indicated that the client's room required only regular maintenance; 23.8% indicated that the room required minor repairs; and 4.8% indicated that the room required major repairs. All of the respondents indicated that no improvements needed to be made to clients' rooms with respect to: air circulation, lighting, mirrors, taps, temperature control, noise level, and floors. However, 38.1% of respondents indicated that improvements were needed with respect to room size. For example, respondents commented that the room size should be more appropriate "for the patient's lift" and "for client transfers" and "because there are two patients in the same room".

Respondents were also asked to indicate whether modifications to clients' rooms were required because of a physical or health condition. Respondents indicated that no modifications were required with respect to: the width of doorways; handrails; or toilet height or location. Some 36.3% of respondents indicated that more space was needed in general in the clients' rooms, 27.3% of respondents indicated that bathroom modifications were required and 22.7% of respondents indicated that bathtub modifications were required. For example, one respondent noted that a "therapeutic bath would be better." It appeared that identified modifications had not been made due to financial constraints. For example, respondents noted that there is "nothing (for modifications) in the budget" and "the budget does not permit modifications".

5.5.3 Paid Health Care Providers Perceptions on the Facilities

As noted above, paid health care professionals completed the Client Interview for the majority of individuals who were living in facilities. While this meant that *clients'* perceptions of the facility setting were not available, staff's perceptions were. Since the same staff members responded for several clients, the frequency of responses is not as important as the pattern of responses.⁸⁹

Staff characteristics (such as courtesy, friendliness, helpfulness and professionalism) were generally rated as "Excellent". With the exception of activities, the various departments in the facilities (nursing, dietary, housekeeping, laundry, maintenance, and administration) were rated as "Good" or "Excellent". Social activities were generally rated as "Poor" or "Fair". For

⁸⁹ The client who responded is excluded from the following analyses.

example, respondents noted that: “(there are) no social activities”; “(the client) should be able to participate in activities in the community”; and “it is hard to find activities which would be interesting for (the client)”. On the more positive side, one respondent noted that “community elders come every day”. Several facility services, such as food, overall facilities, overall services, overall staff, and safety, were generally rated as “Good” or “Excellent”. Activities, external sidewalks and the number of visitors were generally rated as “Poor” to “Fair”. Respondents noted that: “(there are) no activities at all”; “(there are) no external sidewalks”; and “(the client) has very few visitors”. Keep in mind that respondents would have been rating themselves and/or their colleagues and their organization on all of these questions.

The majority of respondents (71.4%) indicated that they had a “Poor understanding” of the resident contribution/rent, 14.3% indicated they had a “Fair understanding” and 14.3% indicated they did not know about the contribution/rent.

Approximately 42.9% of respondents felt that the facility should offer more services, 38.1% did not feel more services were required, and 19.0% did not know if additional services were required. Respondents who felt more services should be offered noted that there was a need for physiotherapy, social and recreational activities, and specialized education (for children with special needs).

All of the respondents felt that the clients’ rooms were safe and all but one respondent felt that the facility was safe. This individual commented that “Too many people have access to the facility, especially at night”. The majority (95.2%) of respondents indicated that they would recommend the facility to others.

5.6 Availability of Caregivers

It had been anticipated, based on research conducted by Hollander et al. (2002) that approximately 86% of clients would have a family caregiver. This was not observed. Of the 57 clients living at home, 20 (35.1%) indicated they had a family caregiver. Of the 22 clients living in a facility, 1 (4.5%) indicated he/she had a family caregiver. Seven clients indicated that they had recently lost someone who used to provide them with care and support. One of these individuals indicated he/she was receiving care and support from a family caregiver (this individual is included above), two were receiving care and support from family members (but did not consider them to be family caregivers), one was receiving care and support from the formal care system and three were not receiving any care or support.

In some cases, clients indicated that they had more than one family caregiver. Together, the 21 clients who had a family caregiver identified 30 caregivers. Table 5-14 presents data regarding the family caregivers, as identified by the clients (Chapter 6 presents similar information gathered from the caregivers themselves). Some 38.1% of clients were cared for by parents, generally a mother. An additional 33.3% of clients were cared for by children; daughters provided care more frequently than sons. Spouses (all wives) provided care to 23.8% of the clients. Thus, consistent with the non-Aboriginal caregiving literature, females tend to provide informal care more frequently than males.

Clients were asked how long they had been receiving help or support from their family caregiver. Of the 17 individuals who responded to this question, 14 (82.3%) had been receiving care and/or support for more than two years.

Clients were asked how far away their main/primary family caregiver lived. Of the 19 individuals who responded to this question, 78.9% indicated that the caregiver lived in the same house; the remaining 21.1% indicated the caregiver lived in the same community.

Table 5-14: Characteristics of Family Caregivers as Identified by Clients

Characteristic		#	%
Relationship of family caregiver to Client	Spouse	5	23.8*
	Child (including in-laws)	7	33.3
	Sibling (including in-laws)	3	14.3
	Parent	8	38.1
	Grandchildren	3	14.3
	Other relative	1	4.8
	Friend	1	4.8
	Neighbour	1	4.8
	Other	1	4.8
Length of time client has been receiving help/support from family caregiver	Less than 1 year	2	11.8**
	1 to 2 years	1	5.9
	More than 2 years but less than 5 years	5	29.4
	More than 5 years	9	52.9
	Total	17	100
Distance main/primary family caregiver lives from client	In the same house	15	78.9**
	Very close	0	0
	In the same community	4	21.1
	Far away	0	0
	Total	19	100

* Percentages are based on the number of clients who indicated they had a family caregiver (n=21).

** Percentages are based on the total number of clients who responded.

5.7 Use of Health Related Services

Clients were asked several questions regarding their use of health related services. Many of these questions were included in order to gain an understanding of costs associated with the provision of continuing care services. Issues regarding the *use* of health related services are discussed in this chapter. Issues related to *costs* associated with the health related services are discussed in Chapter 7.

Clients were asked if they required assistance with several activities, and if so, who provided the assistance. If the assistance was provided by family caregivers, clients were asked how much of the assistance was due to their *increased* need for care.⁹⁰ Finally, clients were asked if they required any additional assistance.

⁹⁰ In continuing care studies which consider costs, it is important to distinguish between the assistance that is provided because of a family relationship, and the assistance that is provided because of an individual's health condition. The former does not have costing implications while the latter does.

Table 5-15 identifies the activities clients received assistance with, and who provided the assistance, by location. Clients could indicate that more than one individual provided them with assistance. Overall, the three most frequently provided activities were: assistance with obtaining medical equipment, medical supplies and medications; assistance with coordinating and arranging medical appointments and health services; and assistance with identifying professionals who can provide services and/or medical equipment.

For clients receiving services at home, the three most frequently provided activities were: obtaining medical equipment, medical supplies and medications; assistance with coordinating and arranging medical appointments and health services; assistance with house maintenance and chores outside; and house maintenance inside.

For clients receiving services in a facility, the most frequently provided activities were: assistance with financial tasks; assistance with identifying professionals who can provide services and/or medical equipment; assistance with coordinating and arranging medical appointments and health services; and assistance with obtaining medical equipment, medical supplies and medications (nursing and/or medical care was fifth on the list).

Consistent with findings reported above, clients living at home receive services from family caregivers; clients living in a facility receive assistance from multiple paid caregivers. Considering only those individuals who received assistance with one or more tasks, family caregivers provided a lot of assistance with house maintenance (both inside and outside) while formal care providers provided a lot of assistance with mobility and communication.

Clients who indicated that they received assistance from a family caregiver were also asked how much of the assistance was provided because of their increased need for care. The findings from this question are presented in Table 5-16. The findings should be interpreted cautiously, however, as there were several individuals who indicated they did not know how much of the assistance they were receiving was due to their increased need for care. For the most part, clients do not seem to feel that the assistance they receive from family caregivers is due to their increased need for care.

There are at least three explanations for this finding. First, many clients may not have understood the question, given their difficulties in understanding what was meant by “family caregiver”. Second, clients may have understood the question, but may have been reluctant to indicate that their health condition(s) was (were) getting worse and they needed assistance. Third, clients may normally receive a large amount of assistance because of family relationships.

Table 5-15: Assistance Provided to Clients by Location

Activities	Assistance Provided							Who Provides Assistance (if provided)*			
		Yes		No		Total		Family Caregiver		Formal Care System**	
		#	%	#	%	#	%	#	%	#	%
Eating, meal planning, meal preparation	Home	10	33.3	47	95.9	57	72.2	9	30.0	1	3.3
	Facility	20	67.7	2	4.1	22	27.8	0	0.0	38	126.7
	Total	30	100	49	100	79	100	9	30.0	39	130.0
Personal care (e.g., bathing, dressing, toileting)	Home	13	41.9	44	91.7	57	72.2	8	25.8	4	12.9
	Facility	18	58.1	4	8.3	22	27.8	0	0.0	33	106.5
	Total	31	100	48	100	79	100	8	25.8	37	119.4
Communication (e.g., vision, being understood by others)	Home	9	34.6	48	90.6	57	72.2	7	26.9	1	3.8
	Facility	17	65.4	5	9.4	22	27.8	0	0.0	34	130.8
	Total	26	100	53	100	79	100	7	26.9	35	134.6
Financial tasks (e.g., budgeting, bill payments, completing forms)	Home	14	38.9	42	100	56	71.8	11	30.6	2	5.6
	Facility	22	61.1	0	0	22	28.2	0	0.0	32	88.9
	Total	36	100	42	100	78	100	11	30.6	34	94.5
Light housekeeping and home maintenance (e.g., light cleaning, laundry)	Home	19	73.1	38	74.5	57	74.0	13	50.0	6	23.1
	Facility	7	26.9	13	25.5	20	26.0	0	0.0	10	38.5
	Total	26	100	51	100	77	100	13	50.0	16	61.6
House maintenance inside (e.g., heavier cleaning, painting)	Home	20	76.9	35	72.9	55	74.3	13	50.0	8	30.8
	Facility	6	23.1	13	27.1	19	25.7	0	0.0	9	34.6
	Total	26	100	48	100	74	100	13	50.0	17	65.4
House maintenance and chores outside (e.g., shoveling snow)	Home	22	78.6	34	72.3	56	74.7	10	35.7	12	42.9
	Facility	6	21.4	13	27.7	19	25.3	0	0.0	6	21.4
	Total	28	100	47	100	75	100	10	35.7	18	64.3
Mobility inside the house/facility (e.g., walking inside)	Home	4	22.2	53	86.9	57	72.2	3	16.7	1	5.6
	Facility	14	77.8	8	13.1	22	27.8	0	0.0	28	155.6
	Total	18	100	61	100	79	100	3	16.7	29	161.2
Mobility outside the house/facility (e.g., getting to other places)	Home	9	37.5	48	88.9	57	73.1	8	33.3	2	8.3
	Facility	15	62.5	6	11.1	21	26.9	0	0.0	30	125.0
	Total	24	100	54	100	78	100	8	33.3	32	133.3
Nursing or medical care (e.g., foot care, medications)	Home	15	41.7	42	97.7	57	72.2	11	30.6	6	16.7
	Facility	21	58.3	1	2.3	22	27.8	0	0.0	37	102.8
	Total	36	100	43	100	79	100	11	30.6	43	119.5
Identifying professionals who can provide services and/or medical equipment	Home	17	43.6	39	100	56	71.8	12	30.8	7	17.9
	Facility	22	56.4	0	0	22	28.2	0	0.0	26	66.7
	Total	39	100	39	100	78	100	12	30.8	33	84.6
Coordinating and arranging medical appointments and health services	Home	25	53.2	32	100	57	72.2	12	25.5	18	38.3
	Facility	22	46.8	0	0	22	27.8	0	0.0	27	57.4
	Total	47	100	32	100	79	100	12	25.5	45	95.7
Obtaining medical equipment, medical supplies and medications	Home	29	56.9	28	100	57	72.2	11	21.6	24	47.1
	Facility	22	43.1	0	0	22	27.8	0	0.0	30	58.8
	Total	51	100	28	100	79	100	11	21.6	54	105.9
Obtaining traditional healer/traditional medicines	Home	1	6.7	45	100	46	76.7	1	6.7	0	0
	Facility	14	93.3	0	0	14	23.3	0	0.0	0	0
	Total	15	100	45	100	60	100	1	6.7	0	0

* Different individuals may receive assistance with different tasks. Thus, while the number of individuals receiving assistance may be the same, it may not be the same individuals making up the total.

** Percentages based on the number of individuals receiving assistance. Numbers greater than 100 indicate that the client received assistance from multiple individuals.

Table 5-16: Client's Perceptions of Amount of Help Provided by Family Caregivers Because of the Client's Increased need for Care

Activity	Amount of Help Provided									
	None		A little		A lot		All/Almost All		Total	
	#	%*	#	%	#	%	#	%	#	%
Eating	5	55.6	1	11.1	0	0.0	3	33.3	9	100
Personal care	4	50.0	1	12.5	0	0.0	3	37.5	8	100
Communication	4	57.1	0	0.0	1	14.3	2	28.6	7	100
Financial tasks	7	63.6	1	9.1	1	9.1	2	18.2	11	100
Light housekeeping	8	72.7	1	9.1	1	9.1	1	9.1	11	100
House maintenance inside	8	72.7	1	9.1	1	9.1	1	9.1	11	100
House maintenance and chores outside	6	75.0	1	12.5	0	0.0	1	12.5	8	100
Mobility inside house	2	66.7	0	0.0	0	0.0	1	33.3	3	100
Mobility outside house	4	57.1	2	28.6	0	0.0	1	14.3	7	100
Nursing or medical care	8	66.7	2	16.7	1	8.3	1	8.3	12	100
Identifying professionals	9	75.0	1	8.3	0	0.0	2	16.7	12	100
Coordinating and arranging medical care	9	75.0	1	8.3	1	8.3	1	8.3	12	100
Obtaining medical equipment, medical supplies and medications	9	81.8	0	0.0	0	0.0	2	18.2	11	100
Obtaining traditional healer/traditional medicines	1	100	0	0.0	0	0.0	0	0	1	100

* Percentages throughout the table are based on the number of individuals who responded to this question (that is, the values in the Total column).

5.8 Clients' Satisfaction with Health Related Services

5.8.1 Clients' Satisfaction with Services Provided by Family Caregivers

As noted above, 21 clients indicated that they had a family caregiver. These clients were asked several questions regarding the support provided by their family caregivers.⁹¹ Proxies were not asked these questions. The findings are summarized in Table 5-17. Clients felt that they were supported by their family caregivers most of the time. Only one client indicated that he/she paid for services most of the time and this individual indicated that he/she could almost or almost always afford to pay.

5.8.2 Clients' Satisfaction with Services Provided by the Formal Care System

Clients were asked several questions regarding the continuing care services they received from the formal care system. Proxies were not asked these questions. The first question was similar to that asked of clients who had a family caregiver. The findings are presented in Table 5-18. In general, clients felt supported by the formal care system most of the time.

Satisfaction with formal care services was also assessed using questions that addressed clients' satisfaction with the services received, worker characteristics and care concerns. The findings are presented in Table 5-19. The findings indicated that clients are very satisfied with workers and are generally satisfied with how their care needs are met. However, they also

⁹¹ Proxies were not asked these questions.

indicated that they had little input into what care services were provided, who provided them, and when the services were provided. It is not part of Inuit culture to complain about services that are available. Inuit are generally happy with what they receive. However, this does not mean that additional services are not required; only that Inuit may not request the services.⁹²

Table 5-17: Clients' Satisfaction with Care and Support Provided by Family Caregivers

Question	Rating	#	%
Do you receive the care/service you need often enough?	Sometimes	6	28.6
	Always/Almost always	15	71.4
	Total	21	100
Is the care you need available at the time you need it?	Sometimes	3	14.3
	Always/Almost always	18	85.7
	Total	21	100
Is the length of time that you receive the care long enough?	Sometimes	2	10.5
	Always/Almost always	17	89.5
	Total	19	100
Is the care you receive provided by the right person?	Sometimes	3	14.3
	Always/Almost always	18	85.7
	Total	21	100
Do the people who provide you with care respect, understand and listen to you?	Sometimes	2	9.5
	Always/Almost always	19	90.5
	Total	21	100
Are the people who provide you with care sensitive to your needs, beliefs and practices?	Sometimes	2	9.5
	Always/Almost always	19	90.5
	Total	21	100
Do you receive care from someone you feel comfortable with?	Sometimes	2	9.5
	Always/Almost always	19	90.5
	Total	21	100
Does your family feel it is their responsibility to look after you?	Never	0	0.0
	Sometimes	3	14.3
	Always/Almost always	18	85.7
	Total	21	100

⁹² E. Klimczak and R. Grey, personal communication, February, 2006.

Table 5-18: Client's Perceptions of the Care and Support Provided by the Formal Care System

Question	Rating	#	%
Do you receive the care/service when you need it?	Never	0	0.0
	Sometimes	7	22.6
	Always/Almost always	24	77.4
	Total	31	100
Is the care you need available at the time you need it?	Never	1	3.2
	Sometimes	8	25.8
	Always/Almost always	22	71.0
	Total	31	100
Is the length of time that you receive the care long enough?	Never	0	0.0
	Sometimes	4	13.8
	Always/Almost always	25	86.2
	Total	29	100
Do the people who provide you with care respect, understand and listen to you?	Never	1	3.2
	Sometimes	1	3.2
	Always/Almost always	29	93.5
	Total	31	100
Are the people who provide you with care sensitive to your needs, beliefs and practices?	Never	0	0.0
	Sometimes	2	6.9
	Always/Almost always	27	93.1
	Total	29	100
Do you receive care from someone you feel comfortable with?	Never	0	0.0
	Sometimes	4	13.3
	Always/Almost always	26	86.7
	Total	30	100
Is it easy to access the care/service you need?	Never	1	3.3
	Sometimes	6	20.0
	Always/Almost always	23	76.7
	Total	30	100
How often do you pay for this care?	Never	30	96.8
	Sometimes	0	0.0
	Always/Almost always	1	3.2
	Total	31	100
Are you satisfied with where the services are provided (e.g., inside your home, outside your home, outside of the community)?	Never	0	0.0
	Sometimes	6	20.0
	Always/Almost always	24	80.0
	Total	30	100

Table 5-19: Clients' Satisfaction with Formal Care Services

Subscale	Question			#	%
Satisfaction with services	How often do you have a say in	who will provide you with services?	Never	14	56.0
			Sometimes	6	24.0
			Always	5	20.0
			Total	25	100
		what services are provided?	Never	9	36.0
			Sometimes	7	28.0
			Always	9	36.0
			Total	25	100
		when services are provided?	Never	11	44.0
			Sometimes	7	28.0
			Always	7	28.0
			Total	25	100
Satisfaction with workers	How often would you say that workers	are easy to get along with?	Never	0	0
			Sometimes	2	7.7
			Always	24	92.3
			Total	26	100
		come when you expect them to?	Never	1	4.3
			Sometimes	2	8.7
			Always	20	87.0
			Total	23	100
		are polite and courteous?	Never	0	0
			Sometimes	2	7.7
			Always	24	92.3
			Total	26	100
		respect you, understand you and listen to you?	Never	0	0
			Sometimes	2	7.7
			Always	24	92.3
			Total	26	100
		do a good job; one that meets your standards?	Never	0	0
			Sometimes	2	7.7
			Always	24	92.3
			Total	26	100
		are willing to help you with things they are not expected to, but which you might need?	Never	0	0
			Sometimes	3	12.0
			Always	22	88.0
			Total	25	100
		know when to assist and when to let you do things yourself?	Never	0	0
			Sometimes	4	16.0
			Always	21	84.0
			Total	25	100
		are skillful in teaching you to look after some of your own needs?	Never	0	0
			Sometimes	3	12.5
			Always	21	87.5
			Total	24	100
		speak the language(s) with which you are most comfortable?	Never	1	3.8
			Sometimes	7	26.9
			Always	18	69.2
			Total	26	100

Subscale	Question		#	%*	
Satisfaction with care concerns	How often	does the same person come to provide you with help	Never	0	0
			Sometimes	7	36.8
			Always	12	63.2
			Total	19	100
		do you receive adequate notice of a change when someone else will come to help you?	Never	5	27.8
			Sometimes	3	16.7
			Always	10	55.6
			Total	18	100
		does the helper know if there are any changes in the kind of care he/she should be providing?	Never	1	6.7
			Sometimes	4	26.7
			Always	10	66.7
			Total	15	100
		is family involved in the planning of all the care you receive?	Never	5	25.0
			Sometimes	5	25.0
			Always	10	50.0
			Total	20	100

Clients and proxies were asked whether clients had experienced difficulties in receiving services in several different areas during the last year. The findings are presented in Table 5-20. Clients did not appear to have difficulty with any services, other than arranging transportation. Clients were also asked whether they had experienced difficulties in affording several services (for example, transportation costs; medication, medical supplies and medical equipment; direct cost of care/service; and childcare costs) in the last year. However, because of the way continuing care services are provided in the region, these questions were not applicable (see Chapter 7 for more information).

5.8.3 Satisfaction with Services Provided Outside of the Community

Clients were asked if they had been referred for services outside the community, and if so, if they were satisfied with the care they received. Nine clients indicated that they had been referred for services. Of these, eight (88.9%) indicated they were satisfied with the care they received. The client who was dissatisfied was sent back to the community before he/she had received care.

Table 5-20: Difficulties in Receiving Services in Last Year

Difficulties		Home		Facility		Total	
		#	%	#	%	#	%
Arranging transportation	Yes	5	13.5	1	4.8	6	10.3
	No	32	86.5	20	95.2	52	89.7
	Total	37	100	21	100	58	100
Getting traditional care	Yes	0	0.0	1	100	1	11.1
	No	8	100	0	0.0	8	88.9
	Total	8	100	1	100	9	100
Receiving respect, being understood or listened to	Yes	4	10.8	0	0.0	4	7.1
	No	33	89.2	19	100	52	92.9
	Total	37	100	19	100	56	100
Obtaining spiritual care/support	Yes	0	0.0	1	16.7	1	5.0
	No	14	100	5	83.3	19	95.0
	Total	14	100	6	100	20	100
Obtaining services in client's area	Yes	0	0.0	2	10.0	2	3.5
	No	37	100	18	90.0	55	96.5
	Total	37	100	20	100	57	100
Obtaining services when needed	Yes	0	0.0	0	0.0	0	0.0
	No	36	100	20	100	56	100
	Total	36	100	20	100	56	100

5.8.4 Refusal of Services

Clients and proxies were asked if clients had refused any treatment or service in the last year. Of the 77 clients who responded to this question, seven (9.1%; three living at home and four living in a facility) indicated that they had refused treatments and/or services in the last year. The individuals who completed the Functional Status measure on behalf of the clients were also asked if a client had refused any treatments or services in the past year. Of the 78 respondents, 66 (84.6%) indicated that the client had not refused care or services, 5 (6.4%) indicated that the client had refused care or services occasionally, 3 (3.8%) indicated that the client had refused care or services several times and 4 (5.1%) indicated that they did not know whether clients had refused treatment or services. These respondents indicated that clients refused treatment or services because: the client hated injections; the client was tired of relying on medication; the client would like to be living outside of the facility; the client felt he/she was able to do things on his/her own; and the client's family provided assistance. While the total number of self-identified and respondent-identified individuals who had received services in the past year was similar, only five clients were identified as having refused services by both groups of respondents.

Clients and proxies were also asked if clients had been refused any treatment or service in the last year. Of the 77 clients who responded to this question, 3 (3.9%) indicated that they had been refused treatment or service. Only one of these individuals provided a reason for the refusal, namely, that the treatment/service required could not be provided where the client wished.

5.9 Perceptions of Health and Quality of Life

Clients were asked a number of questions regarding their perceived health and quality of life. Proxies were not asked these questions. With the exception of two individuals, the findings reflect the perceptions of clients living at home; perceptions of individuals living in facilities were generally not included.

Clients were asked what things affected their health. Clients could identify more than one item. Of the 39 clients who provided a response to this question (see Table 5-21), 25.6% indicated that their health was affected by physical, emotional, mental and spiritual balance, 20.5% indicated it was affected by stress/worry related to medications and 17.9% indicated that their health was affected by emotional well-being. Nine individuals indicated that “Other” things affected their health. These things, none of which was reported more than once, included: old age, an old injury, not having a job, and not being invited to go fishing. In addition, 15.4% of clients indicated that nothing affected their health.

Table 5-21: Things That Are Perceived to Affect a Client’s Health

Item	#	%*
Diet	5	12.8
Stress/worry related to medication(s)	8	20.5
Stress/worry related to financial issues	3	7.7
Stress/worry related to personal bereavement	1	2.6
Stress/worry related to community bereavement	0	0
Stress/worry related to involuntary separation from spouse	0	0
Social supports	2	5.1
Lack of proper sleep/rest	5	12.8
Emotional well-being	7	17.9
Lack of exercise/activity	2	5.1
Physical, emotional, mental, and spiritual balance	10	25.6
Other	9	23.1
Nothing	6	15.4
Total number of individuals	39	N/A

Note: Percentages based on the number of individuals who responded to this question. Clients could provide multiple responses.

Clients were also asked to rate their overall health. Of the 52 individuals who responded to this question (50 clients living at home, 2 clients living in a facility), 7.7% rated their health as “Very Good”, 42.3% rated it as “Good”, 36.5% rated it as “Fair” and 13.5% rated it as “Poor”.

Clients’ perceptions of their quality of life were assessed using three questions: “What things make you happy?”, “What things make you unhappy?” and “In general, would you say you are happy with your life?”.

Overall, 51 clients provided an indication of the things that make them happy and the things that make them unhappy. Clients could provide multiple responses to both of these questions. A total of 42 different responses were provided to the question “What things make you happy?” Because many of these responses were only provided once or twice, the responses were regrouped into 11 categories. A total of 31 different responses were provided to the

question “What things make you unhappy?” Again, because many of the responses were only provided once or twice, they were regrouped into nine categories. All of the responses to both questions are provided in Appendix F. The findings from both questions are summarized in Table 5-22. The things that make people the happiest are: outdoor activities; being with other individuals (including family and friends); and leisure activities (such as playing cards, watching TV and playing bingo). The things that make people the saddest are: drug and/or alcohol use (for example, people drinking alcohol); negative family issues (such as the grandchildren being taken away); and noise (such as noise at night).

The majority (96.1%) of clients indicated they were generally happy with their life. Respondents noted that: “I am happy to be well and satisfied (with) how I live”; “My daughter-in-law is less unhappy and more calm in her life and that makes me happy”; and “This past summer, my life has gone a lot better”.

Table 5-22: Things That May Influence Clients Well-Being

	Item	#	%*
Things That Make Clients Happy	Being with family (e.g., family being together)	8	9.8
	Being with others (e.g., being with friends)	12	14.6
	Outdoor activities (e.g., camping, hunting, fishing)	29	35.6
	Craft-related activities (e.g., sewing, carving)	6	7.3
	Sports (e.g., playing ice hockey)	2	2.4
	Leisure activities (e.g., playing cards)	10	12.2
	Quiet activities (e.g., being quiet)	2	2.4
	Good health (e.g., being well)	7	8.5
	Satisfaction with health-related services and programs	2	2.4
	Working	1	1.2
	Miscellaneous	3	3.7
	Total	82	100
Things That Make Clients Unhappy	Family issues (e.g., grandchildren taken away)	8	15.7
	Financial issues (e.g., debts)	4	7.8
	Emotional issues (e.g., feeling unwanted)	4	7.8
	Poor health (e.g., not mobile enough to go camping)	5	9.8
	Drug and/or alcohol use	13	25.5
	Noise (e.g., awakened by people arguing)	6	11.8
	Violence (e.g., violence within the community)	5	9.8
	Deaths	4	7.8
	Miscellaneous	2	3.9
	Total	51	100
Things That Influence Clients' Health and/or Life	Spiritual beliefs/values ⁹³	16	50.0
	Being with others	2	6.3
	Emotional aspects (both positive and negative)	5	15.6
	Problems with health and/or social services	2	6.3
	Leisure activities	1	3.1
	Nothing – everything's okay	6	18.9
	Total	32	100

*Percentages based on the number of responses. Clients could provide multiple responses.

⁹³ These included both a general statement regarding spiritual beliefs and/or values, as well as visits from a minister or attending church.

Clients were asked “How do your personal, cultural and spiritual beliefs and values influence your health and your life?” This seemed to be a difficult question to understand and/or answer, as the individuals who provided responses did not answer the question *per se*. Rather, they appeared to answer a question more along the line of “What things influence your health and your life?” As with the happy/unhappy questions discussed above, 29 people provided several different responses, many of which were only provided once or twice. People could provide multiple responses. The responses were recategorized into six categories (see Table 5-22); the original responses are presented in Appendix F. Spiritual beliefs and/or values were identified most frequently as having a major effect on people’s health and/or lives.

5.10 Preferences for Services

As shown in Table 5-23, clients were asked several questions regarding their preferences for services. For example, clients were asked “If you had complete choice for your living situation, what kind of housing situation would you prefer?” As proxies were not asked this question, the findings primarily reflect the perceptions of individuals living at home. Clients could provide more than one response. Of the 53 clients who responded to this question (51 living at home and 2 living in a facility), 60.4% indicated that they would prefer to live in their own home and 43.4% indicated they would prefer to live in the home of a family member. One might think that clients who were already living in a facility setting would prefer a facility rather than another housing option. This was not observed; of the two clients living in a facility who answered this question, both indicated they preferred to live in their own home; one also indicated he/she would be comfortable living in an elders/seniors home.

Clients were asked where they would prefer to live – either in their own community or where services could be accessed easily, even if it meant living outside of their community. Of the 53 clients who responded to this question, 96.2% indicated that they would prefer to live in their own community, 1.9% indicated that they would prefer to live where services could be accessed easily and 1.9% indicated that they would prefer to live in another community (where family members live).

Clients were also asked from whom they would prefer to receive care and/or support. Clients could provide more than one response. Of the 53 clients who responded to this question, 75.5% indicated they would prefer to receive care from a family member and 50.9% indicated they would prefer to receive care from the formal care system.

Clients were asked if they felt there was a need for other housing options in their community. Proxies were not asked this question. Of the 53 individuals who responded to this question, 60.4% indicated that there was a need for other housing options, 24.5% indicated that there was no need for other housing options, and 13.2% indicated they did not know. Clients were also asked if they were aware of other housing options. Some 56.7% indicated they were aware of other housing options; 37.7% indicated they were not aware of other housing options. Clients were not asked to identify what these other housing options might be. Several respondents noted that there was a need for additional housing in the community: “In our community we are always short of houses”; “(There is) not enough houses in town.” Some respondents commented on the social consequences of not having enough housing: “Family

houses are crowded resulting in overnight living within the community”; “If there is more housing in our community maybe there would be less violence among close families”.

Several respondents commented on the need for appropriate housing:

- “(Housing should be) appropriate for handicapped persons or others with special needs.”
- “(It) would be nice if there (were housing) available for others who do not get help at home.”
- “(There is a need for an) elders home and daycare services.”
- “(There is a need for a) facility with services for old people.”

Table 5-23: Clients’ Preferences for Services

Question		#	%*
What kind of housing situation would you prefer?	Living in own home	32	60.4
	Living in the home of a family member	23	43.4
	Living in a personal care home	3	5.7
	Living in an elders/seniors home	4	7.5
	Living in a group home	0	0
	Living in a facility or institutional setting	0	0
Where would you prefer that housing be available?	In own community	51	96.2
	Where services can be easily accessed	1	1.9
	Other	1	1.9
Who would you prefer to receive care/support from?	Family members	40	75.5
	Friends	3	5.7
	Formal care system	27	50.9
	Other	1	1.9

* Based on the total number of respondents (n=53; 51 living at home, 2 living in a facility). Clients could provide multiple responses.

Clients were asked two questions regarding their preferences for care and services in the future; proxies were not asked these questions. One question related to the need for services if one’s health deteriorates, the other related to palliative/end-of-life care. Clients could provide more than one response to each question.

Overall, 41 clients (39 living at home, 2 living in a facility) provided 55 responses to the question regarding a deterioration in his/her health condition. Fifteen different responses were received. Thirty-six clients (35 living at home, 1 living in a facility) provided 51 responses regarding palliative/end-of-life care. A total of 13 different responses were received. Since several of the responses to both questions only occurred once or twice, the responses were recategorized (see Table 5-24); the original responses for both questions are presented in Appendix G.

Clients appeared to respond to parts of the questions. For example, a client may have provided a response regarding where he/she would like to receive services, but not what the services should entail. The responses appeared to cluster into three groups: clients’ preferences

for where services would be provided; their preferences for whom should provide the services; and their preferences for the services that are provided. Similar findings were obtained for both questions. Approximately 70% of the clients preferred to receive services in a home or community setting, while approximately another 25% preferred to receive services in a hospital. Clients indicated a preference for care to be provided by family members rather than the formal care system.

Table 5-24: Future Requirements

Question			#	%
If your health deteriorates, what would you want to do about the services and care you receive and where you receive them?	Location of Service	Home or community setting	28	68.3
		Elder's home	2	4.9
		Hospital	10	24.4
	Service Provided by	Family	4	9.8
		Formal care system	2	4.9
		Other	3	7.3
	Type of Service	Basic needs (e.g., food, water)	2	4.9
		What was provided previously	2	4.9
		Be well taken care of	2	4.9
	Total number of respondents*		41	N/A
In the future, if you require palliative/end-of-life care, what would you want to do about the services and care you receive and where you receive them?	Location of Service	Home or community setting	26	72.2
		Hospital or health centre	10	27.8
	Service Provided by	Family	5	13.9
		Formal care system	3	8.3
	Type of Service	Basic needs (e.g., food, water)	3	8.3
		Available 24 hours	1	2.8
		Fair treatment	1	2.8
		Communication with family regarding treatment	1	2.8
		No excessive treatment	1	2.8
	Total number of respondents*		36	N/A

* Percentages based on the number of respondents. Clients could provide multiple responses.

5.11 Summary

A total of 79 individuals who were receiving continuing care services either at home or in a facility participated in the study. A functional status measure, which is part of Québec's provincial continuing care assessment tool, was used to determine care levels. The findings indicated that the majority of home care clients were in the low to moderate levels (indicating higher levels of functioning) and that the facility clients were in the moderate to high levels (indicating lower levels of functioning). While the home care clients covered the full age range (from 0 to 80 years and older), approximately half of the facility clients were under the age of 35.

Both home and facility clients received assistance with case management like activities, namely assistance with obtaining medical equipment, medical supplies and medications, assistance with coordinating and arranging medical appointments and health services, and assistance with identifying professionals who can provide services and/or medical equipment. Less than half of the clients indicated that they received assistance from family caregivers. In general, clients were satisfied with the continuing care services they were receiving. It is

cautioned, however, that this finding should not be interpreted as indicating that no additional services are required.

Overall, half of the clients rated their health as “Very Good” or “Good”. The three things most frequently reported as affecting an individual’s health were: physical, emotional, mental and spiritual balance; stress/worry related to medications; and emotional well-being. Spiritual beliefs and/or values were identified most frequently as having a major effect on people’s health and/or lives. Clients were asked what things made them happy and what things made them unhappy. The things that make people the happiest are: outdoor activities; being with other individuals; and leisure activities, such as playing bingo. The things that make people the saddest are: drug and/or alcohol use; negative family issues; and noise.

Over 96% of clients indicated that they would prefer to receive continuing care services in their own community. Over 60% of clients indicated that they would prefer to receive services in their own home and 43% indicated they would prefer to receive in the home of a family member.⁹⁴ Over 75% of clients indicated they would prefer to receive care from a family member. Another 51% indicated they would prefer to receive care from the formal care system.⁹⁵ Over 60% of clients indicated that there was a need for other housing options. Some respondents note that there was need for additional housing in general in the communities. Other respondents commented on the need for appropriate housing. When asked where they would prefer to receive care and services in the future, approximately 70% of the clients indicated that they would prefer to receive services in a home or community setting. Approximately 25% of the clients indicated that they would prefer to receive services in a hospital.

⁹⁴ Some clients provided more than one response to this question.

⁹⁵ Again, some clients provided more than one response to this question.

6. FINDINGS FOR CAREGIVERS

6.1 Introduction

This chapter presents findings from the Caregiver Interview. As noted earlier, one of the questions of interest in this study was the extent to which clients' and caregivers' perceptions of the client's continuing care needs were the same. Thus, several sections on the Caregiver Interview were similar to sections on the Client Interview. In addition, several questions were asked about the impact providing care is having on the caregiver. Information is provided about: caregiver demographics; the types of care both family caregivers and the formal care service provide to clients; clients' use of health services from the caregivers' perspective; caregivers' satisfaction with the services clients receive; caregivers' preferences for where clients receive services in the future; and the impact of caregiving on the caregiver. Although the primary interest had been on family caregivers, the involvement of so many formal care providers enabled a number of unanticipated comparisons to be made.

6.2 Demographics

Based on previous research conducted by Hollander et al. (2002), it had been anticipated that approximately 86% of the clients would report having a family caregiver.⁹⁶ This was not observed. A total of 38 caregivers, representing 48% of the clients, participated in the study. Based on discussions with the Inuit study representatives, it had been anticipated that there would be a mixture of caregivers – family caregivers, family care aides (who are paid through the formal care system to provide the types of care and support family members may provide), and formal care providers (which include a variety of health care personnel).⁹⁷ This was supported: the caregivers included 14 family caregivers (all of whom provided care to individuals living at home), 2 family helpers/social aides (who also provided care to individuals living at home), and 22 formal caregivers (all of whom provided care to individuals living in a facility). Because the family care aides are paid through the formal care system, they were generally included with the other formal caregivers in the analyses reported below.

Table 6-1 presents demographic information on the caregivers. Over 92% of caregivers, whether they were family caregivers or formal caregivers, were female. The majority (84.2%) of caregivers were less than 45 years of age. None of the caregivers was less than 18 years of age or over 74 years of age; only 7.9% of caregivers were over 55 years of age, even for those clients who are receiving care at home.

⁹⁶ Note that the term family caregiver as used in this study is similar to the term informal caregiver used in the Hollander et al. study. In both cases, the term refers to family members and others who provide care and support to the clients.

⁹⁷ Formal care providers included physicians, nurses, therapists, personal care workers, dietary workers, and housekeeping workers.

Table 6-1: Description of the Caregiver Sample

Characteristic		Client Living at Home				Client Living in a Facility		Total	
		Family Caregivers		Formal Caregivers		Formal Caregivers ⁹⁸			
		#	%	#	%	#	%	#	%
Gender	Male	1	7.1	0	0.0	2	9.1	3	7.9
	Female	13	92.9	2	100	20	90.9	35	92.1
	Total	14	100	2	100	22	100	38	100
Age	18-24	1	7.1	0	0.0	5	22.7	6	15.8
	25-34	4	28.6	0	0.0	9	40.9	13	34.2
	35-44	4	28.6	2	100	7	31.8	13	34.2
	45-54	2	14.3	0	0.0	1	4.5	3	7.9
	55-64	2	14.3	0	0.0	0	0.0	2	5.3
	65-74	1	7.1	0	0.0	0	0.0	1	2.6
	75+	0	0.0	0	0.0	0	0.0	0	0.0
	Total	14	100	2	100	22	100	38	100
Language Spoken ⁹⁹	English	6	42.9	1	50.0	22	100	29	76.3
	French	1	7.1	0	0.0	17	77.3	18	47.4
	Inuktitut	14	100	2	100	18	81.8	34	89.5
Language Understood ¹⁰⁰	English	8	57.1	2	100	22	100	32	84.2
	French	2	14.3	0	0.0	17	77.3	19	50.0
	Inuktitut	14	100	2	100	18	81.8	34	89.5
Language Used Most Often on a Daily Basis	English	0	0.0	0	0.0	2	9.1	2	5.3
	French	0	0.0	0	0.0	2	9.1	2	5.3
	Inuktitut	13	92.9	2	100	5	22.7	20	52.6
	More than one language equally	1	7.1	0	0.0	13	59.1	14	36.8
	Total	14	100	2	100	22	100	38	100
Education Level	No formal schooling	2	14.3	0	0.0	0	0.0	2	5.3
	Kindergarten to Grade 3	0	0.0	0	0.0	0	0.0	0	0.0
	Grades 4 to 7	4	28.6	1	50.0	0	0.0	5	13.2
	Some High School	8	57.1	1	50.0	5	22.7	14	36.8
	Some technical/trade school, college or university	0	0.0	0	0.0	12	54.5	12	31.6
	University degree or equivalent ¹⁰¹	0	0.0	0	0.0	5	22.7	5	13.2
	Total	14	100	2	100	22	100	38	100
Currently Working for Pay	Yes	10	71.4	2	100	22	100	34	89.5
	No	4	28.6	0	0.0	0	0.0	4	10.5
	Total	14	100	2	100	22	100	38	100

⁹⁸ It is noted that the same caregivers may have provided information on behalf of more than one client. Therefore, the demographic information for these individuals does not represent 22 different individuals.

⁹⁹ Respondents could indicate that they spoke more than one language. Percentages are based on the number of respondents in each group (that is, 14 for family caregivers, 2 for formal caregivers for clients living at home, 22 for formal caregivers for clients living in a facility).

¹⁰⁰ Respondents could indicate that they understood more than one language. Percentages are based on the number of respondents in each group (that is, 14 for family caregivers, 2 for formal caregivers for clients living at home, 22 for formal caregivers for clients living in a facility).

¹⁰¹ This category includes individuals who have received a degree/diploma/certificate from a trade or technical school as well as individuals who have a Bachelor's degree, Master's degree, PhD, MD or similar certification. The education level of the participants in the study may be higher than for most paid health care workers in the region (E. Klimczak, personal communication, February 2006) and may be a reflection of the type of worker that participated.

Caregivers were asked what language(s) they spoke; respondents could indicate that they spoke more than one language. As can be seen in Table 6-1, the majority (89.5%) of respondents spoke Inuktitut, although a substantial number (76.3%) also spoke English. The formal caregivers working in facilities could speak English, French and Inuktitut. Caregivers were also asked what language(s) they understood. Again, respondents could indicate that they understood more than one language. The majority of respondents (89.5%) indicated that they could understand Inuktitut; 84.2% of respondents indicated they could understand English. Caregivers were asked what language they used most often on a daily basis. Over half (52.6%) indicated that they used Inuktitut; another 36.8% indicated they used more than one language equally (42.9% spoke English and Inuktitut; 57.1% spoke English and French). One of the questions of interest is the extent to which clients and caregivers are able to communicate in the same language. As shown in Table 6-2, 92.9% of family caregivers and 50.0% of formal caregivers generally used the same language as the client.

Table 6-1 also indicates that less than half of the caregivers, including the formal caregivers, had some post-secondary education. Of the five individuals who had obtained a degree, diploma, or certificate, three had completed the Northern Assistant course, one had received training as a Beneficiary Attendant, and one had received training as a Nurse Assistant. Furthermore, Table 6-1 indicates that of the 14 family caregivers, 10 (71.4%) were currently working for pay. Of these, four worked 20 hours or less a week, two worked between 20 and 35 hours a week, and three worked 30 to 40 hours per week.¹⁰²

Table 6-2: Preferred Language for Both Clients and Caregivers

		Language Used Most Often on a Daily Basis by Client					
		Inuktitut		Other		Total	
		#	%	#	%	#	%
Language Used Most Often on a Daily Basis by Family Caregiver	English	0	0.0	0	0.0	0	0.0
	French	0	0.0	0	0.0	0	0.0
	Inuktitut	13	92.9	0	0.0	13	92.9
	English & Inuktitut	0	0.0	1	7.1	1	7.1
	English & French	0	0.0	0	0.0	0	0.0
	Total	13	92.9	1	7.1	14	100
Language Used Most Often on a Daily Basis by Formal Caregiver	English	2	8.3	0	0.0	2	8.3
	French	1	4.2	1	4.2	2	8.3
	Inuktitut	7	29.2	0	0.0	7	29.2
	English & Inuktitut	5	20.8	0	0.0	5	20.8
	English & French	2	8.3	6	25.0	8	33.3
	Total	17	70.8	7	29.2	24	100

¹⁰² The number of hours worked in a week was not provided for one individual.

Table 6-3 presents information regarding the family caregivers as identified by the caregivers themselves (Table 5-13 provides similar information from the clients). As shown, 50% of the family caregivers were parents; another 35.7% were spouses. No children indicated that they provided assistance to parents. The majority of family caregivers (64.3%) had been providing care for more than five years; only one family caregiver (7.1%) indicated that he/she had been providing care for less than two years. All family caregivers lived with the client.

All of the family caregivers considered themselves the client's primary caregiver. Ten caregivers (71%) indicated that they received help with caregiving; 80% received assistance from other family relatives and 30% received assistance from the formal care system.¹⁰³ Half of the family caregivers indicated that they provided care to someone in addition to the client; four respondents indicated they provided care for four or fewer individuals, while three respondents indicated that they provided care for five or more individuals.

Table 6-3: Characteristics of Family Caregivers as Identified by the Caregivers

Characteristic		#	%
Relationship of family caregiver to Client	Spouse	5	35.7
	Sibling (including in-laws)	1	7.1
	Parent	7	50.0
	Grandchildren	1	7.1
	Total	14	100
Length of time client has been receiving help/support from family caregiver	Less than 1 year	0	0.0
	1 to 2 years	1	7.1
	More than 2 years but less than 5 years	3	21.4
	More than 5 years	9	64.3
	Unknown	1	7.1
	Total	14	100
Distance main/primary family caregiver lives from client	In the same house	14	100
	Very close	0	0
	In the same community	0	0
	Far away	0	0
	Total	14	100

6.3 Type of Care Currently Provided by Family Caregivers

Table 6-4 presents information regarding the type of assistance both family caregivers and formal caregivers provide to the clients from the perspective of family caregivers (similar information is provided from the clients' perspective in Table 5-14).¹⁰⁴ Individuals could receive assistance from family caregivers and/or formal caregivers; that is, they could receive assistance from more than one source. Family caregivers assist most frequently with: financial tasks; light housekeeping and home maintenance; and house maintenance inside. Often, family caregivers provide the majority of assistance. However, in some cases, such as coordinating and arranging medical appointments and services and obtaining medical equipment, medical supplies and medications, both family caregivers and formal caregivers provide assistance.

¹⁰³ Respondents could indicate that they received assistance from more than one source.

¹⁰⁴ The assistance only applies to individuals receiving services at home.

Table 6-4: Type of Assistance Provided by Both Family Caregivers and Formal Caregivers

Activity	Assistance from Family Caregivers				Assistance from Formal Caregivers		Total	
	Yes		No		Yes ¹⁰⁵			
	#	%	#	%	#	%	#	%
Eating, meal planning, meal preparation	9	64.3	5	35.7	0	0.0	14	100
Personal care (e.g., bathing, dressing, toileting)	8	57.1	6	42.9	0	0.0	14	100
Communication (e.g., vision, being understood by others)	9	64.3	4	28.6	1	7.1	14	100
Financial tasks (e.g., budgeting, bill payments, completing forms)	13	92.9	1	7.1	0	0.0	14	100
Light housekeeping and home maintenance (e.g., light cleaning, laundry)	11	78.6	1	7.1	2	14.3	14	100
House maintenance inside (e.g., heavier cleaning, painting)	10	66.7	2	13.3	3	20.0	15	100
House maintenance and chores outside (e.g., shoveling snow)	9	60.0	4	26.7	2	13.3	15	100
Mobility inside the house/facility (e.g., walking inside)	6	40.0	8	53.3	1	6.7	15	100
Mobility outside the house/facility (e.g., getting to other places)	6	40.0	8	53.3	1	6.7	15	100
Nursing or medical care (e.g., foot care, medications)	9	56.3	4	25.0	3	18.8	16	100
Identifying professionals who can provide services and/or medical equipment	11	64.7	2	11.8	5	29.4	17	100
Coordinating and arranging medical appointments and health services	10	52.6	1	5.3	8	42.1	19	100
Obtaining medical equipment, medical supplies and medications	9	47.4	1	5.3	9	47.4	19	100
Obtaining traditional healer/traditional medicines	0	0.0	10	90.9	1	9.1	11	100

Note: Percentages throughout the table are based on the number of individuals who responded to this question (that is, the values in the Total column).

Table 6-5 presents data regarding family caregivers' perceptions of how much assistance they provide to clients because of the clients' need for increased care. Similar information is provided from the client's perspective in Table 5-15. Although most caregivers indicated the assistance they provided was not due to the client's increased need for assistance, this was not the case for about 20% to 35% of caregivers.

6.4 Family Caregivers' Satisfaction with the Services Clients are Receiving

Table 6-6 presents caregivers' perceptions regarding the formal care services the client is receiving. Similar information from the clients' perspective is presented in Table 5-17. Note that the data from both family caregivers and formal caregivers are included in Table 6-6. One family caregiver noted that he/she sometimes paid for services for the client and that he/she could afford to pay. The data from the formal caregivers primarily reflect the fact that respondents are rating themselves, their co-workers and their organization, and therefore, should be viewed with caution. Nevertheless, the data are included in order to determine if formal caregivers feel that clients (particularly those in facilities) are receiving the care and services they require. An interesting finding is that less than 20% of formal caregivers are satisfied with the distance clients have to travel to receive services.

¹⁰⁵ "No" responses were not obtained from formal caregivers.

Table 6-5: Amount of Assistance Provided by Family Caregivers Because of Clients' Increased Need

Activity	Amount of Help Provided (if provided)									
	None		A little		A lot		All/Almost All		Total	
	#	%*	#	%	#	%	#	%	#	%
Eating	6	66.7	0	0.0	0	0.0	3	33.3	9	100
Personal care	5	62.5	0	0.0	0	0.0	3	37.5	8	100
Communication	5	55.6	0	0.0	1	11.1	3	33.3	9	100
Financial tasks	10	76.9	0	0.0	0	0.0	3	23.1	13	100
Light housekeeping	8	72.7	1	9.1	0	0.0	2	18.2	11	100
House maintenance inside	8	80.0	0	0.0	0	0.0	2	20.0	10	100
House maintenance and chores outside	7	77.8	0	0.0	0	0.0	2	22.2	9	100
Mobility inside house	4	66.7	0	0.0	0	0.0	2	33.3	6	100
Mobility outside house	4	66.7	0	0.0	0	0.0	2	33.3	6	100
Nursing or medical care	7	77.8	0	0.0	0	0.0	2	22.2	9	100
Identifying professionals	9	81.8	0	0.0	0	0.0	2	18.2	11	100
Coordinating and arranging medical care	7	70.0	1	10.0	0	0.0	2	20.0	10	100
Obtaining medical equipment, medical supplies and medications	6	66.7	0	0.0	0	0.0	3	33.3	9	100
Obtaining traditional healer/traditional medicines	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0

Note: Percentages throughout the table are based on the number of individuals who responded to this question (that is, the values in the Total column).

Table 6-7 presents family caregivers' satisfaction with the formal care services the client is receiving. Table 5-18 presents similar information from the clients' perspective. Given the small number of responses, a Cronbach's alpha was not conducted on this measure. The data from the formal caregivers are not provided in Table 6-7 as they reflect formal caregivers' ratings of themselves and their co-workers. Nevertheless, it is noted that in response to the question "How often is family involved in care planning?" 83.3% of formal caregivers said "Never", 12.5% said "Sometimes", and 4.2% said "Always". Given that most of the formal caregivers are providing care to individuals in a facility, this would suggest that family caregivers are generally not involved in the care of individuals who are living in the facility.

Caregivers were asked whether clients had experienced difficulties in receiving services in several different areas during the last year. The findings are presented in Table 6-8. Similar information is provided in Table 5-19 from the clients' perspective. In general, both family caregivers and formal caregivers felt that clients received treatments and/or services when they required them. None of the caregivers indicated that either they or the clients had had difficulties affording treatments or services.

Caregivers were asked if clients had been referred for services outside the community, and if so, if they (the caregivers) were satisfied with the care the clients had received. Only three caregivers (two family caregivers and one formal caregiver) indicated that clients had been referred for services outside of the community. Of these, two indicated that they were satisfied and one indicated that he/she was dissatisfied.

Table 6-6: Caregivers' Perceptions of the Care and Support Provided to Clients by the Formal Care System

Question	Family Caregivers			Formal Caregivers ¹⁰⁶			Total		
	Rating	#	%	Rating	#	%	Rating	#	%
Does the client receive the care/service when he/she needs it?	Never	0	0.0	Never	0	0.0	Never	0	0.0
	Sometimes	4	33.3	Sometimes	0	0.0	Sometimes	4	11.1
	Always/Almost Always	8	66.7	Always/Almost Always	24	100	Always/Almost Always	32	88.9
	Total	12	100	Total	24	100	Total	36	100
Is the care/service the client needs available at the time he/she needs it?	Never	0	0.0	Never	0	0.0	Never	0	0.0
	Sometimes	3	25.0	Sometimes	0	0.0	Sometimes	3	8.3
	Always/Almost Always	9	75.0	Always/Almost Always	24	100	Always/Almost Always	33	91.7
	Total	12	100	Total	24	100	Total	36	100
Is the length of time that the client receives care long enough?	Never	0	0.0	Never	0	0.0	Never	0	0.0
	Sometimes	2	18.2	Sometimes	0	0.0	Sometimes	2	5.7
	Always/Almost Always	9	81.8	Always/Almost Always	24	100	Always/Almost Always	33	94.3
	Total	11	100	Total	24	100	Total	35	100
Do the people who provide the client with care respect, understand and listen to him/her?	Never	1	9.1	Never	0	0.0	Never	1	2.9
	Sometimes	1	9.1	Sometimes	1	4.2	Sometimes	2	5.7
	Always/Almost Always	9	81.8	Always/Almost Always	23	95.8	Always/Almost Always	32	91.4
	Total	11	100	Total	24	100	Total	35	100
Are the people who provide the client with care sensitive to his/her needs, beliefs and practices?	Never	0	0.0	Never	0	0.0	Never	0	0.0
	Sometimes	3	27.3	Sometimes	0	0.0	Sometimes	3	8.6
	Always/Almost Always	8	72.7	Always/Almost Always	24	100	Always/Almost Always	32	91.4
	Total	11	100	Total	24	100	Total	35	100
Is it easy to access the care the client needs?	Never	1	8.3	Never	0	0.0	Never	1	2.7
	Sometimes	4	33.3	Sometimes	2	8.3	Sometimes	6	16.7
	Always/Almost Always	7	58.3	Always/Almost Always	22	91.7	Always/Almost Always	29	80.6
	Total	12	100	Total	24	100	Total	36	100
Are you satisfied with where the services are provided to the client?	Never	0	0.0	Never	0	0.0	Never	0	0.0
	Sometimes	3	25.0	Sometimes	4	16.7	Sometimes	7	19.4
	Always/Almost Always	9	75.0	Always/Almost Always	20	83.3	Always/Almost Always	29	80.6
	Total	12	100	Total	24	100	Total	36	100
For service that is provided outside of the client's home, are you satisfied with the distance the client has to travel to receive the care?	Never	4	33.3	Never	7	33.3	Never	11	33.3
	Sometimes	2	16.7	Sometimes	10	47.6	Sometimes	12	36.4
	Always/Almost Always	6	50.0	Always/Almost Always	4	19.0	Always/Almost Always	10	30.3
	Total	12	100	Total	21	100	Total	33	100

¹⁰⁶ Includes formal caregivers who are providing services to individuals at home as well as to individuals in a facility.

Table 6-7: Family Caregivers' Satisfaction with the Formal Care Services Clients Receive

Subscale	Question		#	%	
Satisfaction with services	How often do you have a say in	who will provide the client with services?	Never	5	45.5
			Sometimes	4	36.4
			Always	2	18.2
			Total	11	100
		what services the client gets?	Never	3	27.3
			Sometimes	7	63.6
			Always	1	9.1
			Total	11	100
		when the services are provided?	Never	3	27.3
			Sometimes	5	45.5
			Always	3	27.3
			Total	11	100
Satisfaction with workers	How often would you say that workers	are easy to get along with?	Never	0	0.0
			Sometimes	2	16.7
			Always	10	83.3
			Total	12	100
		come when they are expected?	Never	1	8.3
			Sometimes	3	25.0
			Always	8	66.7
			Total	12	100
		are polite and courteous?	Never	0	0
			Sometimes	1	8.3
			Always	11	91.7
			Total	12	100
		respect the client, understand him/her and listen to him/her?	Never	1	9.1
			Sometimes	2	18.2
			Always	8	72.7
			Total	11	100
		do a good job; one that meets your standards?	Never	0	0.0
			Sometimes	2	18.2
			Always	9	81.8
			Total	11	100
		are willing to help the client with things they are not expected to, but which the client might need?	Never	1	9.1
			Sometimes	2	18.2
			Always	8	72.7
			Total	11	100
		know when to assist the client and when to let the client do things him/her self?	Never	0	0.0
			Sometimes	1	10.0
			Always	9	90.0
			Total	10	100
		are skillful in teaching the client to look after some of his/her own needs?	Never	0	0.0
			Sometimes	1	10.0
			Always	9	90.0
			Total	10	100
		speak the language(s) with which the client is most comfortable?	Never	1	8.3
			Sometimes	2	16.7
			Always	9	75.0
			Total	12	100

Subscale	Question			#	%
Satisfaction with care concerns	How often	does the same person come to provide the client with help?	Never	1	10.0
			Sometimes	5	50.0
			Always	4	40.0
			Total	10	100
		does the client receive adequate notice of a change when someone else will come to help him/her?	Never	5	50.0
			Sometimes	1	10.0
			Always	4	40.0
			Total	10	100
		does the helper know if there are any changes in the kind of care he/she should be providing?	Never	3	33.3
			Sometimes	3	33.3
			Always	3	33.3
			Total	9	100
		is the family involved in the planning of all the care the client receives?	Never	3	27.3
			Sometimes	3	27.3
			Always	5	45.5
			Total	11	100

Table 6-8: Caregivers' Perceptions Regarding Clients' Difficulties in Receiving Services in the Last Year

Difficulties		Family Caregivers		Formal Caregivers ¹⁰⁷		Total	
		#	%	#	%	#	%
Arranging transportation	Yes	1	8.3	1	4.5	2	5.9
	No	11	91.7	21	95.5	32	94.1
	Total	12	100	22	100	34	100
Getting traditional care	Yes	0	0.0	0	0.0	0	0.0
	No	4	100	0	0.0	4	100
	Total	4	100	0	0.0	4	100
Receiving respect, being understood or listened to	Yes	0	0.0	0	0.0	0	0.0
	No	12	100	23	100	35	100
	Total	12	100	23	100	35	100
Obtaining spiritual care/support	Yes	0	0.0	1	8.3	1	5.6
	No	6	100	11	91.7	17	94.4
	Total	6	100	12	100	18	100
Obtaining services in client's area	Yes	0	0	2	8.7	2	5.7
	No	12	100	21	91.3	33	94.3
	Total	12	100	23	100	35	100
Obtaining services when needed	Yes	1	7.7	2	8.3	3	8.1
	No	12	92.3	22	91.7	34	91.9
	Total	13	100	24	100	37	100

¹⁰⁷ Includes formal caregivers who are providing services to individuals at home as well as to individuals in a facility.

Caregivers were asked if they had refused any treatment or service on behalf of clients in the last year. They were also asked if clients had been refused any care or service. One family caregiver indicated that he/she had refused services on behalf of the client when the individual would have had to leave his/her community to obtain services. None of the family caregivers indicated that a client had been refused treatment or service. Two of the formal caregivers indicated that they had refused services on behalf of the client. For one client, there was not enough time to do everything the client wanted. No reason was provided for the second client. One of the formal caregivers indicated that a client had been refused treatment/service because the client required special equipment that was not available outside of the facility.

6.5 Impact of Providing Care on Caregivers

Caregivers were asked what impact providing care had had on them as individuals. Of interest for family caregivers was the impact providing care had had on their living and employment situation. The findings for family caregivers are presented in Table 6-9. As shown in the table, some of the family caregivers had had to take time off work or had to leave work suddenly in order to provide care. In general, however, family caregivers' living and employment situation did not appear to be negatively impacted because of providing care.

Table 6-9: Impact of Providing Care on Family Caregivers' Living and Employment Situation

Impact	Yes		No		Total	
	#	%	#	%	#	%
Caregiver had to change where he/she lived	0	0.0	14	100	14	100
Caregiver had to change job or employer	0	0.0	14	100	14	100
Caregiver had to change job situation (for example, change in hours worked)	1	7.1	13	92.9	14	100
Caregiver's performance at work was affected	1	7.7	12	92.3	13	100
Caregiver had to take time off work to help the client receive care	3	21.4	11	78.6	14	100
Caregiver had to leave work suddenly to take care of client	3	21.4	11	78.6	14	100
Caregiver lost wages because of providing care to the client	1	7.7	12	92.3	13	100
Caregiver quit his/her job	0	0.0	14	100	14	100
Caregiver considered quitting his/her job	1	7.1	13	92.9	14	100

Note: Percentages throughout the table are based on the number of individuals who responded to this question (that is, the values in the Total column).

Caregivers were asked about the positive and negative impacts (benefits and challenges) of providing care. The findings are presented in Table 6-10. Caregivers could provide more than one response. Note that a distinction is made between caregivers that indicated they perceived there were no benefits or challenges and those that did not provide a response.

Approximately 28% to 50% of family caregivers did not answer these questions. Of the caregivers that did respond, the majority indicated that they liked being able to provide care for the client. For example, one individual noted "I feel better when I help someone else who I love." Family caregivers also expressed concern about the care that the client requires and the impact providing care has on the caregivers' personal life. For example, one caregiver commented on the client's current health and noted that he/she had to do a lot of heavy work alone as the client was no longer able to provide assistance.

In general, formal caregivers indicated that providing care had no positive or negative impact on them and noted that it “was part of the job”. However, one third of formal caregivers indicated that the work was providing them with an educational opportunity and/or was helping to develop their skills: “I’m learning lots of things”; “(it is) a good skill to have”. Formal caregivers also noted that they found it: “emotionally difficult that clients are not always supported by their family or the community; “(emotionally difficult) to encounter the death of a client”; “(emotionally difficult) to see a client go to the hospital for the rest of his/her life” and “hard to forget my job at home.”

Table 6-10: Positive and Negative Impacts of Providing Care

Impacts		Family Caregivers		Formal Caregivers		Total	
		#	%*	#	%*	#	%
Positive (Benefits)	Like being able to provide care	5	35.7	2	8.3	7	18.4
	Appreciation of own life	0	0.0	1	4.2	1	2.6
	Educational Opportunity	0	0.0	5	20.8	5	13.2
	Good skill to have	0	0.0	3	12.5	3	7.9
	None	2	14.3	15	62.5	17	44.7
	No response	7	50.0	0	0.0	7	18.4
	Total number of respondents	14	N/A	24	N/A	38	N/A
Negative (Challenges)	Concern regarding the care that is required	4	28.6	0	0.0	4	10.5
	Need more time for clients	0	0.0	5	20.8	5	13.2
	Impact of work on personal life	3	21.4	3	12.5	6	15.8
	None	4	28.6	15	62.5	19	50.0
	No response	4	28.6	0	0.0	4	10.5
	Total number of respondents	14	N/A	24	N/A	38	N/A

Note: Percentages based on number of respondents in each group. Caregivers could provide more than one response.

Caregivers were also asked for suggestions to improve the care and quality of life of the clients. Caregivers could provide more than one response. The findings are presented in Table 6-11. A substantial proportion of family caregivers indicated they had no suggestions for improving the client’s care and quality of life. This could mean that they are satisfied with the care the client is receiving. It could also be a reflection of the fact that Inuit tend not to ask for additional services, but are happy with what they receive. Formal caregivers commented on the need for several clients to be in more appropriate care settings (for example, an elders home preferably in the client’s own community), to have more services (for example, physiotherapy), and more family contact (for example, more visits from family).

6.6 Perceived Need for Continuing Care Services in the Future

Family caregivers were asked several questions regarding their preferences for where clients received services. These were similar to questions asked of clients. For example, caregivers were asked “If you had complete choice of the client’s living situation, what kind of housing situation do you think would be best for him/her?” As shown in Table 6-12, the majority (85.8%) of family caregivers (all of whom were providing care for someone at home) felt it would be best if the client lived in his/her own home or in the home of a family member.

Approximately one third of formal caregivers (most of whom were providing services for individuals living in a facility) also felt that clients should be receiving services in their own home or in the home of a family member. Another third of formal caregivers felt that clients should be receiving services in an elders home (note that only one of the study communities currently has an elders home).

Table 6-11: Caregivers' Suggestions for Improving Care and Quality of Life for Clients

Suggestions for Improving Clients' Life	Family Caregivers		Formal Caregivers		Total	
	#	%*	#	%*	#	%
More family contact	1	7.1	5	20.8	6	15.8
More personnel	0	0.0	1	4.2	1	2.6
More services/equipment	1	7.1	6	25.0	7	18.4
More activities	0	0.0	4	16.7	4	10.5
More appropriate care location	0	0.0	9	37.5	9	23.7
None	6	42.9	4	16.7	10	26.3
Don't know	1	7.1	0	0.0	1	2.6
No response	5	35.7	0	0.0	5	13.2
Total number of respondents	14	N/A	24	N/A	38	N/A

Note: Percentages based on number of respondents in each group. Caregivers could provide more than one response.

Table 6-12: Caregivers' Preferences for Services for Clients

Question		Family Caregivers		Formal Caregivers		Total	
		#	%*	#	%*	#	%
What kind of housing situation do you think would be best for the client? ¹⁰⁸	Living in his/her own home	6	42.9	5	20.8	11	28.9
	Living in the home of a family member	6	42.9	3	12.5	9	23.7
	Living in a personal care home	0	0.0	3	12.5	3	7.9
	Living in an elders/seniors home	0	0.0	8	33.3	8	21.1
	Living in a group home	0	0.0	6	25.0	6	15.8
	Living in a facility or institutional setting	0	0.0	7	29.2	7	18.4
	Other	0	0.0	2	8.3	2	5.3
	Don't know	3	21.4	0	0.0	3	7.9
	Total number of respondents	14	N/A	24	N/A	38	N/A
Where would you prefer that housing be available for the client?	In client's own community	14	100	24	100	38	100
	Where services can be easily accessed	0	0.0	0	0.0	0	0.0
	Other	0	0.0	0	0.0	0	0.0
	Total number of respondents	14	N/A	24	N/A	38	N/A
From whom would you prefer the client receive care/support?	Family caregivers only	5	35.7	1	4.2	6	15.8
	Formal care system only	3	21.4	6	25.0	9	23.7
	Both family caregiver and the formal care system	6	42.9	17	70.8	23	60.5
	Other	0	0.0	0	0.0	0	0.0
	Total number of respondents	14	N/A	24	N/A	38	N/A

Note: Percentages based on number of respondents in each group. Caregivers could provide more than one response.

¹⁰⁸ One individual chose more than one type of setting.

Caregivers were asked where they would prefer that clients live – either in the clients' own community or where services could be accessed easily, even if it meant that the client had to live outside of his/her community. All of the caregivers (both family caregivers and formal caregivers) indicated that they would prefer that clients be able to receive services in their own community.

Caregivers were also asked from whom they would prefer clients receive care and/or support. Some 42.9% of family caregivers indicated that they would prefer that clients receive services from both family caregivers and the formal care system; another 35.7% indicated that they would prefer clients receive services from family caregivers only. Some 70.8% of formal caregivers felt that clients should receive services from both family caregivers and the formal care system; another 25.0% felt clients should receive services from the formal care system only.

Caregivers were asked if they felt there was a need for other housing options in their community. Four family caregivers (28.6%) indicated that they are aware of other housing options. Eight family caregivers (57.1%) indicated that there is a need for other housing options in the community, five (35.7%) indicated there is no need for other housing options, and one (7.1%) indicated that he/she did not know if other housing options are needed. Fifteen formal caregivers (62.5%) indicated that they are aware of other housing options. Seventeen formal caregivers (70.8%) indicated there is a need for other housing options in the community, six (25.0%) indicated there is no need for other housing options and one (4.2%) indicated that he/she did not know whether other housing options are needed. Caregivers commented that there was a need for:

- “a bigger house.”
- “an elders home in (the client's) community. The client currently lives at the hospital and off and on with elders in another community.”
- “special housing for elders only. At this time, other people stay there permanently.”
- “a facility for handicapped persons.”
- “adapted facilities for people who need them.”
- “everything that's possible for the community.” (The existing facilities are limited.).

Family caregivers were asked two questions regarding future services and care for the client. One question related to the need for services if the client's health deteriorates. The other related to palliative/end-of-life care. Formal caregivers were only asked the question regarding palliative/end-of-life care. Caregivers could provide more than one response to each question. The findings are presented in Table 6-13. Many caregivers chose not to answer either one or both of these questions.

Table 6-13: Future Requirements

Question		Family Caregivers		Formal Caregivers		Total	
		#	%*	#	%*	#	%*
If the client's health deteriorates, what would you want to do about the services and care he/she receives and where he/she receives them?	Home or community setting	1	7.1	N/A	N/A	1	7.1
	Hospital	2	14.3	N/A	N/A	2	14.3
	Same services client has now	1	7.1	N/A	N/A	1	7.1
	More services than client has now	1	7.1	N/A	N/A	1	7.1
	Better help than client has now	1	7.1	N/A	N/A	1	7.1
	No response	9	64.3	N/A	N/A	9	64.3
	Number of respondents	14	N/A	24	N/A	38	N/A
In the future, if the client requires palliative/end-of-life care, what would you want to do about the services and care he/she receives and where he/she receives them?	Home or community setting	3	21.4	3	12.5	6	15.8
	Elders home	0	0.0	6	25.0	6	15.8
	Hospital or health centre	4	28.6	8	33.3	12	31.6
	Appropriate location with comfort care	0	0.0	6	25.0	6	15.8
	Don't Know	1	7.1	0	0.0	1	2.6
	No response	6	42.9	5	20.8	11	28.9
	Number of respondents	14	N/A	24	N/A	38	N/A

Note: Percentages based on number of respondents in each group. Caregivers could provide more than one response.

6.7 Summary

A total of 38 caregivers, 14 family caregivers and 24 formal caregivers, participated in the study. Over 90% of the caregivers were women. While 93% of family caregivers were able to communicate in the client's preferred language, only half of the formal caregivers were able to do so.

Both family caregivers and formal caregivers provide assistance with coordinating and arranging medical appointments and services and obtaining medical equipment, medical supplies and medications. Family caregivers were more likely than formal caregivers to assist with financial tasks, light housekeeping and home maintenance, and house maintenance inside. Family caregivers are generally satisfied with the services clients receive through the formal care system.

In general, family caregivers' living and employment situation did not appear to be negatively impacted because of providing care. The majority of family caregivers did not respond to questions regarding the positive and negative impacts of providing care. The majority of formal caregivers indicated that providing care had no positive or negative impacts because it was part of their job.

Caregivers were asked for suggestions to improve the care and quality of life for clients. A substantial proportion of family caregivers indicated that they had no suggestions. However, formal caregivers commented on the need for clients to be in more appropriate care settings, to have more services, and to have more family contact.

When asked where clients should receive services, all of the caregivers indicated that the client should receive them in his/her own community. Over 85% of family caregivers felt that clients should receive services in his/her own home or in the home of a family member. The

findings from the formal caregivers were more mixed, consistent with the perspective that clients should receive services in appropriate care settings. Since the needs of clients vary, it is not unreasonable to expect that what constitutes an “appropriate care setting” may also vary. Approximately 43% of family caregivers and 71% of formal caregivers felt that clients should receive services from both family caregivers and the formal care system.

Over 57% of family caregivers and 70% of formal caregivers indicated that there is a need for additional housing options in the community. Many of the family caregivers and the formal caregivers did not respond to questions regarding where clients should receive services in the future if their health deteriorates.

7. COSTS OF RECEIVING AND PROVIDING CARE

7.1 Estimated Out of Pocket Expenditures for Clients and Caregivers

Clients were asked several questions regarding what supplies, aids, and devices they had received within the last month, and whether any major expenditures had been made (by them, or someone else on their behalf) within the last year. Clients who had received supplies, aids and/or devices were asked to identify who had covered the cost, and the amount involved.

Of the 79 clients, 58 (73.4%) indicated that they had received supplies, aids and/or devices in the last month.¹⁰⁹ As shown in Table 7-1, the majority (96.6%) had obtained medications. With one exception (for vision care), clients indicated that the costs were covered by the Québec government and as a result, they did not know what the costs were. This finding reflects the fact that, under the James Bay and Northern Québec Agreement, health care costs for the people in Nunavik are covered by the Province of Québec.

Only three clients indicated that they had purchased (or had had purchased on their behalf) supplies, aids or devices costing less than \$100 in the last month. All three clients indicated that they had purchased medical supplies.¹¹⁰ Four clients indicated that they had purchased (or had had purchased on their behalf) supplies, aids or devices costing more than \$100 in the last year. Three clients had obtained a wheelchair and one had obtained a walker. In all cases, clients indicated that they did not know how much things had cost.

Table 7-1: Supplies, Aids and Devices Received and/or Purchased by Clients

		Yes		No		Cost covered by (if applicable)
		#	%	#	%	
In last month, client received	Wheelchair	1	1.7	58	98.3	Québec government
	Walker	2	3.4	57	96.7	Québec government
	Cane	3	5.1	56	94.9	Québec government
	Dressings	3	5.1	56	94.9	Québec government
	Syringes	1	1.7	58	98.3	Québec government
	Pillows	1	1.7	58	98.3	Québec government
	Ostomy supplies	2	3.4	57	96.7	Québec government
	Diabetic foods	0	0.0	59	100	Not applicable
	Drugs/medications	57	96.7	2	3.4	Québec government
	Traditional medicines	1	1.7	57	96.7	Québec government
	Vision care	3	5.1	55	93.2	Québec government; Client

Clients were also asked to indicate whether they had been referred for services within the community and/or outside of the community, and if so, what the services had cost. Ten clients indicated they had been referred for services within the community in the last month. Of these, one was referred for medical supplies, eight were referred for care-related services, and one was referred for social services. In each case, clients were unable to say how much the service cost.

¹⁰⁹ Other clients may not have received anything in the last month, but may have received something in the past year.

¹¹⁰ Coding categories for the various types of expenditures are described in more detail in Appendix H.

Nine clients indicated that they were referred for services outside the community in the last month. Of these, one was referred for care related services, seven were referred for services involving major expenditures (usually involving a trip to Montreal) and one was referred for social services. Again, clients were unable to say how much the services had cost.

Caregivers were also asked what supplies, aids and devices clients had received in the last month and whether any major expenditures had been made. Twenty-six of the 38 caregivers indicated that clients had received supplies, aids or devices. The findings are presented in Table 7-2 (note that 13 of the 14 family caregivers responded; all of the formal caregivers responded). While the table distinguishes between family caregivers (who provide care to individuals living at home) and formal caregivers (most of whom provided care to individuals living in a facility), the pattern of responses is similar: the vast majority of clients received medications in the last month but few received any other supplies, aids or devices. This confirms what was noted by the clients. In addition, as with the clients, caregivers noted that the Québec government covered the cost of all supplies, aids and devices; caregivers and/or clients did not contribute to the costs.

Table 7-2: Caregivers' Perspectives on the Supplies, Aids and Devices Received and/or Purchased by Clients

		Family Caregivers				Formal Caregivers				Total			
		Yes		No		Yes		No		Yes		No	
		#	%*	#	%	#	%	#	%	#	%	#	%
In last month, client received	Wheelchair	1	7.7	12	92.3	2	8.3	22	91.6	3	8.1	34	91.9
	Walker	1	7.7	12	92.3	1	4.2	23	95.8	2	5.4	35	94.6
	Cane	1	7.7	12	92.3	0	0.0	24	100	1	2.7	36	97.3
	Dressings	0	0.0	13	100	4	16.7	20	83.3	4	10.8	33	89.2
	Syringes	0	0.0	13	100	2	8.3	22	91.6	2	5.4	35	94.6
	Pillows	1	7.7	12	92.3	0	0.0	24	100	1	2.7	36	97.3
	Ostomy supplies	0	0.0	13	100	2	8.3	22	91.6	2	5.4	35	94.6
	Diabetic foods	0	0.0	13	100	0	0.0	24	100	0	0.0	37	100
	Drugs/medications	9	69.2	4	30.8	20	83.3	4	16.7	29	78.4	8	21.6
	Traditional medicines	0	0.0	13	100	0	0.0	24	100	0	0.0	37	100
	Vision care	2	15.4	10	83.3	1	4.2	22	91.6	3	8.6	32	91.4

* All percentages based on total number of respondents (n = 13 for family caregivers; n = 24 for formal caregivers).

None of the family caregivers or the formal caregivers indicated that either they or clients had purchased supplies, aids or devices costing less than \$100 in the last month. One family caregiver and one formal caregiver indicated that wheelchairs costing more than \$100 had been purchased for two clients in the last year. Once again, it was indicated that neither the client nor the caregiver had contributed to the cost of the wheelchairs.

One family caregiver noted that the client had been referred for a care-related service within the community within the last month; no cost was identified for this service. Three family caregivers noted that clients had been referred for services outside the community within the last month (one for care-related services, one involving major expenditures, and one for social services). Again, no costs were identified. Six formal caregivers noted that clients had been

referred for services within the community in the last month; four of these involved care-related services and two involved major expenditures. Two formal caregivers noted that clients had been referred for services outside the community in the last month; one involved a major expenditure and the other involved an activity.

Given the fact that neither clients nor caregivers appeared to pay for any supplies, aids or devices, it is difficult to estimate out-of-pocket expenditures at the individual level. As well, since neither clients nor caregivers were able to provide estimates of the amount provided by the Québec government to cover the various items, it is difficult to estimate government costs based on the data collected in this study.

7.2 Estimated Expenditures for Assistance

Clients were asked several questions regarding the types of assistance they received and who provided the assistance. Findings related to service utilization are presented in Chapter 5. This chapter focuses on the amount of assistance clients received, and who provided the assistance, with the goal being to develop costing estimates.

Clients were asked to think of all the family caregivers who provided them with care and support, to identify what types of assistance those individuals provided and to estimate the amount of time they spent providing care and support in an average week. Clients could indicate that more than one type of family caregiver provided them with assistance (for example, that both family members and other relatives assisted them with meal preparation). Clients could also indicate that each type of family caregiver provided them with more than one type of assistance (for example, that a family member provided assistance with housekeeping as well as meal preparation). The findings from clients are presented in Table 7-3; similar findings from both family caregivers and formal caregivers are presented in Table 7-4. As can be seen in both tables, family members are more likely to provide assistance than other types of family caregivers. However, Table 7-4 confirms findings reported earlier for clients living in facilities. Namely, that clients in facilities have very little contact with family caregivers. As shown in Table 7-3 and the upper part of Table 7-4 (that is, information provided by family caregivers), while some individuals require assistance 24 hours a day, the majority requires less than 15 hours per week.

Table 7-3: Clients' Perceptions of the Assistance Provided by Family Caregivers*

		Family Members		Other Relatives		Friends		Volunteers		Spiritual Care		Total	
		#	%	#	%	#	%	#	%	#	%	#	%
Type of Assistance¹¹¹	Clinical Necessities	4	28.6									4	17.4
	Housekeeping	6	42.9	1	20.0							7	30.4
	Meal Preparation	6	42.9									6	26.1
	Maintenance	2	14.3	2	40.0	1	50.0			1	50.0	6	26.1
	Psychological/social activities	2	14.3	1	20.0	1	50.0			1	50.0	5	21.7
	Respite											0	0.0
	Companionship	2	14.3	1	20.0							3	13.0
	Organization of health and/or social services											0	0.0
	Any needed assistance	2	14.3	1	20.0	0	0.0	0	0.0	0	0.0	3	13.0
	Total number of clients receiving assistance**	14	N/A	5	N/A	2	N/A	0	N/A	2	N/A	23	N/A
Amount of Assistance (per week)	1 hour or less	1	7.1			1	50.0			2	100	4	17.4
	More than 1 but less than 5 hours	2	14.3	2	40.0							4	17.4
	More than 5 but less than 10 hours	3	21.4			1	50.0					4	17.4
	More than 10 but less than 15 hours											0	0.0
	More than 15 but less than 20 hours			1	20.0							1	4.3
	More than 20 but less than 30 hours	2	14.3	1	20.0							3	13.0
	More than 30 hours											0	0.0
	24 hours a day	4	28.6									4	17.4
	Daily	1	7.1									1	4.3
	When required	1	7.1	1	20.0							2	8.7
	Total number of clients receiving assistance	14	100	5	100	2	100	0	0.0	2	100	23	100

*To facilitate reading, empty cells have been left blank (except for totals).

** Caregivers could provide more than one response.

¹¹¹ These categories are described in more detail in Appendix H.

Table 7-4: Caregivers' Perceptions of the Assistance Provided by Family Caregivers*

From the Perspective of			Family Members		Other Relatives		Friends		Volunteers		Spiritual Care		Total	
			#	%	#	%	#	%	#	%	#	%	#	%
Family Caregivers	Type of Assistance	Clinical Necessities	3	20.0									3	13.6
		Housekeeping	5	33.3	1	33.3							6	27.3
		Meal Preparation	4	26.7									4	18.2
		Maintenance	4	26.7	1	33.3	1	50.0			1	50.0	7	31.8
		Psychological/social activities	2	13.3			1	50.0			1	50.0	4	18.2
		Respite											0	0.0
		Companionship	1	6.7									1	4.5
		Organization of health and/or social services											0	0.0
		Any needed assistance	6	40.0	2	66.7							8	36.4
		Total number of clients receiving assistance**	15	N/A	3	N/A	2	N/A	0	N/A	2	N/A	22	N/A
	Amount of Assistance (per week)	1 hour or less			1	33.3	1	50.0			1	50.0	3	13.6
		More than 1 but less than 5 hours	2	13.3	1	33.3							3	13.6
		More than 5 but less than 10 hours	2	13.3			1	50.0					3	13.6
		More than 10 but less than 15 hours	1	6.7									1	4.5
		More than 15 but less than 20 hours	1	6.7									1	4.5
		More than 20 but less than 30 hours	2	13.3									2	9.1
		More than 30 hours	2	13.3	1	33.3							3	13.6
		24 hours a day	4	26.7									4	18.2
		Daily											0	0.0
		When required	1	6.7									1	4.5
		Once a month									1	50.0	1	4.5
		Total number of clients receiving assistance	15	100	3	100	2	100	0	0.0	2	100	22	100

*To facilitate reading, empty cells have been left blank (except for totals).

** Caregivers could provide more than one response.

From the Perspective of			Family Members		Other Relatives		Friends		Volunteers		Spiritual Care		Total	
			#	%	#	%	#	%	#	%	#	%	#	%
Formal Caregivers	Type of Assistance	Clinical Necessities											0	0.0
		Housekeeping	1	50.0									1	33.3
		Meal Preparation											0	0.0
		Maintenance											0	0.0
		Psychological/social activities	1	50.0									1	33.3
		Respite											0	0.0
		Companionship			1	100							1	33.3
		Organization of health and/or social services											0	0.0
		Any needed assistance											0	0.0
		Total number of clients receiving assistance**	2	N/A	1	N/A	0	N/A	0	N/A	0	N/A	3	N/A
	Amount of Assistance (per week)	1 hour or less			1	100							1	33.3
		More than 1 but less than 5 hours	1	50.0									1	33.3
		More than 5 but less than 10 hours											0	0.0
		More than 10 but less than 15 hours											0	0.0
		More than 15 but less than 20 hours											0	0.0
		More than 20 but less than 30 hours											0	0.0
		More than 30 hours											0	0.0
		Daily											0	0.0
		When required	1	50.0									1	3.33
		24 hours a day											0	0.0
		Total number of clients receiving assistance	2	100	1	100	0	0.0	0	0.0	0	0.0	3	100

*To facilitate reading, empty cells have been left blank (except for totals).

** Caregivers could provide more than one response.

Clients were asked to think of all the formal caregivers who provided them with care and support, to identify what types of assistance those individuals provided and to estimate the amount of time they spent providing care and support in an average week. Clients could indicate that more than one type of formal caregiver provided them with assistance (for example, that both nurses and therapists provided assistance). Clients could also indicate that each type of formal caregiver provided them with more than one type of assistance (for example, that a nurse provided assistance with clinical necessities as well as the organization of health and social services).

The findings from clients are presented in Table 7-5; similar findings from caregivers are presented in Table 7-6.¹¹² As can be seen in both tables, the vast majority of clients received assistance from health care professionals (that is, nurses and physicians) when required, particularly when clients lived in a facility. Clients also received assistance from therapists (particularly physiotherapists), although this was often for 10 hours or less a week according to clients and as required according to formal caregivers.

The findings presented in Tables 7-5 and 7-6 should be interpreted cautiously as, in some cases, the amount of time provided seemed to be based on the amount of time the formal caregiver worked in a week, rather than the amount of time spent providing care to individual clients. In addition, in a previous question which examined who assisted clients with specific tasks (such as eating, personal care, mobility inside), licensed practical nurses and beneficiary attendants were often identified for facility clients, but estimates of the amount of time they provide did not seem to be identified here.

7.3 Estimating Costs Based on Other Sources

As neither clients nor caregivers were able to provide information regarding the continuing care services they accessed, the Nunavik Regional Health and Social Services Board was asked for cost information regarding the costs of providing both home and community care and facility care. Funding for health and social services in the region is integrated. As a result, the region was unable to provide costing information the way it was requested. However, the region was able to identify several factors that affect the provision of home care services.

Due to a shortage of trained continuing care personnel within the region, individuals are often hired from southern communities (e.g., Montreal). The average cost of hiring a professional (such as a home care nurse) from the south is \$150,000 per annum (this includes the individual's salary, northern benefits cargo premium and housing). One of the benefits for professionals from the south is three or four annual trips south paid by the employer; the average cost for a round trip between the region and southern communities is \$2,000. There is a major housing shortage in the region. The cost of building a house for an employee is estimated to be \$250,000 on average. Given that 99% of health care professionals are from southern communities,¹¹³ these expenditures can have substantial financial consequences for the region.

¹¹² For ease of interpretation, some professionals have been grouped together in both tables.

¹¹³ E. Klimczak, personal communication, February 2006.

Table 7-5: Clients' Perceptions of the Assistance Provided by Formal Caregivers ^{*114}

		Support Worker		Health Care Aides		Health Care Professionals		Therapists		Spiritual Care		Total	
		#	%	#	%	#	%	#	%	#	%	#	%
Type of Assistance	Clinical Necessities	7	63.6	2	33.3	17	40.5	16	94.1			42	53.2
	Housekeeping	5	45.5									5	6.3
	Meal Preparation	1	9.1									1	1.3
	Maintenance	3	27.3									3	3.8
	Psychological/social activities	1	9.1	1	16.7			2	11.8			4	5.1
	Respite											0	0.0
	Companionship											0	0.0
	Organization of health and/or social services			3	50.0							3	3.8
	Any needed assistance	1	9.1			3	7.1					4	5.1
	As required ¹¹⁵					25	59.5	3	17.6	3	100	31	39.2
	Total number of clients receiving assistance**	11	N/A	6	N/A	42	N/A	17	N/A	3	N/A	79	N/A
Amount of Assistance (per week)	1 hour or less	2	18.2	1	16.7	7	16.7	5	29.4			15	19.0
	More than 1 but less than 5 hours	4	36.3					10	58.8			14	17.7
	More than 5 but less than 10 hours			1	16.7	1	2.4	1	5.9			3	3.8
	More than 10 but less than 15 hours											0	0.0
	More than 15 but less than 20 hours	1	9.1									1	1.3
	More than 20 but less than 30 hours											0	0.0
	More than 30 hours	2	18.2					1	5.9			3	3.8
	24 hours a day					3	7.1					3	3.8
	Daily											0	0.0
	When required			3	50.0	23	54.8			3	100	29	36.7
	One to five times a week	2	18.2	1	16.7	3	7.1					6	7.6
	Once or twice a month					2	4.8					2	2.5
	Once in a while					1	2.4					1	1.3
	Once a year					2	4.8					2	2.5
	Total number of clients receiving assistance	11	100	6	100	42	100	17	100	3	100	79	100

*To facilitate reading, empty cells have been left blank (except for totals).

** Caregivers could provide more than one response.

¹¹⁴ Support workers include homemakers, home support workers, maintenance workers and welfare workers. Health care aides include home care aides, personal care aides and wellness coordinators. Health care professionals include nurses and physicians. Therapists include occupational therapists, occupational technicians, physiotherapists, physio technicians and massage therapists. Spiritual care includes traditional healers and spiritual providers.

¹¹⁵ It is likely that these activities involve clinical necessities, at least for the health care professionals and the therapists. However, the information was not specified as such, and it was not considered appropriate to assume that this was the case.

Table 7-6: Caregivers' Perceptions of the Assistance Provided by Formal Caregivers^{* 116}

			Support Worker		Health Care Aides		Health Care Professionals		Therapists		Spiritual Care		Total	
			#	%	#	%	#	%	#	%	#	%	#	%
Family Caregivers	Type of Assistance	Clinical Necessities	1	50.0	3	100	4	80.0	5	100			13	81.3
		Housekeeping	2	100									2	12.5
		Meal Preparation											0	0.0
		Maintenance	1	50.0									1	6.3
		Psychological/social activities	1	50.0							1	100	2	12.5
		Respite											0	0.0
		Companionship					1	20.0					1	6.3
		Organization of health and/or social services											0	0.0
		Any needed assistance											0	0.0
		As required ¹¹⁷					1	20.0					1	6.3
		Total number of clients receiving assistance**	2	N/A	3	N/A	5	N/A	5	N/A	1	N/A	16	N/A
	Amount of Assistance (per week)	1 hour or less			1	33.3	1	20.0	2	40.0			4	25.0
		More than 1 but less than 5 hours	1	50.0	1	33.3			3	60.0			5	31.3
		More than 5 but less than 10 hours											0	0.0
		More than 10 but less than 15 hours											0	0.0
		More than 15 but less than 20 hours	1	50.0									1	6.3
		More than 20 but less than 30 hours											0	0.0
		More than 30 hours											0	0.0
		24 hours a day											0	0.0
		Daily											0	0.0
		When required					1	20.0			1	100	2	12.5
		One to five times a week			1	33.3	2	40.0					3	18.9
		Once or twice a month					1	20.0					1	6.3
		Once in a while											0	0.0
		Once a year											0	0.0
		Total number of clients receiving assistance	2	100	3	100	5	100	5	100	1	100	16	100

^{*}To facilitate reading, empty cells have been left blank (except for totals).

^{**} Caregivers could provide more than one response.

¹¹⁶ Support workers include homemakers, home support workers, maintenance workers and welfare workers. Health care aides include home care aides, personal care aides and wellness coordinators. Health care professionals include nurses and physicians. Therapists include occupational therapists, occupational technicians, physiotherapists, physio technicians and massage therapists. Spiritual Care includes traditional healers and spiritual providers.

¹¹⁷ It is likely that these activities involve clinical necessities, at least for the health care professionals and the therapists. However, the information was not specified as such, and it was not considered appropriate to assume that this was the case.

			Support Worker		Health Care Aides		Health Care Professionals		Therapists		Spiritual Care		Total	
			#	%	#	%	#	%	#	%	#	%	#	%
Formal Caregivers	Type of Assistance	Clinical Necessities	1	12.5			7	17.9	6	42.9			14	18.9
		Housekeeping	2	25.0									2	2.7
		Meal Preparation	1	12.5									1	1.4
		Maintenance	1	12.5							4	57.1	5	6.8
		Psychological/social activities			1	16.7			2	14.3			3	4.1
		Respite											0	0.0
		Companionship											0	0.0
		Organization of health and/or social services			5	83.3							5	6.8
		Any needed assistance	5	62.5									5	6.8
		As required ¹¹⁸					32	82.1	6	42.9	3	42.9	41	55.4
		Total number of clients receiving assistance**	8	N/A	6	N/A	39	N/A	14	N/A	7	N/A	74	N/A
	Amount of Assistance (per week)	1 hour or less			1	16.7	5	12.8					6	8.1
		More than 1 but less than 5 hours	1	12.5									1	1.4
		More than 5 but less than 10 hours											0	0.0
		More than 10 but less than 15 hours											0	0.0
		More than 15 but less than 20 hours											0	0.0
		More than 20 but less than 30 hours											0	0.0
		More than 30 hours	1	12.5	2	33.3			6	42.9			9	12.2
		24 hours a day	1	12.5									1	1.4
		Daily											0	0.0
		When required	5	62.5	3	50.0	33	84.6	7	50.0	7	100	55	74.3
		One to five times a week											0	0.0
		Once or twice a month					1	2.6	1	7.1			2	2.7
		Once in a while											0	0.0
		Once a year											0	0.0
		Total number of clients receiving assistance	8	100	6	100	39	100	14	100	7	100	74	100

*To facilitate reading, empty cells have been left blank (except for totals).

** Caregivers could provide more than one response.

¹¹⁸ It is likely that these activities involve clinical necessities, at least for the health care professionals and the therapists. However, the information was not specified as such, and it was not considered appropriate to assume that this was the case.

The salary for home care workers is approximately \$15 to \$18 dollars an hour; this is doubled when northern benefits are included.

The majority of clients in the region primarily communicate in Inuktitut. Therefore, professional services (such as nursing services) need to be offered with the assistance of an interpreter whose salary is similar to that of a home care worker.

In order to provide some community-based services, such as physiotherapy, occupational therapy and audiology, professionals (or clients and their escorts) may need to travel from one community to another. All of the travel is by air. Medical equipment, supplies, etc. are also transported to communities; materials come by boat in the summer and by air the rest of the year. The costs of providing other resources to continuing care clients is also substantial. For example, a wheelchair ramp in the south would cost approximately \$3,000. In Nunavik, it would cost, on average, \$15,000. This includes costs related to materials, shipping and workers (most of whom are from southern communities).

The annual cost for professional services and maintenance for the Elder's Home in Kuujuaq is \$824,000. These funds do not cover food for the clients nor do they cover any major repairs.

There are budgetary constraints that affect the development and maintenance of programs in the health and social service sector. For example, money comes from multiple sources such as Health Canada, INAC, the provincial government and the regional government. Nine different sources of funding are used to provide home care services. Each of these funding sources has different requirements with respect to access and reporting. Some budgets are requested and obtained annually. Others are provided for a two to three year period.

7.4 Summary

In order to gain an understanding of the costs associated with the provision of continuing care services to Inuit, clients were asked several questions regarding their out-of-pocket expenditures over the last year. While 73% of clients indicated that they had received supplies (primarily medications), they indicated that the costs were covered under the James Bay and Northern Québec Agreement and thus, they were not aware of what the supplies and services cost. Similar findings were obtained from the caregivers.

Clients appeared to receive little assistance from family members. This finding is consistent with the finding that relatively few clients indicated they had a family caregiver. The majority of clients received assistance from health care professionals (that is, nurses and physicians) when required, particularly when they lived in a facility. It was not possible to cost services based on the available data.

Neither clients nor caregivers were able to provide information regarding the continuing care services they accessed. The Nunavik Regional Health and Social Services Board was therefore asked for information regarding the costs of providing both home and community care and facility care. As funding for health and social services in the region is integrated, the region

was unable to provide costing information the way it was requested. However, several factors that affect the provision of home care services were identified. These included benefits and salaries for health professionals (including nurses and home care workers), the need to have interpreters assist with provision of care, and transportation costs related to both people and resources.

8. DISCUSSION AND CONCLUSIONS

8.1 Introduction

As noted previously, several research questions were addressed by the Continuing Care Research and Costing Project. These were:

- What is the number of individuals assessed as having continuing care needs (by type of care) in First Nations/Inuit communities?
- What are the type and magnitude of services required at each care level in home and facility care?
- What are the contributions of informal caregivers?
- What are the differences in service provision by community isolation?
- What are the clients' preferences for care settings?
- What is their existing level of satisfaction with the continuing care services they receive?
- What is their quality of life?
- Have clients been appropriately placed in home care and facility care, respectively?
- What are the costs of providing services?

The Continuing Care Research and Costing Project involved several components; the interviews with clients and caregivers in the three Inuit communities in Nunavik examined in this document constituted only one of these components. This chapter provides commentary on each of the research questions from the perspective of these interviews (note that the order of the questions has been changed slightly in the following sections). This chapter also highlights issues regarding the provision of continuing care services in Inuit communities, identifies policy and practice issues, and provides suggestions for future research.

8.2 Individuals Requiring Continuing Care Services in Inuit Communities

The Continuing Care Research and Costing Project was intended to examine continuing care requirements in four groups of clients: children with special needs; adults with chronic diseases or conditions; adults with mental health needs; and seniors. Clients were included from all four groups, in part, because of the inclusion of clients from Inukjuak (which has both a number of children with special needs and the Reintegration Centre for individuals with mental health needs).¹¹⁹

The target sample of 90 was determined by available funds. Although the obtained sample represents 87.8% of the target, which resulted in small numbers in several instances where the sample was divided, this would likely have been the case had the full sample been realized. It is important to note that the facility sample represents 85% of the number of available

¹¹⁹ R. Ferguson, personal communication, November 2004.

beds. Thus, even if a larger sample had been obtained, only a maximum of four more individuals would have been available for the facility sample (assuming all were able to participate, which was not the case in this study). Overall, the home sample represented 19.3% of clients receiving continuing care services at home (and 8.8%, 30.6% and 22.5%, for Kuujuaq, Puvirnituk and Inukjuak, respectively). Thus, the sample appears reasonable, given the number of eligible individuals in the three study communities.

Approximately equal numbers of males and females require continuing care services, even for individuals living in a facility.¹²⁰ This finding has several implications. For example, continuing care related services and activities need to meet the needs of both male and female clients. Currently, over 90% of caregivers are female (this is consistent with findings in the non-Aboriginal literature). Both male and female paid health care providers should be available, particularly for those living in a facility. Given the limited number of rooms available in the facilities, it may be difficult at times to use the space efficiently (for example, with regard to the sharing of rooms), depending on the specific number of males and females.

One of the key findings is the number of younger individuals who are receiving continuing care services, particularly in a facility; 22.8% of clients receiving services at home and 45.5% of clients receiving services in a facility were under the age of 35. In many continuing care studies involving non-Aboriginal populations, the majority of clients are seniors (generally defined as individuals 65 and older). For the Inuit, 43.9% of those receiving services at home and 22.7% of those receiving services in a facility were 65 years of age and older. As a population, Inuit tend to be younger and may experience age related conditions at a younger age. Thus, if one considers seniors to be those aged 55 and older, the proportions increase to 66.7% and 31.8% for individuals receiving services at home and in a facility, respectively. This finding would suggest that services for individuals living in a facility setting need to be designed for children with special needs and young adults (some of whom may have come into the facility as children), as well as seniors.

8.3 Location of Clients Based on Their Current Care Needs

The findings from the SMAF suggest that clients receiving continuing care services at home generally have low to moderate care needs. Clients receiving continuing care services in a facility generally have moderate to high care needs. While this suggests a potential overlap in the mid-range, it also suggests that clients at the upper and lower care levels are located in appropriate care settings. A closer examination of individuals in the mid-range indicates that individuals living in facilities have more difficulties with mental functions than those living at home, a finding that is consistent with the belief that difficulties with mental functioning may be a risk factor for facility placement. This appears to be particularly the case for those with head injuries and/or mental health conditions. Individuals living at home appear to have more difficulties with activities of daily living and mobility than those living in a facility. These findings would suggest that clients in the mid-range may also be located in appropriate care settings, given the limited number of facility beds available.

¹²⁰ Continuing care studies involving non-Aboriginal clients generally find that females outnumber males.

8.4 Types of Services Required For Individuals Living at Home and in Facilities

Despite the fact that clients may be located in appropriate care settings, there are several indications that they are not receiving sufficient services, or a broad enough range of services. For example, while many clients receive care-related services (that is, clinical necessities), few clients living at home receive housekeeping, meal preparation or house maintenance services. This appears to be the case even though the majority of clients living at home lived with other individuals. This finding should be interpreted with caution, however, as it may be the case that clients receive these services, but do not perceive that a caregiver provides them because of clients' understanding of what constitutes a caregiver. Very few clients appeared to receive opportunities for psychological/social activities, respite services, or companionship time. In fact, one of the areas for improvement highlighted for individuals living in facilities was the need for more activities. Despite these findings, neither clients nor caregivers indicated that they had difficulties receiving services.

8.5 Clients' and Caregivers' Satisfaction with Current Continuing Care Services

In general, clients appeared to be satisfied with the services they receive from both family caregivers and the formal care system with respect to: services being provided when they are needed; how long services are provided for; and the characteristics of the individuals who are providing the services. Clients receiving services from formal caregivers noted, however, that they have little say in who will provide services and when services will be provided. They also noted that the same person generally provides them with services, that they are often aware of when a different person will provide the services, and that a new individual is generally aware of what services are required. These findings likely reflect the fact that there are a limited number of formal caregivers available. Family caregivers also indicated that they were satisfied with the formal care services clients received.

Approximately 9% of clients indicated that they had refused treatments or services in the past year. In all cases, the refusals were related to clients' preferences rather than their perceptions of the quality of care they were receiving. Approximately 8% of caregivers had refused treatments or services on behalf of the clients. Again, these refusals were not due to the quality of care being provided.

Approximately 11% of clients were referred for services outside of the study communities. These individuals usually noted that they needed to go to Montreal for care-related services such as physician visits. In general, clients appeared to be satisfied with the care they received outside of their communities.

8.6 Clients' Perceived Health and Quality of Life

About half of the clients considered their health to be "Good" or "Very Good", despite the fact that they were experiencing functional difficulties, sometimes in several areas. Approximately 25% of clients indicated that their health was affected by physical, emotional, mental and spiritual balance; another 20% indicated that their health was affected by concerns regarding medications. Despite the fact that few people indicated they had used the services of a

traditional healer or spiritual care provider in the past month, spiritual beliefs and/or values were frequently identified as having a major influence on people's health and/or lives. The things that make clients the happiest are outdoor activities, being with other individuals, and leisure activities. These components could be incorporated into any additional activities that were made available to continuing care clients, particularly those living in facilities.

8.7 Clients' and Caregivers' Preferences for Where Services are Received

Both clients and caregivers indicated a preference for clients to receive continuing care services in their own community. Clients generally indicated a preference to receive services at home (either in their own home or in the home of a family member); most of these clients currently receive services at home. This perspective was supported by family caregivers, all of whom were providing care to individuals living at home.

Formal caregivers, most of whom were providing care to individuals living in a facility, provided mixed responses. It was felt that about a third of the clients should be living either in their own home or in the home of a family member. It was also felt that approximately one-half of clients would benefit from living in a personal care home or an elders/seniors home. Only Kuujuaq currently has an elders home for individuals with functional loss. Only 29% of the 22 clients currently living in a facility were considered by formal caregivers to need a facility or institutional setting.

The findings from the formal caregivers suggest that not all clients were living in an appropriate location with respect to the type of care they required and/or the type of care that was available to them. While this may seem to contradict the conclusion drawn above that clients were located in appropriate care settings, this is not, in fact, the case. The findings reported earlier refer to whether, based on their functional status, clients are living in an appropriate location. The findings from the formal caregivers reflect whether the available housing options are appropriate to meet the needs of the clients. The findings from both clients and formal caregivers suggest that additional *appropriate* housing and services are required.

Clients and caregivers were also asked who should provide services to clients. The majority of clients living at home generally indicated that they would prefer to receive services from family members, although about half of the clients also indicated that they would prefer to receive services from the formal care system.¹²¹ This is an interesting finding in view of the fact that: few clients indicated that they had a family caregiver; very few clients receiving services at home indicated that they were receiving services from formal care providers; and most clients did not indicate that they had experienced any difficulty in receiving services. It is, therefore, not clear if clients receiving services at home are receiving sufficient services from family caregivers or whether additional services are required. Formal caregivers indicated that over 70% of clients currently living in a facility should receive care from both family caregivers and the formal care system. However, it would appear that individuals living in a facility currently have little contact with their families. This would suggest that (further) attempts should be made to involve family members in the care of clients living in a facility.

¹²¹ Clients could indicate a preference for assistance from more than one source.

Both clients and caregivers were asked where clients should receive services in the future should their health deteriorate and/or should they require palliative/end-of-life care. About 50% of clients indicated that they would prefer to receive care at home in both cases; approximately 19% indicated that they would prefer to receive care in a hospital setting in both cases. These findings are consistent with those noted above (that is, that clients would prefer to receive services at home from their family caregivers). The findings also suggest that consideration needs to be given to the skill sets of family caregivers as well as clients' living situations. Many clients live in crowded homes, many of which are multigenerational. It may take considerable effort to ensure that clients receive what they require from individuals with the appropriate skill sets.

8.8 The Contributions of Family Caregivers

Few family caregivers were identified, even for those clients receiving services at home. Of the clients living at home, 35.1% indicated that they had a family caregiver; 4.5% of clients living in a facility indicated they had a family caregiver. Not all of the identified family caregivers participated in the current study. The finding that few clients indicated they had a family caregiver may, in part, reflect clients' understanding of what a caregiver is. The majority of family caregivers may not have been seen as caregivers *per se* as they were either parents or spouses. The small number of identified family caregivers may also reflect clients' beliefs regarding dependency and self-esteem, but it also suggests that very few clients feel they have someone who can provide them with care and support on an ongoing basis.

It is noted that 71% of family caregivers work. Of these, half work more than 20 hours a week. Half of the family caregivers also indicated that they provided care to someone in addition to the client. Thus, family caregivers may be unable to provide a lot of assistance to the client on an ongoing basis.

While some family caregivers provide assistance with housekeeping, personal care, and nursing or medical care, they also assist with: identifying professionals who can provide medical services and/or equipment; coordinating and arranging medical appointments; and obtaining medical equipment, supplies and medications. These findings suggest that family caregivers work with the formal care system to ensure that clients' basic health care needs are met and are consistent with the conclusions drawn above that clients receive clinical necessities, but little else. They are also consistent with the finding that family caregivers' living and employment situation do not appear to be negatively impacted because of providing care.

8.9 The Effects of Community Location

As with other Inuit communities in Canada, the communities included in this study are located in northern, remote locations. While the study communities are large compared to other Inuit communities, they are relatively small compared to "large" First Nations communities (which may consist of 5,000 people or more), and they are definitely smaller than many southern communities. Both the size and the location of the communities have a substantial impact on the provision of continuing care services for Inuit.

For example, funding based on a per capita formula is likely to be insufficient to meet the needs, given some of the costs associated with the location of the communities (see below). This is highlighted by the fact that funding for home care comes from nine different sources.¹²² Lack of economies of scale are also a problem, but the region has been able to integrate both services and funding, at least to some extent, thus potentially increasing efficiencies.

With regard to location, it is difficult to recruit and retain health care workers within the region. Many health professionals come from southern communities and, as noted earlier, there are substantial costs associated with their salaries and benefits. This includes the provision of housing in an area where there is a housing shortage, and where continuing care clients may live in overcrowded, multigenerational homes.

Health care professionals from outside of the region will likely require the assistance of an interpreter when providing care. Being able to provide medical interpreter services requires considerable skill and it may not always be easy to find individuals who have the appropriate knowledge. The need for interpreter services also has substantial financial consequences for the provision of services.

Many specialist services are only available in the region two or three times a year. At other times, clients may not be able to access the services, may be able to access limited services, or may need to leave the region and travel to southern communities (often Montreal) to obtain the services. This can have substantial consequences for the client, his/her family members and the health system within the region.

Transportation costs have a substantial impact on the provision of continuing care services in the region as much of the transportation of people and medical supplies and equipment must be done by air. While there are several health services available in the three study communities, health professionals within these communities travel to other areas within the region and/or clients and their families travel to the larger communities for services. Clients may need to travel to southern communities to obtain more specialized health services. Medical aids, equipment and supplies need to be transported by air much of the year. Building and other materials related to the provision of grab bars, wheelchair ramps, and so on also need to be imported into the region.

8.10 Cost of Providing Services

The findings from this study do not enable conclusions to be made regarding the cost of providing continuing care services to home and facility clients by level of care. Nevertheless, it is clear that “hidden” costs associated with the provision of such services are substantial. As noted previously, salaries, benefits and transportation costs all have substantial impacts on the provision of services. In order to provide required services, the two health centres have operated in a deficit situation. However, the goal of the region is to reduce and ultimately eliminate the deficit. Additional funding will be required to realize this goal.

¹²² E. Klimczak, personal communication, February 2006.

8.11 Cultural Aspects of Continuing Care

Several factors likely influence the provision of continuing care services for Inuit. These include: language issues and educational levels; housing conditions; the location of Inuit communities; cultural beliefs regarding dependency; and the availability of Inuit health care providers.

8.11.1 Language Issues and Educational Levels

The majority of clients only spoke Inuktitut. This was also the case with family caregivers, although formal caregivers often spoke Inuktitut as well as another language. While it appeared that almost 93% of family caregivers preferred the same language as clients, this was only true for about 50% of the formal caregivers. The preservation of one's traditional language is essential to preservation of one's culture. It is, therefore, very important that care be provided by individuals who know the language, culture and traditions. When that is not possible (for example, because a shortage of workers), it is critical that medical interpreters be present to ensure that clients understand what services are required and why and that care providers understand any concerns regarding the provision of those services.

In health care, it is important that clients (and family members) be able to identify and communicate health-related concerns and that they understand what is required in the way of assistance. Communication challenges are likely to occur when health care providers do not speak the same language as clients, and can be dangerous in some cases (such as taking medications, monitoring symptoms and adhering to dietary restrictions). Communication challenges may be exaggerated when clients receive services outside of their own community and/or the region. While translation assistance is available (and it is understood that translators accompany individuals who need to leave the region to obtain assistance¹²³), the translation of medical information is a highly skilled task.

It is also noted that clients tended to have a low education level. This means that health care providers, particularly nurses, physicians and therapists may need to make considerable effort to ensure that clients and their families are aware of what is required and why, with respect to the provision of continuing care services.

8.11.2 Housing Conditions

Clients receiving services at home often lived in crowded conditions, a finding that is consistent with several other sources (for example, Inuit Tapiriit Kanatami, 2004b). Individuals who require continuing care services because of a chronic contagious condition such as tuberculosis may pass it on to others living in the same household. The presence of others in the household may mean that individuals requiring continuing care services may receive all the assistance they require, although the findings from the current study do not provide clear support for this. Formal care providers may have difficulty providing continuing care services to individuals living in very crowded situations. This may be particularly problematic if a client requires careful monitoring or palliative care.

¹²³ R. Ferguson, personal communication, April 2005.

8.11.3 Location of Inuit Communities

The specific Inuit communities included in this study are similar to other communities in Nunavik as well as in other Inuit regions with respect to the availability of health services. Clients may need to leave their own communities to receive health care services in other, larger communities (this was the case with some of the clients in the current study). They may also need to leave the region to obtain more specialized health services. In Nunavik (as in the other Inuit regions), travel from one location to another generally has to occur by air. With the possible exception of emergency medical evacuations, this means clients have to be well enough to travel, funding needs to be available to cover the cost of transportation, family members may not be able to accompany the client, and communication issues may occur between clients and health care providers. While there are attempts within Nunavik to keep individuals within the region (for example, through resources such as the hospitals in Kuujuaq and Puvirnituq and the Reintegration Centre in Inukjuak), there is probably more that can be done to ensure that clients receive services closer to home. Resources such as the Module du Nord Québécois assist clients when they need to travel to Montreal for services. But when clients need to travel to other communities (for example, in other provinces), the (potentially negative) impact of receiving services in an unfamiliar location, from unfamiliar care providers, could be substantial.

8.11.4 Cultural Beliefs Regarding Dependency

It is understood that at least some Inuit may feel that needing to rely on others for assistance may diminish their sense of worth. As a consequence, it may make it difficult to determine an individual's functional status, his/her perceptions of health and well-being, and what he/she is feeling both physically and emotionally. The direct involvement of Inuit individuals in the assessment of continuing care needs and the provision of continuing care services is essential. Additional steps need to be taken to ensure that Inuit are provided with appropriate training and employment opportunities.

8.11.5 Availability of Inuit Health Care Providers

While it is likely that some of the formal caregivers in the current study were Inuit, this does not seem to be the case for all providers.¹²⁴ This may be one of the reasons why many of the formal caregivers felt that providing continuing care services had neither positive nor negative impacts. It may also account for why some of the questions were not answered by formal caregivers (for example, regarding changes in clients' health status). As noted above, though, there are several advantages to having Inuit caregivers involved in the provision of continuing care services and attempts should be made to improve training and employment opportunities.

¹²⁴ Formal caregivers were not asked if they were Inuit or not, but based on the three questions regarding language use, it would appear that some were and some were not.

8.12 Future Directions

8.12.1 Introduction

The findings from this phase of the Continuing Care Research and Costing Project indicated that there are several areas in which improvements can be made. Development and implementation of the recommendations would likely entail enhanced collaboration among several levels of government and several departments within each level. As noted earlier, Inuit are generally happy with what they have and are unlikely to make requests for additional services. That does not mean, however, that existing services are sufficient. To the extent that it is possible to do so, from both a practical and a financial perspective, the improvements should be made at the community level. Where that cannot be done, attempts should be made to improve services at the sub-regional and regional levels. The focus should be on the clients and their needs. Creative solutions, such as those already in place in the region, will be required to meet the needs.

8.12.2 Data Collection

As a result of having the Home and Community Care Program, the Nunavik Region is able to collect substantial information regarding current users of the program (e.g., their gender, age, reason(s) for needing services, etc.). Information is also available on why services are not provided. The data is generally collected at the community level by professional staff (such as nurses or social workers). These individuals carry out data collection in addition to their other responsibilities and often after hours. When they leave their positions, the knowledge they have gained may go with them. Although regional data is available, the resources required to analyze it and provide reports are limited. There is a need to have trained individuals who can collect the necessary information, analyze it and provide detailed reports. Funding is required to recruit, train, and retain individuals to carry out these activities.

8.12.3 Existing Housing

The findings from this phase of the Continuing Care Research and Costing Project indicated that required modifications and repairs to existing housing may need to be made.

In general, it appeared that available housing for clients living at home was in relatively good condition, although some homes did have mold and mildew. As the presence of either of these could have a substantial impact on individuals with respiratory and other conditions, steps should be taken to ensure that all houses are mold and mildew free. In general, it was noted that required renovations/repairs to homes are made and that grab bars, wheelchair ramps and other resources are available when required. Given the substantial cost of providing these resources, steps should be taken to ensure that any required funds will be available as needed. Health care providers (including home support workers) may need to advocate for necessary equipment, if clients and/or family members are unwilling to do so.

The long term care facilities in the region also generally seem to be in good condition. However, it was noted that there is no budget for making improvements to these buildings.

Again, steps should be taken to ensure that funding is available to ensure that existing buildings are maintained at a level that meets both the needs of clients and health care providers. For example, perhaps double rooms should be explicitly identified as such and enlarged to accommodate the needs of individuals who may require medical equipment such as wheelchairs and lifts.

8.12.4 Additional Housing

The findings from this phase of the Continuing Care Research and Costing Project also indicated that there is a need for additional housing. For individuals who require continuing care services at home, overcrowded living conditions may not be healthy either for them or for their family members. For example, infectious conditions such as tuberculosis can spread quickly in such situations. Overcrowded situations may also make it difficult to provide certain types of care, such as dressings. For individuals who require continuing care services in a facility setting, there is a need for assisted living settings, elders' lodges, homes for the physically challenged and homes for the mentally challenged. Although the region has a number of resources now, there appears to be a need for additional resources to ensure that individuals are able to receive the care they require in appropriate settings. If some of these new housing settings were built with multiple purposes in mind, they could also be used to provide respite care, palliative care, intergenerational programs, etc., as required. Steps should be taken to explore a variety of housing options for the region. The Canada Mortgage and Housing Corporation (CMHC) may be able to provide assistance with researching, developing and funding appropriate housing options in the region.¹²⁵

8.12.5 Continuing Care Services

The interviews with both clients and caregivers indicated that many individuals, both at home and in facilities, receive case management like services (for example, assistance with obtaining medical equipment and medications and coordinating and arranging medical appointments). While this may be appropriate for home care clients, given the types of difficulties most of them are experiencing (based on the functional status measure), it does not seem to be sufficient for individuals living in facilities. Individuals living in facilities need more appropriate care settings, activities that are designed to both meet their needs and ensure they remain an important part of the community, and more involvement with family members. Key areas to consider include physiotherapy, social and recreational activities, and specialized education for children with special needs. Social and recreational activities could include time with peers and family members (such as being together to share stories or to participate in outdoor activities), and intergenerational activities (such as the sharing of cultural traditions, stories, and crafts). Steps should be taken to increase the number of people who can assist with these activities (this may include family members as well as paid staff and children as well as adults). Steps also need to be taken to ensure that funding is available to meet these needs. There is a particular need to develop services for children with special needs.

¹²⁵ A recent article by CMHC provides commentary regarding a number of different aspects that could be considered (CMHC, 2005). As well, they have been involved in developing a number of innovative housing solutions for individuals with dementia, individuals with physical challenges and other groups.

8.12.6 Increasing Human Resources

There is considerable need to increase local capacity. In order to increase capacity at the local level, interested individuals need to be identified and trained. Training and support need to be ongoing to ensure that individuals have the necessary knowledge, but also to facilitate the retention of trained individuals. There is also a need for motivation incentives to ensure that individuals remain interested. Ideally, “pools” of trained individuals would be developed for high need occupations such as medical interpreters, home support workers, nurses, etc., so that the necessary resources were available at the community level when they were required. While the recruitment, training and retention of Inuit health care providers is critical, the recruitment, training and retention of family caregivers is also very important. The availability of trained family members is particularly important for individuals at higher care levels who may wish to remain at home and/or for whom no facility bed is available within the region.

While some funding is currently available for developing local capacity, additional funding is required to both maintain and build on existing capacity. There needs to be funding for individuals who are primarily responsible for training in the region, for interpreters to assist with the training sessions, for ongoing training and support, for opportunities for health care workers to share their experiences with one another on a regular basis, and so on. Distance education, for example through videoconferencing or telehealth technology, may enable individuals to receive training and support in their own communities.¹²⁶

8.13 Conclusion

The Nunavik Region has established a number of resources for individuals who require continuing care services. It is hoped that the findings from this phase of the Continuing Care Research Project will enable the region to improve these resources for current clients and their families as well as for individuals who may require the services in the future.

¹²⁶ It is noted that training opportunities for several groups of health and social service providers were offered in fiscal 2004/2005 (Nunavik Regional Board of Health and Social Services, 2005). This is a very positive step.

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