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

Review of Literature and National Health Data Sources

Canada

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EXECUTIVE SUMMARY

1. Introduction

The term “continuing care” refers to a complex system of service delivery rather than to a type of service (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).

As used in the Continuing Care Research and Costing Project, 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 (Government of Canada, 2004). 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 is not a major focus of this study.

The purposes of the Continuing Care Research and Costing Project are to:

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

The project primarily focuses on First Nations living on reserves and Inuit living in communities south of 60^0 L. The findings from the study will feed into the development of continuing care policy options for First Nations and Inuit in Canada.

The Continuing Care Research and Costing Project involves several components. This document presents the findings from the review of the published and unpublished literature and the national databases. The findings from other components of the Continuing Care Research and Costing Project are presented in separate documents.

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[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. Methodology

The search of the continuing care literature regarding First Nations and Inuit populations in Canada and Indigenous populations internationally covered the following areas:

- Perspectives on continuing care and service options;
- Health status indicators related to continuing care;
- Service utilization relevant to continuing care;
- Assessment of needs and data collection tools on health status service outcomes (such as satisfaction, quality of life) and informal (family) caregivers;[2]
- Service delivery models for First Nations, Inuit and Indigenous populations; and
- Cost-effectiveness of continuing care services.

Information in the grey literature[3] was identified by members of the Continuing Care Policy Development Working Group, the Expert Advisors on the Planning of the Continuing Care Research Project, the Manitoba Regional Advisory Group, and the Continuing Care Regional Roundtable.[4] In addition, a review of the reports from the approximately 140 projects conducted from Health Canada’s original Health Transition Fund (HTF) was carried out to identify any projects that might be relevant to the current project. Finally, a review of previous continuing care studies conducted by Hollander Analytical Services Ltd. (the company contracted to carry out the Continuing Care Research and Costing Project) was conducted.

Information was also obtained from Health Canada, Statistics Canada, Indian and Northern Affairs Canada, the Canadian Institute for Health Information, the Assembly of First Nations, the National Aboriginal Health Organization (NAHO) and the University of Toronto Government Documents Library.

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[2] Much of the non-Aboriginal/non-Indigenous literature uses the term “informal caregiver” to refer to individuals who are often close family members or friends who provide (generally) unpaid assistance to individuals requiring care and/or support. Several keywords were used to identify this group, including: informal caregiver, family caregiver and unpaid caregiver.

[3] The term “grey literature” is used to refer to committee, research, technical or government reports, standards, discussion papers, working papers and other documents that are generally not reported in academic journals. The grey literature is often an important source of information on programs, projects and policies.

[4] The Continuing Care Policy Development Working Group was actively involved in the development of continuing care policy options. The Expert Advisors on the Planning of the Continuing Care Research Project served as the national advisory group for this project. The Manitoba Regional Advisory Group and the Continuing Care Regional Roundtable served as informal advisory groups for the researchers.

3. Findings

3.1 Continuing Care and the Broader Context of Health

The *Canada Health Act*, which was passed in 1984, is founded on five principles: accessibility, comprehensiveness, portability, universality and public administration. The *Act* identifies two major categories of service: Insured Health Services (which include acute, rehabilitative and chronic hospital care and services provided by physicians) and Extended Health Care Services (which include long term care, home care, facility care, and ambulatory health care services). The principles of the *Canada Health Act* apply only to Insured Health Services; they do not apply to Extended Health Care Services. Provinces and territories can choose to cover services delivered by health practitioners other than physicians in their respective health care insurance plans (for example, physiotherapists, chiropractors, and psychologists). Some services, such as home support and adult day care, are not covered by the *Canada Health Act* but are covered under the general Canada Health and Social Transfer.

Continuing care has evolved differently in each of the provinces and territories of Canada. Although there is a considerable amount of overlap, there are also important differences in the organization of services, the policies adopted, and the terminology used, across jurisdictions (see Hollander and Walker, 1998). Services are generally not fully integrated/coordinated, there may be gaps in service delivery, and/or there may be policy and funding “stovepipes”[5] across various continuing care systems (Hollander & Prince, 2002).

3.2 First Nations and Inuit Health and Well-being

First Nations and Inuit have a holistic view of health and well-being; that is, health or wellness is considered to involve physical, mental, spiritual and emotional harmony and balance, rather than simply the absence of disease. This perspective is consistent with the concept of continuing care being used in the Continuing Care Research and Costing Project, and with a population health approach.

First Nations and Inuit have not, and currently do not, benefit from Canada’s health care system to the same extent as non-Aboriginals. Romanow (2002) noted that there are at least five underlying reasons for this disconnect: competing constitutional assumptions; fragmented funding for health services; inadequate access to health care services; poorer health outcomes; and different cultural and political influences. These factors make it very challenging to address First Nations and Inuit health issues. In recent years, a number of initiatives have been developed for First Nations and Inuit peoples that attempt to address some of the determinants of health rather than simply treating illnesses. These initiatives have focused on breaking down the barriers that exist between health policy and social policy areas.

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[5] The term “stovepipe” is used in this document to refer to a structural, policy, financial and/or program entity that functions separately from other, sometimes related, entities. The term “silo” is sometimes used for the same concept.

3.3 The Need for, Demand for, and Use of, Continuing Care Services by First Nations and Inuit

To some extent, the care needs of First Nations and Inuit are similar to those of the general population. However, there are several unique factors that affect the need for, demand for, and use of, continuing care services by First Nations and Inuit, including: population demographics; morbidity and disability rates within the population; availability of a continuum of health care services; and cultural context.

Both the First Nations and Inuit populations are growing. Overall, between 1996 and 2001, the First Nations population grew by 15.2% and the Inuit population grew by 12.1% (Statistics Canada, 2004). In both cases, the largest increase has been in the 65 and older age group.

In addition to a review of the published and grey literature, a review of Canadian national health and social survey databases was conducted in order to identify reliable information regarding the health status of Aboriginal peoples. The focus was on health status related to chronic conditions, disability and functional limitations, as these health problems result in the need for continuing care. Many of the national health surveys do not identify respondents by cultural background and several surveys explicitly exclude Aboriginal individuals living on reserves, in northern territories and/or in remote areas. Even when Aboriginal individuals are included in the survey sample, the accuracy of the data may be questionable because of small sample sizes and limited participation rates. In addition, the usefulness of existing data may be limited because of variability in the collection and reporting of non-mandatory data, differences in the type of information collected by various provinces/territories, and differences in the type of information collected within provinces/territories. Unfortunately, the lack of adequate data on Aboriginal/Indigenous populations is not unique to Canada.

There are only two surveys that have focused specifically on Aboriginal peoples – the 1997 First Nations and Inuit Regional Longitudinal Health Survey and the 2001 Aboriginal Peoples Survey. Both surveys took a very broad view of health. However, the samples for the two surveys differ substantially. The First Nations and Inuit Regional Longitudinal Health Survey included both First Nations and Inuit individuals.[6] The focus was on individuals living on-reserve/in communities; individuals from some non-reserve communities in Québec and the territories were also included. The 2001 Aboriginal Peoples Survey is representative of Aboriginal individuals living off-reserve/outside communities; the total Aboriginal population in the Northwest Territories was included in this survey.

The First Nations and Inuit Regional Longitudinal Health Survey found that almost half of the individuals under 55 years of age indicated that their health was very good or excellent (National Aboriginal Health Organization, nd).[7] The 2001 Aboriginal Peoples Survey found that 56% of respondents had good to excellent health (Statistics Canada, 2003). In comparison, 65%

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[6] The Inuit only participated in the 1997 survey. The name of the survey has been changed to reflect participation by First Nations only.

[7] Although a second round of data have been collected, findings are not available at this time.

of the Canadian population who participated in the 2001 Census indicated that their health was good or excellent (Statistics Canada, 2004a).

Particular health issues affecting the First Nations population include a high incidence of diabetes, cardiovascular and lung diseases, and injuries as well as social and emotional issues related to the impact of the residential school system, family breakdown, unemployment and social stress (INAC, 2003; Kirby, 2002). National and regional health data on Inuit is severely limited. However, where regional data do exist, they indicate that: life expectancy for Inuit males is substantially less than that of both other Aboriginal men and the Canadian average; suicide, tuberculosis and lung cancer rates are higher than the national average; and Inuit health and safety is being negatively impacted by climate change and environmental contaminants (Archibald & Grey, 2000; Inuit Tapiriit Kanatami, 2004a; Kusugak, 2002). In addition, compared to the non-Aboriginal population, First Nations and Inuit populations also have a generally higher health risk profile due to: the remoteness of many communities from full health and social service resources; the loss of traditional family supports; and the loss of traditional community supports (INAC, 2003; Kusugak, 2002).

In general, chronic conditions are likely to occur two to three times more frequently among First Nations and Inuit than among non-Aboriginals. The six most common chronic conditions among non-reserve First Nations are: arthritis, high blood pressure, asthma, stomach problems or intestinal ulcers, diabetes and heart problems (Statistics Canada, 2004a). The Inuit reported lower levels of these six conditions (Statistics Canada, 2004a). This finding may be due to undiagnosed conditions among the Inuit and/or to differences in the age composition of First Nations and Inuit populations. The likelihood of having one or more chronic conditions increases with age. Differences between First Nations/Inuit and non-Aboriginal populations with respect to health status appear in early adulthood and increase throughout the adult years with the greatest differences occurring in old age (Statistics Canada, 2004a).

For First Nations and Inuit, particularly those living in remote and isolated communities, being able to access adequate health services can be very challenging because of geographic location, community size, the availability of health professionals, the availability of services, and funding issues.

Federal funding is provided for health programs and services in First Nations and Inuit communities. However, sustainability of funding for community health services for First Nations in the provinces and for Inuit communities in Labrador is currently an issue. Some health services (such as home care) which are not covered by the *Canada Health Act*, but which may be provided by provincial governments, may or may not be provided to First Nations and Inuit communities. The grey area between federal and provincial/territorial control can affect a wide range of services for First Nations and Inuit, including mental health programming, home-based palliative care and community long term care institutions (Lemchuk-Favel & Jock, 2004).

It is very important that First Nations and Inuit individuals have the opportunity to obtain culturally appropriate health services. This may mean: having health services provided by First Nations and Inuit personnel and/or in the individuals' own language; having access to traditional healing approaches as well as "western" medicine; and having the support of family and community members. In short, it is important that First Nations and Inuit be able to receive the care they need, while at the same time, having the opportunity to maintain close ties to their culture and community.

It may be difficult for First Nations and Inuit individuals to leave their community and their cultural environment to obtain health care services that are only available outside of their community. Some of the negative social effects of moving First Nations and Inuit to off-reserve facilities include loss of identity, social isolation, culture shock (particularly for individuals from isolated communities) and cultural deprivation. The potentially negative consequences of receiving care outside of their community strongly encourages many individuals to remain in, or to return to, their communities. Access to health services can be improved by making services familiar, non-threatening and reflective of the local culture. First Nations and Inuit in front line health delivery have positive effects on access to care. However, there are relatively few First Nations and Inuit health providers in Canada (Lemchuk-Favel & Jock, 2004). Telehealth may play an important role in improving access to health services in First Nations and Inuit communities (although it is recognized that a lack of information and communication technology in some communities limits accessibility).

3.4 Models of Integrated Continuing Care Service Delivery

There is a wide variety of non-Aboriginal continuing care delivery systems in Canada and internationally. With few exceptions, most of the better known models were described in the late 1980s and 1990s; there are few new models. There is relatively little documentation of Canadian models, perhaps because of a lack of evaluation, and/or the fact that most models are operated by Ministries of Health or Regional Health Authorities that typically document their systems to meet internal requirements rather than publishing descriptions in the scientific literature.

In 2001, Health Canada initiated a major research project to analyze the strengths and weaknesses of care delivery systems across Canada for four populations of individuals with ongoing, or long term, care needs. Separate studies were conducted on care delivery systems for the frail elderly, individuals with disabilities, individuals with chronic mental health conditions, and children with special needs. Table 1 identifies a number of service components that are mandated for continuing care for the general population. The table also includes service components that are currently mandated for First Nations and Inuit under FNIHB’s Home and Community Care Program and INAC’s Assisted Living Program.

While examples of integrated continuing care models can be found in the non-Aboriginal literature, this is not the case in the literature on Aboriginal/Indigenous peoples. In the latter case, the emphasis has been on more general integrated health systems. With respect to Aboriginal populations in Canada, an integrated health system can be defined as a health services network which is responsible and accountable for the provision of publicly funded services, including those delivered through federal funding (for example, home and community care, non-insured health benefits) and those currently included under the *Canada Health Act* and funded by provincial or territorial governments (for example, hospital and physician services) (National Aboriginal Health Organization, 2001).

Table 1: Continuing Care Service Components

Type of Service	Seniors	Persons with Disabilities	Mental Health	Children with Special Needs	Services Mandated by FNIHB’s and INAC’s Continuing Care Programs
Community/Home Based Services					
System Level Case Management[8]	X	X	X	X	
Information/Referral Services	X	X	X	X	X
Meal Programs	X				X
Self-Managed Attendant Services		X			X
In-Home Nursing Care	X	X		X	X
Home/Community Rehabilitation (PT/OT)	X	X	X	X	
Homemakers/Home Support Services/Care Aids/Attendants	X	X	X	X	X
Day Care/Day Support (special and integrated)	X		X	X	X
Group Homes		X	X	X	X
Respite Care	X	X	X	X	X
Palliative Care	X				X
Technical Aids, Equipment & Supplies	X	X		X	X
Supportive Housing	X	X	X		
Life & Social Skills Training & Support Groups	X	X	X	X	
Outpatient/Ambulatory Care Services			X	X	
Primary Care/Family Physicians			X	X	
Day Hospitals	X		X		
Community Emergency Services/Crisis Support	X	X	X	X	
Specialty Transportation Services	X	X	X	X	X
Foster Care	X			X	X
Mental Health Services for Children				X	
Buddy Programs				X	
Summer Camps				X	
Drug Benefits Services	X	X	X	X	
Physician Specialists (psychiatry, pediatrics)	X		X	X	
Institutional Services					
Institutional Services	X	X	X		X
Extended or Chronic Care Facilities	X	X		X	
Specialty Hospital Services (pediatrics, geriatrics, rehab)	X		X	X	
Children’s Hospital				X	
Psychiatric Hospital/Beds			X		
Palliative Care	X			X	X
Hospital Based Emergency Services	X		X		
Regular Hospital Services	X	X	X	X	

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[8] As noted earlier, case management is a component of FNIHB’s Home and Community Care Program, but does not appear to be present at a broader systems level.

Type of Service	Seniors	Persons with Disabilities	Mental Health	Children with Special Needs	Services Mandated by FNIHB's and INAC's Continuing Care Programs
Respite Care	X	X			X
Educational/Vocational Services					
Special Integrated Preschool Programs				X	
Integrated School Programs				X	
In Home Teachers/Tutors				X	
Vocational Training/Support		X	X	X	
Income Support Programs					
Financial Assistance to Purchase Equipment and Supplies for Home Renovations	X	X		X	
Income Assistance	X	X	X		
Judicial/Criminal Justice Services					
Judicial/Criminal Justice Services				X	

Lemchuk-Favel and Jock (2003; see also Marriott & Mabel, 2003) present a framework for Aboriginal health systems that focuses on governance, system design and financing. They propose that an Aboriginal health system should:

- be organized around multi-disciplinary primary health service delivery and administration and include both a single entry point and case management;
- involve the establishment of a health authority which is accountable to member communities;
- involve practitioners in system planning and governance in order to encourage a sense of ownership in the system;
- define the population to be served by the health authority;
- structure the health authority in such a way as to promote collaboration of the various service partners both within and outside of the system;
- include a broad range of health and health-related services;
- develop community health plans through extensive consultation;
- include a common clinical information system or connected information infrastructure;
- provide practitioners with the necessary skills for multi-disciplinary care; and
- provide funds based on capitation and a rostered population.[9,10]

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[9] The term "rostered population" refers to a group of individuals who are defined as constituting the population who are in care using specific characteristics, such as age, type of chronic illness, living situation and so on.

[10] The amount of funding would need to be weighted or adjusted to reflect the characteristics of the rostered population. These characteristics would need to include, at a minimum, age and gender, but could also include other

Existing integrated Aboriginal health systems have many different forms and include both functional (financial and/or administrative) and clinical models. Successful and sustainable client-focused health systems share many characteristics. These characteristics include (Lemchuk-Favel & Jock, 2004; see also Lemchuk-Favel & Jock, 2002, National Aboriginal Health Organization, 2001):

- Self-empowerment – Aboriginal ownership and control of health services contributes to self-empowerment and improves access to supportive, culturally appropriate services.
- A holistic approach – The Aboriginal concepts of holism and wellness are incorporated into the design of community programs, from the individual care level to the administrative integration of health and social services.
- Synergism of traditional and western health philosophies – Traditional healing practices include physical, spiritual, emotional, social and mental well-being. They may be combined with western medical approaches to develop unique approaches to health services (such as the inclusion of traditional healers on a multi-disciplinary team). Community preferences with regard to traditional and western approaches vary.
- A focus on primary care – The health system emphasizes primary care and includes multi-disciplinary teams and linkages to external health resources. The multi-disciplinary teams can include physicians, nurses, nurse practitioners, nutritionists, pharmacists, social workers, traditional healers and so on. One of the key features is that physicians are remunerated on a salary rather than a fee-for-service basis.
- Collaborations with provincial services – Provincial governments are the administrators of physician and hospital services. Aboriginal peoples are high users of these services. Collaboration may simply involve establishing effective referral mechanisms and sharing patient information as required.
- Integrated health services delivery – Where feasible, partnerships are created among communities to achieve economies of scale.
- Administrative reform – The health system is accountable to both the community and the funders. Ideally, the number of funding agreements are reduced so as to allow flexibility in the allocation of resources and a minimization of paperwork.[11]

Despite the development of various integrated Aboriginal health systems, the health inequity gap between Aboriginal and non-Aboriginal individuals still exists. Health care that is delivered or managed within or for First Nations/Inuit/Métis communities is still fragmented with respect to programs and funding. Direct responsibility by Aboriginal communities for funding and organization is generally limited to community and primary care services;

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characteristics such as geographic location, general health status, and specific health problems (Marriott & Mabel, 2003).

[11] At the present time, 12 federal departments offer programs and services for First Nations, Inuit and Métis (Kirby, 2002). Funding may also come from provincial governments and Aboriginal organizations. The number of reports First Nations and Inuit communities are required to produce to account for funding on a yearly basis is substantial (Lavoie, O'Neil, Sanderson, Elias, Mignone, Bartlett, Forget, Burton, Schmeichel & McNeil, 2004).

secondary, tertiary, and quaternary services are generally accessed outside of communities and are owned and/or funded by external authorities (such as provincial governments and regional health authorities). As a result, there is no continuing care system available in Aboriginal communities, Aboriginal governments and people do not have a "health system" and the desire for substantial control of Aboriginal health services by Aboriginal peoples that serve *their* needs has not been met (Marriott & Mabel, 2003).

3.5 Cost-Effectiveness of Continuing Care Services

An important aspect of the Continuing Care Research and Costing Project involves an analysis of the cost-effectiveness (that is, the costs and outcomes) of First Nations and Inuit continuing care services. Cost-effectiveness analysis is often equated with an analysis only of costs for the purpose of determining expenditure reductions. This is *not* what cost-effectiveness analysis is, or should be, all about. Cost-effectiveness analysis is a means by which funders and service providers can analyze how services are being delivered and if, and how, they can be delivered more effectively. It is *not* only about costs; there is an equal weighting on *costs* and *outcomes*. As a result, outcome indicators (such as client and informal caregiver satisfaction with care services and the client's quality of life) are as important as the costs of providing the services. The comparative analysis of costs and outcomes may also reveal new information which can be used to change policies, procedures, and clinical practices, in order to provide more efficient and effective services.

There are three main functions of home care. The first function is to act as a substitute for hospital care. This *acute care substitution* function generally focuses on discharging people from hospital at the end of an acute care phase of their illness. Instead of spending the convalescent part of their illness in hospital, people convalesce at home with the assistance of professional health care providers (such as nurses and/or physiotherapists) and home support workers, as required. The second function of home care is to act as a substitute for long term institutional care. This *long term care substitution* function focuses on the provision of home care to clients who have such high level care needs that, in the absence of home care, they would be admitted to a long term care facility. The third function of home care is to maintain clients at their optimal level of care, preventing or delaying further deterioration, for as long as possible. This *maintenance and preventive* function of home care focuses on preventing or delaying admission to a long term care facility or hospital. The Continuing Care Research and Costing Project does not address the acute care substitution function. Thus, the literature review focused primarily on the maintenance and preventive and long term care substitution functions of home care.

Although results are mixed to some extent, the majority of studies in the international literature seem to indicate positive and/or cost-effective outcomes for preventive home care initiatives. There are very few Canadian studies on the maintenance and preventive function of home care. As with the international literature, some studies indicate that home care is not cost-effective while others indicate that it is.

A considerable amount of research has been conducted on studies of home care as a substitute for long term facility/institutional care. Several studies conducted between the late 1970s and the mid 1980s in the United States suggested that home care was not cost-effective compared to long term care. More recent studies, conducted both in the United States and Canada have shown that when the costs of community based services are compared directly with the costs of long term care services, home care may be a cost-effective substitute for facility care.

Assisted living is a new and emerging component of the care continuum for seniors. Currently, there is no agreed upon definition of the term "assisted living". In fact, the term appears to be an umbrella term which incorporates a number of new and previously existing housing arrangements such as group homes, congregate living, group living situations, supportive housing and room and board (to the extent some additional supportive services are included). There are several studies in the international literature that have examined the cost-effectiveness of assisted living; to date there appear to be none in the Canadian literature. Most of the international studies compare the costs, or costs and outcomes, of assisted living with long term facility care and have indicated that assisted living situations may be more cost-effective.

There appear to be four main types of cost drivers in the general health system: inflation; population growth; population aging; and a general category that includes service demand, health need, and system resources. It is likely that First Nations and Inuit populations are affected by all of these cost drivers. The non-Aboriginal perspective on health services focuses primarily on economics and efforts to eliminate waste and duplication. In contrast, an Aboriginal perspective holds that health services need to focus on interdependence and that health is not an economic service-based indicator (National Aboriginal Health Organization, 2001). This perspective fits well with the concept that "cost-effectiveness" involves both costs and outcomes. Very few studies, in either the Canadian or international literature, appear to have examined cost-effectiveness in continuing care systems for Aboriginal/Indigenous populations.

3.6 Benchmarks and Indicators for Continuing Care Services

Nationally, continuing care is not recognized as a major component of the health care system. At the federal, provincial/territorial and regional levels, the focus is generally on component parts (such as home care, facility care, respite care, palliative care and so on) rather than on continuing care as a broad system of care.

One of the difficulties with conducting any review of continuing care services is that services have evolved differently over time in different jurisdictions. Differences with respect to terminology, assessment instruments, the mix of services, policies regarding the role of supportive services, and other related factors, have made it difficult to have any degree of consistency across jurisdictions. While there are some benchmarks and indicators for specific service components, there is little consensus on benchmarks and indicators related to continuing care *per se*.

As a result of the focus on component parts rather than on continuing care as a system of care, organizations such as the Canadian Institute for Health Information (CIHI) have focused on developing indicators for specific service components (such as home care). Until changes are made such that continuing care, and its component parts, are recognized as separate components of the health care system, it will not be possible to have accurate national data on the continuing care sector.

3.7 Measurement Instruments

The issue of conducting cost-effectiveness analyses in the continuing care sector has been a matter of some interest for the continuing care industry and government since the early 1990s. Several initiatives have taken place to identify the type of information required about clients (for example, their characteristics and care needs), costs of care and care outcomes. It has also been recognized that family members, friends, neighbours and others have an important role to play with respect to continuing care clients.

In research studies regarding the continuing care needs of individuals and their families, it is important to collect information regarding three types of variables: socio-demographic variables; variables related to functional status; and variables related to psycho-social functioning, particularly cognitive functioning. Such studies should also include measures of the outcomes of care such as: whether care is effective; whether care is helping people; if people are satisfied with the care they are receiving; if people feel they are able to maintain their quality of life; and so on.

If one is doing a study across jurisdictions, it is important to use tools and procedures that can be used across the range of jurisdictions. It is often not possible, within a relatively limited time frame, and because of privacy laws, to access administrative data such as computerized records of hospital use, purchases of prescription drugs, use of physician services, and so on. If timing and other issues can be resolved, access to administrative data is a preferred option as such data identifies formal costs of care (that is, costs to government). However, administrative data do not include information on the informal costs of care (that is, costs borne by clients, family members, and so on). Informal costs of care include out-of-pocket expenses, estimates of caregiver time and similar costs. In order to obtain a more complete picture of the costs of continuing care, it is important to consider both the formal costs of care as well as the informal costs of care. Diaries offer a practical solution to obtaining comprehensive cost data on continuing care services covered through the formal care system, continuing care services provided by family members, friends and neighbours, and out-of-pocket expenses covered by both clients and family members. However, it is noted that questions regarding major, annual, health related expenditures need to be used to supplement the diaries (as diaries may only cover a relatively small period of time).

4. Discussion

A number of important findings emerged from the review of the literature and existing data sources with respect to continuing care services for both non-Aboriginals and First Nations and Inuit.

First Nations and Inuit have a holistic view of health and well-being. That is, health or wellness is considered to involve physical, mental, spiritual and emotional harmony and balance, rather than simply the absence of disease. This perspective is consistent with the concept of continuing care being used in the Continuing Care Research and Costing Project and a population health perspective. As a result, there are several similarities between a continuing care perspective in the non-Aboriginal literature and the First Nations/Inuit view of health and well-being.

Policy makers generally do not recognize that continuing care is a major component of the health care delivery system. As a result, there is relatively little data on continuing care. With respect to the non-Aboriginal population in Canada, there is little national information on the costs of continuing care, on the comparative sets of services provided across jurisdictions, or on the characteristics and care needs of people receiving care in different continuing care settings. The lack of information is compounded many times over when it comes to Aboriginal/Indigenous populations. There are almost no published studies, in Canada or internationally, on this topic. There is limited information on how services are organized, what they cost, how effective they are, what types of clients are served and so on. In addition, almost nothing is known about the effectiveness of different approaches to addressing language, cultural issues, and traditions with respect to aboriginal populations. There has been almost no development of measurement instruments that are sensitive to the needs of aboriginal populations for program delivery, policy, planning, and research purposes.

There are several similarities between the organization of non-Aboriginal continuing care services and First Nations and Inuit health services. For example, single entry is a key component of both. There is a belief in the benefits of an integrated, client focused, and comprehensive approach to care. There is also a commitment to a psychosocial, rather than strictly medical, model of care. However, both non-Aboriginal and First Nations/Inuit systems face several challenges including: coordinating care with other services; human resource issues; gaps in service; and policy and funding stovepipes. These challenges make it difficult to coordinate and/or integrate care services to meet the needs of the individual in care and his/her family. Multiple funding sources, each with their own rules and policies – some of which may contradict each other and/or lead to blockages in the flow of needed care across service delivery components – are a particular challenge for First Nations and Inuit communities. In addition, there are a number of service components that are mandated for continuing care for non-Aboriginal populations that are not mandated for First Nations and Inuit.

There are opportunities to improve the effectiveness of health and social services for First Nations and Inuit. A key prerequisite is to have a high degree of coordination among funders so that there can be one overall funding envelope for continuing care services.

Several key points need to be considered with respect to the future funding and provision of continuing care services in First Nations and Inuit communities. These include the following:

- The provision of continuing care services in First Nations and Inuit communities should focus on the needs of the individual and his/her family and the most appropriate responses to those needs.
- Professional health services need to be supplemented with various forms of supportive services that assist individuals to maintain their independence for as long as possible.
- The use of traditional healers, culturally relevant support services and culturally relevant community activities needs to be explicitly supported.

- Families and communities caring for individuals with continuing care needs should be supported.
- Although palliative care is not a focus of the Continuing Care Research and Costing Project, consideration needs to be given to the provision of care to individuals who are dying.
- Artificial stovepipes in the way health services are funded, structured and delivered should be eliminated.
- Jurisdictional issues among federal, provincial/territorial, and First Nations/Inuit governments need to be resolved. The identification of roles and responsibilities at each level may contribute to this process.
- Steps need to be taken to better integrate the programs and services offered by various governments.
- The active involvement of First Nations and Inuit in the development of programs and policies and the determination of realistic funding requirements with regard to the provision of continuing care services and related issues (such as the training of First Nations and Inuit health care providers) is critical.

5. Conclusion

There appear to be several areas in which improvements could be made to enhance the funding and delivery of continuing care services for First Nations and Inuit. Such improvements could streamline service delivery and free up some existing resources to be used to enhance care delivery for First Nations and Inuit requiring continuing care services. The Continuing Care Research and Costing Project can contribute to the process. The project also has the potential to contribute substantial new knowledge not only to First Nations and Inuit in Canada, but also to aboriginal populations around the world.

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Our thanks to the Continuing Care Policy Development Working Group, the Expert Advisors on the Planning of the Continuing Care Research Project, the Québec Continuing Care Regional Round Table and the Manitoba Regional Advisory Group for identifying relevant documents in the grey literature and key issues to be considered. The knowledge and expertise provided by the members of these various groups is greatly appreciated.

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1. INTRODUCTION

1.1 Setting the Context

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).[12] 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).

Continuing care service delivery systems were originally developed to respond to the needs of the elderly and individuals with physical disabilities. Relatively recently, however, it has been recognized that a continuing care model of service delivery may also be applicable to other individuals with ongoing care needs.

As used in this project, 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 (Government of Canada, 2004). These individuals include: 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 individuals 55 years of age and older who are unable to care for themselves because of a physical disease or condition or because of a mental health condition. Adults with chronic diseases or conditions were defined as individuals between 18 and 54 years of age who are 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 individuals between 18 and 54 years of age who are 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 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.

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[12] There are a number of terms used throughout this document. When the term first appears, it is defined either in the main body of the report or in a footnote. All defined terms are also presented in the Glossary at the end of this document.

Continuing care services may be provided in the home, in supportive living environments, or in facility settings.[13] Although it is recognized that palliative care is part of the continuum of continuing care services, it is not a major focus of this study.

1.2 Continuing Care Services Currently Being Provided 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)[14,15] 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 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 (institutional) care, which reimburses expenses for Type I and Type II social care in facilities (Government of Canada, 2004; INAC, 2004).[16,17]

INAC’s Assisted Living Program is provided to individuals 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.[18] The Assisted Living Program is available to individuals who do not have the resources to obtain the necessary services themselves. The Assisted Living Program is not available in Inuit communities anywhere in Canada (including Nunavik and Labrador).[19] Although the program is available in

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[13] 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.

[14] Some continuing care services may also be provided through INAC’s Income Assistance program. This program is intended to provide all eligible recipients with financial assistance to cover basic needs such as shelter, food and clothing. Financial assistance may also be provided for special needs that are essential to the physical or social well-being of a recipient but are not included as part of the basic needs. These special needs may include: special diets, special transportation, essential household items, and personal incidentals (INAC, 2005).

[15] INAC was previously known as the Department of Indian Affairs and Northern Development, DIAND.

[16] These care levels refer to federal care levels and are defined in more detail in Appendix A. 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).

[17] Although INAC provides funding for institutional care, restrictions were imposed on the construction and operation of new on-reserve care facilities in 1988 and a greater emphasis was placed on in-home care.

[18] Until 2003, the Assisted Living Program was known as the Adult Care Program. The program was limited to adults and eligible individuals needed to be Band members. Since 2003, the program has included children and all individuals ordinarily resident on-reserve, including all First Nations (not only Band members), Inuit, Métis and non-Aboriginals.

[19] Personal communication, INAC Assisted Living Program, May 2005

the Yukon, it is not available in the Northwest Territories or in Nunavut.[20] The Assisted Living Program is also not available for the Cree or Naskapis in Québec.[21]

In theory, the Assisted Living Program is available for the four groups of clients of interest in the current study (that is, seniors, adults with chronic diseases or conditions, adults with mental health issues and children with special needs). In practice, however, not all services may be available to all of the groups, primarily due to funding constraints.[22] The services available under the Assisted Living Program vary across Canada (see Table 1-1). In-home care can consist of as little as two hours per week for housekeeping (for example, assistance with laundry) to 24-hour care for higher needs clients who refuse to leave their homes. Facility services are technically limited to Type I and Type II care, but some institutions may provide services above these levels in order to allow a resident to remain in the community (INAC, 2003).

Table 1-1: Assisted Living Program Components Available On Reserve by Province[23]

Services	YT	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NF
In-home care	X	X	X	X	X	X	X	X	X	X	X
Foster care	X	X	X	X			X				
Institutional care (Types I and II)	X	X		X	X	X	X		X		

X= available

FNIHB's Home and Community Care Program is an important contributor to continuing care for individuals living in First Nations and Inuit communities. This program complements INAC's Assisted Living Program by providing funding for basic home and community care services, including case management, nursing care, in-home respite care and personal care.[24] Currently, 91% of eligible First Nations communities and 96% of eligible Inuit communities have a Home and Community Care program.[25]

The Home and Community Care Program does not duplicate services that already exist in communities, but coordinates and links with existing programs and services that exist at the community and/or provincial/territorial level. Each community is able to determine who is eligible to receive services (for example, services may be available only to registered members of a given First Nation or services may be available to individuals from other First Nations). In theory, the Home and Community Care program is available to individuals of all ages who have

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[20] In the Northwest Territories and Nunavut, the Assisted Living Program is funded through Canada Health and Social Transfer (CHST transfer) payments and is delivered by the territorial government.

[21] The Inuit, Cree and Naskapis in Québec all operate under the James Bay and Northern Québec Agreement. Services are funded through the province of Québec (personal communication, FNIHB Regional Coordinator for Québec, May 2005).

[22] Personal communication, INAC Assisted Living Program, February 2005.

[23] The information in the table is based on personal communications with regional INAC representatives for the Assisted Living program in February 2005.

[24] The Home and Community Care Program does not provide funding for services that are already provided through the Assisted Living Program and within the program criteria.

[25] Personal communication, FNIHB Home and Community Care Program, January 2006.

an assessed need.[26] 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.[27]

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. In British Columbia and Manitoba, limited services (such as physiotherapy and occupational therapy) may be offered by some Regional Health Authorities to individuals living on reserve (INAC, 2003).[28]

1.3 Introduction to This Project

Despite the availability of the Assisted Living and Home and Community Care programs, there appears to be substantial gaps in the continuum of services being provided to First Nations and Inuit individuals, particularly for those in institutional settings who require higher levels of care. Currently, neither INAC nor Health Canada have the authority to deliver services to these individuals.[29] Provinces (with the exceptions of Québec and Newfoundland and Labrador) generally do not provide services to First Nations and Inuit communities, noting that this is a federal responsibility. Individuals requiring higher levels of care may leave their communities to obtain necessary care in provincial/territorial or private institutions outside of their communities. Alternatively, they may remain in their communities where services may not be sufficient to fully meet their care needs, as funding is only provided for Type I and Type II care.

The current project, the Continuing Care Research and Costing Project, is 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 are to:

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

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[26] Each community is required to adopt and use an assessment process. Eligibility for services is determined at the community or Tribal Council level.

[27] Personal communication, FNIHB Home and Community Care Program, February 2005.

[28] Also personal communication, Expert Advisors on the Planning of the Continuing Care Research Project, May 2005.

[29] 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 (including First Nations living on reserve and Inuit living in settlements). 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, 2004b; Romanow, 2002).

The project primarily focuses on First Nations living on reserves and Inuit living in communities south of 60^0 L. The findings from the study will feed into the development of continuing care policy options for First Nations and Inuit in Canada.

The Continuing Care Research and Costing Project involves several components:

- A review of published and unpublished literature regarding continuing care in First Nations and Inuit populations in Canada, Indigenous populations internationally, non-Aboriginal populations in Canada and non-Indigenous populations internationally;[30]
- A review of national surveys and databases containing information regarding continuing care needs in First Nations and Inuit 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 family caregivers (family members and close friends).

This document presents the findings from the review of the published and unpublished literature and the national databases. The findings from other components of the Continuing Care Research and Costing Project are presented in separate documents.

1.4 Methodology for the Literature Review and Review of the National Databases

1.4.1 Published and Grey Literature

Searches of the published literature were conducted in accordance with topic areas identified in the Phase 1: Literature Scan and Review section of the initial proposal for this study.[31] The search of the continuing care literature regarding non-aboriginal populations (both internationally and within Canada) covered the following areas:

- Indicators of demand for continuing care services (including health status indicators);
- Models of continuing care service delivery;
- Continuing care benchmarks and costs (for Canada only);
- Methodologies for costing continuing care services; and
- Cost-effectiveness of continuing care services.

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[30] Consistent with the Terminology Guidelines developed by the National Aboriginal Health Organization (2003), in this document, 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.

[31] See the document *Technical proposal in response to the request for proposal for an assessment of continuing care requirements in First Nations and Inuit communities (South of 60^oL)* prepared by Hollander Analytical Services Ltd. (February 4, 2004).

The search of the continuing care literature regarding First Nations and Inuit populations in Canada and Indigenous populations internationally covered the following areas:

- Perspectives on continuing care and service options;
- Health status indicators related to continuing care;
- Service utilization relevant to continuing care;
- Assessment of needs and data collection tools on health status service outcomes (such as satisfaction, quality of life) and informal (family) caregivers;[32]
- Service delivery models for First Nations, Inuit and Indigenous populations; and
- Cost-effectiveness of continuing care services.

The searches were limited to articles dating from between 1980 and 2004. A total of 184 published articles (out of 1907 citations) were selected for the literature review on continuing care in general. A total of 72 published articles (out of 455 citations) were selected for the literature review on continuing care in First Nations, Inuit and/or Indigenous populations. For more detailed information on how the searches of the published literature were conducted, see Appendix B.

Information in the grey literature[33] was identified by members of the Continuing Care Policy Development Working Group, the Expert Advisors on the Planning of the Continuing Care Research Project, the Manitoba Regional Advisory Group, and the Continuing Care Regional Roundtable.[34] In addition, a review of the reports from the approximately 140 projects conducted from Health Canada's original Health Transition Fund (HTF) was carried out to identify any projects that might be relevant to the current project. Finally, a review of previous continuing care studies conducted by Hollander Analytical Services Ltd. (the company contracted to carry out the Continuing Care Research and Costing Project) was conducted. While none of the previous studies conducted by Hollander Analytical Services Ltd. focused on First Nations and Inuit populations, it was thought that the previous studies may be useful for: assessing options for continuing care services for First Nations and Inuit populations; identifying potential methodologies for costing continuing care options and services; and providing information regarding the cost-effectiveness of different services in non-Aboriginal populations.

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[32] Much of the non-aboriginal literature uses the term "informal caregiver" to refer to individuals who are often close family members or friends who provide (generally) unpaid assistance to individuals requiring care and/or support. As noted in Appendix B, several keywords were used to identify this group, including: informal caregiver, family caregiver and unpaid caregiver.

[33] The term "grey literature" is used to refer to committee, research, technical or government reports, standards, discussion papers, working papers and other documents that are generally not reported in academic journals. The grey literature is often an important source of information on programs, projects and policies.

[34] The Continuing Care Policy Development Working Group was actively involved in the development of continuing care policy options. The Expert Advisors on the Planning of the Continuing Care Research Project served as the national advisory group for this project. The Manitoba Regional Advisory Group and the Continuing Care Regional Roundtable served as informal advisory groups for the researchers.

1.4.2 National Databases

Information was obtained from Health Canada, Statistics Canada, Indian and Northern Affairs Canada, the Canadian Institute for Health Information, the Assembly of First Nations, the National Aboriginal Health Organization (NAHO) and the University of Toronto Government Documents Library. A search of each source was performed using the key words: First Nations and Inuit health information; national health surveys; and Aboriginal health surveys. The search was restricted to Canadian data sets. When necessary, data sources were contacted by telephone or e-mail to obtain additional information. For more information on the national databases, see Appendix C.

1.5 Organization of This Report

Chapter 2 provides an overview of continuing care and discusses it within the broader context of health. Chapter 3 focuses on the need for, demand for, and the use of, continuing care services by First Nations and Inuit.[35] This chapter also discusses findings from the review of the national surveys and databases. Chapter 4 focuses on continuing care service delivery models in non-Aboriginal/non-Indigenous and First Nations/Inuit populations. Chapter 5 presents a discussion of the cost-effectiveness of continuing care services in non-Aboriginal/non-Indigenous and First Nations/Inuit populations. Chapter 6 provides a discussion of the literature regarding benchmarks and indicators for continuing care services. Chapter 7 provides a discussion of various measurement instruments that can be used to assess care levels, care needs, service demand, service use, and cost-effectiveness with respect to continuing care for both non-Aboriginal/non-Indigenous and First Nations/Inuit populations. Chapter 8 provides a general discussion of continuing care for First Nations and Inuit in Canada, including a review of current FNIHB and INAC policies regarding the provision of continuing care services.

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[35] Or equivalent populations in other countries.

2. CONTINUING CARE AND THE BROADER CONTEXT OF HEALTH

2.1 The Legislative Basis for Continuing Care

The *Canada Health Act*, which was passed in 1984, is founded on five principles: accessibility, comprehensiveness, portability, universality and public administration. The *Act* identifies two major categories of service: Insured Health Services and Extended Health Care Services. Insured Health Services include acute, rehabilitative and chronic hospital care and services provided by physicians. Extended Health Care Services include long term care, home care, facility care, and ambulatory health care services. The principles of the *Canada Health Act* apply only to Insured Health Services. They do <u>not</u> apply to Extended Health Care Services.

Provinces and territories can choose to cover services delivered by health practitioners other than physicians in their respective health care insurance plans (for example, physiotherapists, chiropractors, and psychologists). Some services, such as home support and adult day care, are not covered by the *Canada Health Act* but are covered under the general Canada Health and Social Transfer.

2.2 An Historical Perspective

Continuing care has evolved differently in each of the provinces and territories of Canada. Although there is a considerable amount of overlap, there are also important differences in the organization of services, the policies adopted, and the terminology used, across jurisdictions (see Hollander and Walker, 1998).

Prior to the late 1970s, the components of what is now continuing care were generally housed in three separate areas: acute care, public health and social services. This system of delivering services relied on coordination mechanisms among these three separate and distinct organizational entities, which were typically housed in different divisions and/or different ministries of government. In the 1980s to mid 1990s, there was a trend across much of Canada to develop comprehensive and integrated care delivery systems, which included home care, home support, some community services, case management, facility/institutional care and some aspects of acute care, within one service delivery system in one branch or division. This allowed for system-wide planning, policy making, administration and care provision. More recently, policy and governance changes have altered this trend. In the mid to late 1990s, there was an increased emphasis on primary health care. At the same time, health care services were regionalized in many areas of the country.

At present, continuing care services vary across jurisdictions in Canada. Services are generally not fully integrated/coordinated, there may be gaps in service delivery, and/or there may be policy and funding "stovepipes"[36] across various continuing care systems (Hollander & Prince, 2002).

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[36] The term "stovepipe" is used in this document to refer to a structural, policy, financial and/or program entity that functions separately from other, sometimes related, entities. The term "silo" is sometimes used for the same concept.

2.3 Key Terms and Concepts

Four umbrella terms which have been used to describe systems of service delivery require clarification: “continuing care”, “long term care”, “home support” and “home care”.[37]

As noted previously, the term “continuing care” is generally used to describe a system of service delivery which includes all of the services provided by long term care, home support, home care, and case management. The term reflects two concepts: that care may occur over a long period of time and that there is a continuum of care.

Historically, the term “long term care” was sometimes used to describe a range of facility services related primarily to the care of the elderly, while the term “home care” was used to describe home based services provided by nurses and other professionals (such as physiotherapists). As social welfare related services were added to the range of services provided, supportive or “home support” services (such as homemaker services and meal services), expanded the concept of home care. Currently, the term “home care” includes both professional and supportive services.

In Canada, it is generally agreed that home care has three distinct functions:

- **an acute care substitution function** in which home care meets the needs of people who would otherwise have to remain in, or enter, acute care facilities;
- **a long term facility/institutional care substitution function** in which home care meets the needs of people who would otherwise require institutionalization; and
- **a maintenance and preventive function** in which home care serves people with health and/or functional deficits in the home setting, thus maintaining their ability to live independently, and in many cases, preventing health and functional breakdowns and eventual institutionalization.

> (Adapted from: Federal/Provincial/Territorial Subcommittee on Long Term Care, 1990, p. v).

Major recent reports, such as the Romanow report on the health of Canadians (Romanow, 2002), the Kirby report on the role of the federal government in health care (Kirby, 2002), and the First Ministers Accords on health care renewal (Health Canada, 2003; Health Canada, 2004), recognize that home care may serve multiple functions. However, all of these reports focus primarily on the acute care substitution function.

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[37] The following discussion relates to the way terms were used from the mid-1980s to the mid-1990s. While this discussion is still pertinent today, the advent of regionalization is bringing about a more complex pattern and a wider range of terms.

2.4 First Nations and Inuit Health and Well-being

First Nations and Inuit have a holistic view of health and well-being. That is, health or wellness is considered to involve physical, mental, spiritual and emotional harmony and balance, rather than simply the absence of disease (see Jones, 2000; Mercer, 1996; National Aboriginal Health Organization, 2001). As a consequence, the overall state of health can be affected by the social, cultural, physical, economic and political environments in which people live. This perspective is consistent with the concept of continuing care being used in the Continuing Care Research and Costing Project, and with a population health approach.

First Nations and Inuit have a long tradition of caring for the health and well-being of family and community members. First Nations and Inuit

> have different traditions and approaches to health and healing that must be respected. Aboriginal healing is a way of life rather than a segregated or specialized activity. These traditions, which emphasize the multi-dimensional nature of people as physical, mental, emotional and spiritual beings, must be recognized in addressing the continuing care needs of (Aboriginal) peoples.
>
> (Health Canada, 2001, Appendix A)

First Nations, Inuit and Métis have not, and currently do not, benefit from Canada's health care system to the same extent as non-Aboriginals. Romanow (2002) noted that there are at least five underlying reasons for this disconnect:

- **Competing constitutional assumptions** – 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). The result is a mix of federal and provincial/territorial programs provided directly by some Aboriginal communities.
- **Fragmented funding for health services –** Funding for Aboriginal health services is scattered among the federal government, provincial/territorial governments and Aboriginal organizations. As a result, it is difficult to coordinate and obtain the maximum benefit from the funding that is available. Some of the consequences of having multiple funding sources involved in the delivery of health services include: fragmented programs; problems with coordinating programs; problems with acceptance of referrals; problems with continuity of care; inconsistencies in programs; gaps in service delivery; possible overlaps in programs; problems with information sharing; and problems with reporting mechanisms (Kirby, 2002; Inuit Tapiriit Kanatami, 2004a; Lemchuk-Favel & Jock, 2003; National Aboriginal Health Organization, 2001).

- **Inadequate access to health care services –** Different groups of Aboriginal peoples have different access to programs and services offered by the federal government. Benefits vary according to where people live (for example, on or off reserve), how they are identified (for example, First Nations, Inuit, or Métis) and their legal status (for example, treaty or non-treaty) (see Bartlett & Jock, 2001; Lemchuk-Favel & Jock, 2004). Access to adequate health services is particularly challenging for individuals living in remote and isolated Aboriginal communities. The availability of health care providers also has a substantial impact on access to health care services.[38]
- **Poorer health outcomes –** There are substantial differences between the health of Aboriginal populations and the health of the non-Aboriginal population in Canada.[39] For example, First Nations experience high rates of diabetes, cardiac problems and disability (especially mental disabilities). Inuit experience high suicide, tuberculosis and lung cancer rates. Life expectancy for First Nations is estimated to be 68.9 years for males and 76.6 years for females; for Inuit, the comparable figures are 62.6 years and 71.1 years (Health Canada, 2005; Inuit Tapiritt Kanatami, 2004a). In contrast, the life expectancy for all Canadian men is 77.0 years and for all Canadian women is 82.2 years (Health Canada, 2005a).
- **Different cultural and political influences –** Aboriginal communities may differ substantially with respect to values, customs, languages, needs and circumstances. In addition, there are a large number of political entities that represent Aboriginal populations at different levels. These include: local First Nation Band Councils, regional First Nation Tribal Councils, regional Inuit Land Claims Organizations, provincial organizations, and national organizations as well as more specialized organizations (such as those that represent Inuit women and Métis residing in urban settings).

The above factors make it very challenging to address Aboriginal health issues. In recent years, a number of initiatives have been developed for Aboriginal peoples that attempt to address some of the determinants of health rather than simply treating illnesses. The initiatives have focused on breaking down the barriers that exist between health policy and social policy areas (for example, social services, housing, and education). Breaking down these barriers has generally necessitated the development of partnerships between Aboriginal organizations and various levels of government. A common theme in the development of new initiatives is the proactive involvement of Aboriginal individuals. The active involvement of First Nations, Inuit and Métis is important since it results in increased awareness of services, ensures that needs are being met, and helps identify how satisfied people are with the services they are receiving. Some recent initiatives include the *Blueprint on Aboriginal Health* (2005), the Health Integration Initiative (Health Canada, 2005b) and the current project.

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[38] Both the 1996 Royal Commission on Aboriginal Peoples and the more recent report on *The Health of Canadians: The federal role* (Kirby, 2002) identified the need to train Aboriginal health care workers in a variety of areas. This is particularly important for Inuit communities (Archibald & Grey, 2000). The 2004 First Ministers Accord contains a commitment from the federal government to increase the supply of health care workers in Aboriginal communities (Health Canada, 2004).

[39] This appears to be true in several other countries as well (for example, Dicharry, 1986; Maniapoto & Gribben, 2003; Manson & Callaway, 1988; Mokuau, 1990).

3. THE NEED FOR, DEMAND FOR, AND USE OF, CONTINUING CARE SERVICES BY FIRST NATIONS AND INUIT AND THE CARE EXPERIENCE

3.1 Introduction

To some extent, the care needs of First Nations and Inuit are similar to those of the general population. However, there are several unique factors that affect the need for, demand for, and use of, continuing care services by First Nations and Inuit. These include: population demographics; morbidity and disability rates within the population; availability of a continuum of health care services; personal and social preference; and cultural context.

3.2 Population Demographics

Both the First Nations and Inuit populations are growing (see Table 3-1). Overall, between 1996 and 2001, the First Nations population[40] grew by 15.2% and the Inuit population grew by 12.1%.[41] In both cases, the largest increase has been in the 65 and older age group. Statistics Canada (2005) has estimated that between 2001 and 2017, the annual growth rate for the First Nations population will be 1.9%. For the Inuit, the annual growth rate over the same time period is estimated to be 2.3%.

Table 3-1: Aboriginal Population by Age Group (1996 and 2001 Census Data)[42]

	First Nations			Inuit		
	1996	2001	5 year change (%)	1996	2001	5 year change (%)
0 – 14	199,715	221,800	11.1	16,510	17,460	5.8
15 – 24	98,810	108,540	9.8	7,605	8,260	8.6
25 – 64	236,600	282,820	19.5	15,095	17,950	18.9
65 & older	19,545	25,755	31.8	1,015	1,405	38.4
Total	**554,670**	**638,915**	**15.2**	**40,225**	**45,075**	**12.1**

Source: Statistics Canada (2004). On-line at http://www12.statcan.ca

The 2001 Census Data indicated that 21.6% of First Nations live in Ontario, 19.4% live in B.C., 14.8% live in Manitoba, 14.0% live in Alberta, and 13.8% live in Saskatchewan. Less than half (47.3%) of the First Nations population live on-reserve; 41.2% live in urban centres and a further 11.5% live in rural off-reserve locations. It is expected that by 2017, 57% of First Nations will live on reserve (Statistics Canada, 2005).

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[40] Statistics Canada refers to this group as Native Americans rather than First Nations.

[41] The growth of the First Nations population is due both to high birth rates as well as increased participation in the Census. The growth of the Inuit population is primarily due to two demographic factors – increased birth rates and increased life expectancy (Statistics Canada, 2003a; 2004a).

[42] Based on individuals who self-identified themselves as belonging to one or more Aboriginal groups. Also includes individuals who did not self-identify themselves as being an Aboriginal, but indicated they were a Registered or Treaty Indian and/or they were a member of a Band or First Nation.

The 2001 Census Data indicated that approximately 50.0% of the Inuit population live in Nunavut, 21.2% live in Québec, 10.1% live in Newfoundland and Labrador, and a further 8.7% live in the Northwest Territories. This regional distribution is expected to remain the same until at least 2017 (Statistics Canada, 2005).

The 2001 Census Data also indicated that with the exception of the First Nations population in Saskatchewan, the Inuit had the youngest population.[43] In 2001, the median age of the Inuit population was 20.6 years.[44] In contrast, the median age of the First Nations was 23.5 years. By comparison, the median age of the non-Aboriginal population was 37.7 years. It is estimated that, by 2017, the median age would be 26.6 years for First Nations and 24.0 years for Inuit (Statistics Canada, 2005).

3.3 Overall Health

A review of Canadian national health and social survey databases was conducted in order to identify reliable information regarding the health status of Aboriginal peoples. The focus was on health status related to chronic conditions, disability and functional limitations, as these health problems result in the need for continuing care. Table 3-2 lists the general surveys and data bases that were examined for information relevant to the current project (for more information on each of these, see Appendix C). Many of the national health surveys do not identify respondents by cultural background, and in fact, several surveys explicitly exclude Aboriginal individuals living on reserves, in northern territories and/or in remote areas. Even when Aboriginal individuals are included in the survey sample, the accuracy of the data may be questionable because of small sample sizes and limited participation rates. In addition, the usefulness of existing data may be limited because of variability in the collection and reporting of non-mandatory data, differences in the type of information collected by various provinces/territories, and differences in the type of information collected within provinces/territories. Unfortunately, the lack of adequate data on Aboriginal/Indigenous populations is not unique to Canada (Burhansstipanov, 1995; Goins, Tincher, & Spencer, 2003; Maniapoto & Gribben, 2003).

There are only two surveys that have focused specifically on Aboriginal peoples – the 1997 First Nations and Inuit Regional Longitudinal Health Survey[45]and the 2001 Aboriginal Peoples Survey. Both surveys took a very broad view of health. However, the samples for the two surveys differ substantially. The First Nations and Inuit Regional Longitudinal Health Survey included both First Nations and Inuit individuals.[46] The focus was on individuals living on-reserve/in communities; individuals from some non-reserve communities in Québec and the territories were also included. Most First Nations reserves did not participate in the 2001 Aboriginal Peoples Survey. Nevertheless, the sample is representative of Aboriginal individuals living off-reserve/outside communities. The total Aboriginal population in the Northwest Territories was included.

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[43] The median age of First Nations in Saskatchewan was 18.4 years.

[44] The median age is the point where exactly half of the population is older and the other half is younger.

[45] This survey is intended to provide longitudinal data on First Nations. Although a second round of data have been collected, findings are not available at this time.

[46] The Inuit only participated in the 1997 survey. The name of the survey has been changed to reflect participation by First Nations only.

Table 3-2: List of National Health and Social Services Survey Databases Examined

Sponsor	Name of Survey/Database	Brief Description
Statistics Canada	2001 Census of Population	The census is conducted every 5 years and provides population and dwelling counts for Canada. It also provides the demographic, social and economic characteristics of Canadians. The 2001 Census is the first census which is able to identify Aboriginal peoples by their self-identification with at least one Aboriginal group (North American Indian, Métis and Inuit). The accuracy of data on Aboriginal people may be limited.
	2001 Aboriginal Peoples Survey	The Aboriginal Peoples Survey is a post-censual survey based on Aboriginal self-identification from the Census of Population. The 2001 Survey describes the health status of Aboriginal peoples who live outside of First Nations, Métis and Inuit communities, but contains little information regarding the on-reserve First Nations population.
	Participation and Activity Limitation Survey	Similar to the Health and Activity Limitation Survey, this 2001 survey identifies Canadians with an activity limitation and examines the impact of these limitations on their lives and barriers to participating fully in Canadian life. No data are available for First Nations and Inuit individuals.
	Canadian Community Health Survey	The Canadian Community Health Survey, which began in 2000, is intended to provide regular cross-sectional estimates of health determinants, health status and health system utilization across the country. Individuals living on First Nations reserves and in some remote areas are excluded.
	Health Services Access Survey	The 2003 Health Services Access Survey was administered as a supplement to the Canadian Community Health Survey. The survey is designed to collect information regarding waiting times for key diagnostic and treatment services and access to 24/7 first contact health services. Individuals living on First Nations reserves, in the territories and in some remote areas are excluded.[47]
	National Population Health Survey	The National Population Health Survey, which began in 1994, is a longitudinal survey designed to examine changes in health and health behaviours. Individuals living on First Nations reserves, on Canadian Forces bases or in some remote areas of Ontario and Québec are excluded. In addition, the sample size is not large enough to produce reliable data on Aboriginal peoples.
	General Social Survey	The General Social Survey is intended to monitor changes in the living conditions and well-being of Canadians over time and to provide immediate information regarding specific policy issues of current or emerging interest. The sample size is not large enough to produce reliable data on Aboriginal peoples.
	Residential Care Facilities Survey	The Residential Care Facilities Survey collects data from care facilities across Canada. The survey is mandatory for all facilities which have four beds or more and which are approved, funded, or licensed by provincial/territorial departments of health and/or social services. No information is available specifically on facilities operated by Aboriginal organizations or on the cultural background of individuals in the facilities.
	Canadian Cancer Registry	The Canadian Cancer Registry is used to study cancer patterns and trends and to monitor differences in cancer risks among different populations. Information regarding Aboriginal peoples is not available on a national basis, but is available for the western provinces.
	Canadian Health Measures Survey	This new survey is intended to gather information on the risk of chronic diseases such as diabetes, cancer, asthma, etc. There will be no data collection on First Nations reserves. The chances of obtaining information from a reasonably sized sample of Aboriginal peoples living outside of Aboriginal communities is slight, given the relatively small size of the total sample.

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[47] The term “Territories” is used to refer to the Yukon, Northwest Territories and Nunavat.

Sponsor	Name of Survey/Database	Brief Description
Health Canada	Berger Population Health Monitor	The Berger Population Health Monitor focuses on a variety of health issues. The sample size is too small to allow identification of Aboriginal peoples.
	Administrative Data Sets	FNIHB collects data from the 600 Aboriginal communities for which it provides primary care, public health and health promotion services. Mandatory reporting includes information on communicable disease control and environmental health. Non-mandatory reporting includes vital statistics and chronic diseases. Variability exists in the collection and reporting of the non-mandatory information.
	Maternal Mortality Study and Fetal/Infant Mortality Study	These studies are expected to provide accurate information about the occurrence of maternal and infant mortality among the Aboriginal population
INAC	Surveys and datasets	The Department of Indian and Northern Affairs does not collect health information, but does collect information regarding social services.
Other	The First Nations Regional Longitudinal Health Survey	The First Nations Regional Longitudinal Health Survey is intended to result in a longitudinal database about health, wellness, health determinants and the concerns and issues of First Nations peoples across Canada. The survey contains information regarding First Nations peoples living on participating reserves and in some non-reserve communities in Québec and the Territories. Inuit communities only participated in the 1997 cycle of the survey.
	Canadian Institute for Health Information	Administrative records provided by the provinces to the Canadian Institute for Health Information contain information about health utilization by First Nations and Inuit peoples. However, most provinces do not identify Aboriginal peoples in the databases and, as a result, national information about health utilization that is routinely provided for the Canadian population is not available for First Nations and Inuit peoples.
	Provincial administrative datasets	The provinces of British Columbia, Alberta, Saskatchewan and Manitoba use a variety of mechanisms to identify First Nations clients in their health databases.

The First Nations and Inuit Regional Longitudinal Health Survey found that almost half of the individuals under 55 years of age indicated that their health was very good or excellent (National Aboriginal Health Organization, nd). The 2001 Aboriginal Peoples Survey found that 56% of respondents had good to excellent health (Statistics Canada, 2003). In comparison, 65% of the Canadian population who participated in the 2001 Census indicated that their health was good or excellent (Statistics Canada, 2004).

Particular health issues affecting the First Nations population include:

- A high incidence of diabetes and its associated complications (including blindness, renal disease and amputations);
- A high incidence of cardiovascular disease, resulting from diabetes, poor nutrition, alcohol and drug abuse, inactivity and smoking;
- A higher incidence of injuries (related to self-harm, alcohol and drug abuse) compared to the general population resulting in higher morbidity and mortality;
- Social and emotional issues related to the impact of the residential school system, family breakdown, unemployment and social stress;
- Reactivated tuberculosis caused by inadequate treatment in the past (this may be due to the particular form of tuberculosis);

- A high incidence of lung disease such as chronic obstructive pulmonary disease; and
- An increasing incidence of Hepatitis C (INAC, 2003; see also Kirby, 2002).

National health data on Inuit is severely limited. Data is also lacking at the regional level and for Inuit populations within the four Inuit regions.[48] Regional data, where it does exist, indicates that:

- life expectancy for Inuit males is substantially less than that of both other Aboriginal men and the Canadian average;
- suicide rates are six times higher than the national average;
- tuberculosis rates are four times higher than the national average;
- lung cancer rates are 60% higher than the national average; and
- Inuit health and safety is being negatively impacted by climate change and environmental contaminants (see Archibald & Grey, 2000; Inuit Tapiriit Kanatami, 2004a; Kusugak, 2002).

In addition, compared to the non-Aboriginal population, First Nations and Inuit populations also have a generally higher health risk profile due to: the remoteness of many communities from full health and social service resources; family breakdown; the loss of traditional family supports; and the loss of traditional community supports (INAC, 2003; Kusugak, 2002).

In general, chronic conditions are likely to occur two to three times more frequently among First Nations and Inuit than among non-Aboriginals (Kirby, 2002; National Aboriginal Health Organization, 2004; Statistics Canada, 2004). The six most common chronic conditions among non-reserve First Nations are: arthritis, high blood pressure, asthma, stomach problems or intestinal ulcers, diabetes and heart problems (Statistics Canada, 2004). The Inuit reported lower levels of these six conditions (Statistics Canada, 2004). This finding may be due to undiagnosed conditions among the Inuit and/or to differences in the age composition of First Nations and Inuit populations (as noted in Table 3-1 above, Inuit individuals tend to be younger). The likelihood of having one or more chronic conditions increases with age. Differences between First Nations/Inuit and non-Aboriginal populations with respect to health status appear in early adulthood and increase throughout the adult years with the greatest differences occurring in old age (Statistics Canada, 2004).

3.4 Access to a Continuum of Health Services

As noted in the previous chapter, accessibility to health services is one of the key principles of the *Canada Health Act*. For First Nations and Inuit, particularly those living in remote and isolated communities, being able to access adequate health services can be very challenging.[49] For example, Lemchuk-Favel and Jock (2004) note that for about 35% of First

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[48] Inuit live primarily in four regions: Nunavut; Inuvialuit (Northwest Territories); Nunavik (Northern Québec) and Nunatsiavut (Labrador).

[49] Most Inuit live in isolated areas of Canada (Kusugak, 2002).

Nations communities, physician services are located more than 90 km away. About 60% of these communities do not have road access and must rely on either scheduled or special flights to bring visiting health professionals in and/or to take individuals requiring specialized or hospital-based services out to larger centres. In most Inuit communities, basic health care services are delivered through small health centres that are often staffed by a single nurse (Kusugak, 2002). Many small communities see doctors and other health professionals only a few times every year. Although additional services may be available in larger Inuit communities, access to these communities may be limited by transportation options (most Inuit communities are only accessible by air year round), cost, and the availability of social supports (such as a medical translator).[50]

Another factor that affects access to health services is community size. Lemchuk-Favel and Jock (2004) noted that 43% of First Nations communities in the provinces and the Yukon have populations of 400 or less and an additional 34% have populations between 401 and 1,000. Most Inuit communities have populations of less than 1,000 (Kusugak, 2002). Many health services may not be available at the community level because the population size is unable to support the services, the number of staff is limited, and/or it is difficult to recruit and retain qualified health professionals. For example, smaller communities may find it difficult to provide a base level of services because of the per capita funding formula used by the federal government. It may also not be possible, economically, for smaller communities to support a facility. It is more likely that larger communities are able to provide a broader range of continuing care services than smaller communities (INAC, 2003).

Federal funding is provided for health programs and services in First Nations and Inuit communities. However, sustainability of funding for community health services for First Nations in the provinces and for Inuit communities in Labrador is currently an issue.[51] Health services for Aboriginal peoples outside of First Nations and Inuit communities are under the jurisdiction of the various provinces/territories. Some health services (such as home care) which are not covered by the *Canada Health Act*, but which may be provided by provincial governments, may or may not be provided to First Nations and Inuit communities. The grey area between federal and provincial/territorial control can affect a wide range of services for First Nations and Inuit, including mental health programming, home-based palliative care and community long term care institutions (Lemchuk-Favel & Jock, 2004).

Access to health services can be improved by making services familiar, non-threatening and reflective of the local culture. First Nations and Inuit in front line health delivery have positive effects on access to care. However, there are relatively few First Nations and Inuit health providers in Canada (see Lemchuk-Favel & Jock, 2004). In addition, the recruitment and retention of qualified personnel are major issues for small or remote communities as the

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[50] A large proportion of Inuit only speak Inuktitut and thus the availability of a medical translator is a significant factor with respect to their ability to access health services.

[51] The base funding envelope for Health Canada's community health programs and the Non-Insured Health Benefits (NIHB) program was limited to an annual increase of 3% since fiscal year 1996/1997. Recently, Health Canada made an adjustment to its base – 7.7% for the NIHB program and 3% community health programs (see Lemchuk-Favel & Jock, 2004).

availability of qualified personnel, living and working conditions, and wages can all be problematic (see for example, Archibald & Grey, 2000; Inuit Tapiriit Kanatami, 2004a).

Kirby (2002) suggested that telehealth could play an important role in improving access to health services in Aboriginal communities. Telehealth may also address capacity issues (although it is recognized that a lack of information and communication technology in some communities limits accessibility). Examples of telehealth networks that are currently providing services to First Nations and Inuit include the Manitoba Telehealth Network, the Yukon Telehealth Network and the Ikajuruti Inungnik Ungasiktumi (IIU) Telehealth Project in Nunavut.[52] As of June 2005, Canada Health Infoway was involved in several telehealth projects which could affect the delivery of health services in several First Nations and Inuit communities (Canada Health Infoway, 2005).

3.5 Personal and Social Preferences and Cultural Context

It is very important that First Nations and Inuit individuals have the opportunity to obtain culturally appropriate health services.[53] This may mean: having health services provided by First Nations and Inuit personnel and/or in the individuals' own language; having access to traditional healing approaches as well as "western" medicine;[54] and having the support of family and community members. In short, it is important that First Nations and Inuit be able to receive the care they need, while at the same time, having the opportunity to maintain close ties to their culture and community.

Chapleski, Sobeck and Fisher (2003) asked Great Lakes American Indians where they would prefer to receive care should they no longer be able to take care of themselves. Approximately 62% of Elders indicated that they would prefer to stay in their own home and receive assistance either from paid caregivers (30.4%) or from family members (31.3%). Another 23% indicated that they would prefer to receive care in an assisted living, foster care, or group home setting. Only 8% indicated that they would prefer to receive care in a nursing home (long term care facility). Approximately 60% of the children of these Elders indicated that they would prefer that the Elders remain in their own home with assistance from paid caregivers (13.4%) or from family members (46.3%). In contrast to the Elders, however, an additional 31.3% indicated that they would prefer that the Elders move in with a family member (4.4% of Elders indicated that this would be their preferred option). Only 5.9% of the children indicated that they would prefer the Elders move into an assisted living, foster care or group home setting.

Care provided by non-aboriginal providers (whether provided in aboriginal communities or not) may not be sensitive to the cultural needs of the clients and, as a consequence, may not be well utilized (Schacht, Tafoya & Mirabla, 1989, Walters & Ankomah, 1996; Wellever, Hill & Casey, 1998; Woodruff, 1995). Mercer (1996, p. 188) noted that, "Cultural care practices (are)

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[52] There is also a telehealth project in Labrador which the Nunatsiavut government hopes to link to (ITK representative, personal communication, December 2005).

[53] It is recognized that this may also be important for Métis.

[54] Jones (2000) has cautioned that linkages between these two approaches to care need to be established. In addition, it recognized that not all First Nations and Inuit individuals may choose to access traditional health and healing approaches (National Aboriginal Health Organization, 2001).

required in all aspects of the care process – assessment and intervention, staff selection and training, policy and procedure implementation, and facility location and design. Culturally sensitive care requires accommodation and negotiation with clients as partners in the process."

Boyle, Szymanski and Szymanski (1992) identified several factors that are important for the provision of culturally sensitive care. These include: awareness of clients' preferred (or only) language; determination of the importance of traditional cultural values and beliefs for clients and their families; identification of the extent to which social, cultural and environmental factors influence health (both positively and negatively); and awareness of family and societal relationships. Health providers and other individuals from within the communities may be able to help bridge the gap (Anonymous, 1980; Burhansstipanov, Bad Wound, Capelouto, Goldfarb, Harjo, Hatathlie, Vigil, & White, 1998; Carrese & Rhodes, 2000; DeCourtney, Jones, Merriman, Heavener, & Branch, 2003; Dicharry, 1986: Eboch, 1986; Manson, 1989; Nel & Pashen, 2003). It is important to note that having care providers who are not from the same First Nation or Inuit community as the individuals receiving care may result in problems similar to those which arise with non-Aboriginal care providers (INAC, 2003).

It may be difficult for First Nations and Inuit individuals to leave their community and their cultural environment to obtain health care services that are only available outside of their community. Some of the negative social effects of moving First Nations individuals to off-reserve facilities include loss of identity, social isolation, culture shock (particularly for individuals from isolated communities) and cultural deprivation (Hobus, 1990; Schultz & Farrell, 1998; Schultz & Helander, 1988).[55] The potentially negative consequences of receiving care outside of their community strongly encourages many First Nations and Inuit to remain in, or to return to, their communities.[56] One response to this has been to provide care services in First Nations and Inuit communities in a manner that strives to honour cultural traditions.

An example of how care services can be provided in a way that honours cultural traditions in a First Nations community is provided by Shomaker (1981; see also Mercer, 1996). Shomaker described two facilities that were established on a Navajo reservation in the southwestern United States. The facilities are run by a Navajo organization. They are staffed primarily by Navajos who speak Navajo; this is particularly important for the elderly as few Navajo Elders speak English with any fluency (Mercer, 1996). Both medicine men and general practitioners visit the residents. Activities are designed to continue familiar patterns of Navajo culture (for example, weaving, pottery, participation in festivities on the reserve). Traditional Navajo food is served at meals and snack time. Even though staff understood and respected cultural traditions, residents still needed to make a number of adjustments, including living

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[55] This would likely apply to Inuit as well. The research conducted to date has focused on Native Americans and First Nations.

[56] In Canada, First Nations and Inuit individuals with higher care needs may be able to receive appropriate services through Health Canada's Home and Community Care Program. However, INAC's Assisted Living program is intended for individuals requiring Type I or Type II care only. For individuals requiring higher level institutional care, First Nations often have to make difficult choices: to keep individuals with higher care needs in the community but not provide the needed services; to keep the individuals in the community and provide the needed services without being able to recover the costs from governments (thus going outside of INAC's authority and potentially needing to find ways to compensate for the lack of funding); or to transfer the individuals to appropriate institutions outside of the community.

primarily in-doors after living most of their lives out-of-doors and sharing living areas with unfamiliar individuals. Other adjustments needed to be made with respect to sleeping and approaches to cleanliness (Mercer, 1996).

An example of how culture and care are combined in an Inuit community is provided by Asante (2000). He described a Reintegration Centre for individuals with severe and persistent mental health problems and/or intellectual impairment located in Nunavik. The centre strives to enable individuals to develop the necessary skills to be successfully integrated into their communities. One of the many services that are offered involves enhancing the knowledge and practice of traditional skills.

Both the increased availability and acceptability of services appear to result in increased utilization. For example, in a study examining the use of in-home services by American Indian seniors, Chapleski and Dwyer (1995) found that individuals residing on rural reserves were more likely to use home services (for example, chore, homemaker and meal services), to use a home health aid, and to receive home visits than individuals residing in rural off-reservation areas or in urban areas. High school graduates were more likely to use home visit services, individuals who lived with a spouse (rather than living alone) were less likely to use home chore services or receive home visits, and individuals who lived with others were substantially less likely to use a home health aid. Furthermore, being in poor or very poor health increased the likelihood of using all three types of services. Greater functional impairments (in both activities of daily living and instrumental activities of daily living) had little impact on home visit use, but did affect the use of both home chores and home health aids. Greater awareness of in-home service availability increased the likelihood of using all three types of services.

In a more recent study, Goins, Tincher and Spencer (2003) examined whether American Indian and white elderly differed with respect to their awareness and utilization of home and community-based long term care services. Study participants were asked a set of questions regarding all of the available home and community-based long term care programs in their area (for example, if they were aware of the program and, if so, whether they had used it and how they had learned about it). Overall, American Indians had more functional impairments than their white counterparts. In comparison to the white elderly, the American Indian elderly were almost three times more likely to be aware of the home and community-based long term care services and were over five times more likely to have used the services. The American Indians were most likely to learn about a program through a health care referral (for example, through a physician, nurse or hospital discharge) and through family members. Their white counterparts were most likely to learn about a program through friends and family members. The researchers concluded that the fact that many of the services for the American Indians were tribally run might have resulted in increased awareness and use.

When individuals receive health services outside of their communities and then return to their communities for ongoing treatment, it is essential that the health providers in the community have the training and information required to provide the necessary care. While this may seem obvious, intercultural differences as well as geographic location may compound the issue. For example, Carruthers, Whishaw, Thomas and Thatcher (1995) found that health care providers in small aboriginal communities in Australia were not always able to provide appropriate care for a limited number of dialysis patients, in part because there was high staff turnover and in part because the protocols to be followed were written for individuals with previous dialysis experience. The authors found that providing the necessary information in a user-friendly, easy to read format resulted in improved care management.

3.6 Impact on Family Caregivers

Having sufficient qualified health providers is a major issue for First Nations and Inuit populations in general, and is particularly problematic for those individuals living in small and remote communities (see for example, INAC, 2003; Inuit Tapiriit Kanatami, 2004a, Kusugak, 2002; Lemchuk-Favel & Jock, 2004).[57] In these cases, caregivers, such as family members and friends, may provide the necessary care (Hennessy, John & Anderson, 1999; McCabe, 1988). Many aboriginal cultures also place substantial emphasis on “caring for one’s own”, at both a family and a community level.

In the non-Aboriginal literature, the concept of caregiver burden is central to theoretical conceptualizations of the caregiving process. However, caregiving may have different meanings for different groups.

Strong (1984), for example, examined how culture, interpretation and coping influenced family caregivers’ views regarding caring for elderly relatives. Eleven dimensions that caregivers used to define the caregiving situation were identified. These dimensions included: apprehension; independence; emotional involvement; responsibility; emotional desirability; conflict; respect; control; guilt; anger; and loss. Seven dimensions were used similarly by both American Indian and white caregivers. Feelings of apprehension were experienced by all of the caregivers. Caregivers commented on the value of autonomy and self-reliance (independence), both for themselves and for their relative. They noted the importance of not letting the elderly feel unwanted (emotional involvement) and expressed a sense of duty (responsibility) to their relative. Caregivers also expressed positive emotions (emotional desirability) regarding the caregiving experience (for example, good feelings regarding being able to help) and commented on their own increased self-respect and self-esteem (respect) when the needs of their relatives were met. They also commented on dissension in the family (conflict); the American Indian caregivers also commented on conflict with the larger community. The American Indian and white caregivers differed with respect to four of the eleven dimensions. While white caregivers felt they had influence over the caregiving situation or hoped to gain that influence (control), the American Indian caregivers did not. Slightly more than half of the white caregivers indicated that they felt angry or frustrated at times (anger), while only one of the American Indian caregivers indicated he/she felt this way. In contrast, half of the American Indian caregivers indicated that they felt a sense of loss (of the individual, of tradition and of family ties). Only one white caregiver indicated he/she felt a sense of loss. Both groups of caregivers felt guilty with respect to their ability to care for their relative. The white caregivers used this dimension to express concern regarding feeling mean or unloving towards their relative. This was not the case with the America Indians. American Indian caregivers were more likely than the white caregivers to report using stress management strategies, particularly one Strong termed “passive forbearance” to cope with the caregiving situation. This strategy emphasized acceptance of, and adaptation to,

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[57] This seems to be the case in Canada as well as in other countries.

the caregiving situation rather than an attempt to control it. The sample size in this study was quite small (10 caregivers in each group). As a consequence, the findings need to be interpreted cautiously. Nevertheless, the study provides some preliminary information regarding the impact of providing care in a First Nations context.

In a more recent study, John, Hennessy, Dyeson and Garrett (2001) examined the impact of care provision on 169 Pueblo family caregivers. The care recipients had high care needs: approximately 25% required assistance with activities of daily living (for example, bathing, dressing); over 60% required assistance with instrumental activities of daily living (for example, using the telephone, taking medications); 28% experienced cognitive deficits (for example, remembering recent events, recognizing people); 92% experienced challenging behaviours (for example, wandering, agitation); and 48% could not be left alone for more than an hour. John et al. used a scale that assessed the extent to which caregivers felt their emotional health, physical health, social life and financial status were affected by their caregiving roles and responsibilities. The instrument, which was adapted from the Burden Interview developed by Zarit, Reever and Back-Peterson (1980), used relatively concrete phrasing, temporal characterization of the caregiving experience (by using the phrase "how often do you") and wording that was appropriate to a broad population of caregivers.[58] John et al. reported that family caregivers experienced four emotions as part of the caregiving experience: role conflict; negative feelings; caregiver efficacy; and guilt.

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[58] This scale is described in more detail in Chapter 7.

4. MODELS OF INTEGRATED CONTINUING CARE SERVICE DELIVERY

4.1 Introduction

As noted earlier, in the 1980s and early 1990s there was a movement across Canada to provide care for the elderly, and for persons with disabilities, within integrated care delivery systems, and more specifically, care delivery systems which include home care, home support, some community services, case management, facility care and some aspects of acute care. In the mid to late 1990s, as health care services were regionalized in much of the country, and an increased emphasis was placed on primary health care, most of the earlier integrated care delivery systems were dismantled across Canada. In the late 1990s Health Canada emphasized just one component of continuing care, home care, as one of the priority areas for demonstration and evaluation projects through the original Health Transition Fund. More recently, the Romanow Commission (2002), the Kirby Committee (2002) and First Ministers agreements (Health Canada, 2003, 2004) have contributed to the splintering of the continuing care concept by emphasizing only one of the three functions of home care (specifically the acute care substitution function).

In an extensive program of research on the cost-effectiveness of home care, Hollander and Chappell (2002) presented a number of policy recommendations regarding how home care services should be structured. They noted that in order to more readily make the types of substitutions required to achieve greater effectiveness, home care needs to be part of a broader, integrated system of home care and facility care; that is, part of a continuing care system. By having administrative and fiscal control over a large, integrated system of care, senior executives and policy makers could take steps to substitute appropriate and cost-effective home care services for acute care and facility care. Furthermore, they could ensure that policies, programs and procedures could be formulated on a broader systems basis, that is, a basis that supports a comprehensive approach to care. Hollander and Chappell also recommended a shift in Canadian health policy from a focus on home care on its own to an integrated model of continuing care in which cost-effective substitutions of home care for facility care could be facilitated. Finally, they noted that how care delivery systems are organized and structured has a substantial impact on the efficiency and effectiveness of these care delivery systems. Hollander and Chappell called on policy makers to re-legitimize continuing care as one of the main pillars of the Canadian health care system along with hospitals, physician services, public health and drugs.

Policy makers do not generally recognize that a properly constructed continuing care system would constitute the third largest component of the Canadian health care system in terms of government expenditures, after hospitals and medical services. By extrapolating data from the early 1990s and using the small amount of data that currently exists, Hollander (2003) estimated that in the early 2000s annual public expenditures on continuing care were some $11 to $13 billion dollars. By comparison, Canadians spent some $18 billion on drugs in 2002; only 36% of that amount (or $6.5 billion) was paid for by government (Canadian Institute for Health Information, 2003).

4.2 Integrated Continuing Care Service Delivery Models in the Non-Aboriginal Sector

4.2.1 Introduction

There is a wide variety of non-Aboriginal continuing care delivery systems in Canada and internationally. While it is beyond the scope of this document to describe all such care delivery models, a limited number of models have been well documented in the published and grey literature. With few exceptions, most of the better known models were described in the late 1980s and 1990s; there are relatively few new models. At least for Canada, this is consistent with the previous discussion regarding the disintegration of previously existing continuing care structures. There is relatively little documentation of Canadian models, perhaps because of a lack of evaluation, and/or the fact that most models are operated by Ministries of Health or Regional Health Authorities which typically document their systems to meet internal requirements rather than publishing descriptions in the scientific literature.

4.2.2 Major International and Canadian Models of Continuing Care Service Delivery Systems

Hollander, Miller, Ritter, MacAdam and Straka (2002) examined the cost-effectiveness and cost-benefit of several home and community care programs in the United States and Canada. All of the programs addressed at least one of the functions of home and community care; several addressed more than one function. Four of the models described by Hollander et al. are relevant to the current study. These models are:

- **S/HMO** (Social Health Maintenance Organization) – Developed in the United States, the S/HMO model was developed as a extension of the Health Maintenance Organizations (HMOs). While the HMOs provided integrated hospital and medical care services, S/HMOs were designed to provide a broader range of health and social services to the elderly and individuals with disabilities. S/HMOs were intended to: improve care for vulnerable populations; be more cost efficient; reduce fragmentation; enhance public-private financing for long term care and prescription drug benefits; and prevent unnecessary institutionalization (Leutz & Greenlick, 1998).
- **PACE** (Program of All-Inclusive Care for the Elderly) – Developed in the United States, this program involves coordinated preventive, primary, acute and long term care services. It is intended to help older individuals live as independently as possible in the community. In order to be eligible for the program, participants must be 55 years of age and eligible for long term care facility placement. Chronic conditions such as diabetes, dementia, coronary artery disease and cerebrovascular disease are common among enrollees (Greenwood, 2001).
- **CHOICE** (Comprehensive Home Option of Integrated Care for the Elderly) – Modeled after PACE, this Alberta program is designed to help frail seniors remain in the community for as long as possible. The program is designed to provide a full continuum of care to individuals with multiple and/or complex health needs who are frequent users of acute care services and/or who would otherwise require admission to a long term care facility. Individuals in the program have access to a day health

centre, home care services, respite and treatment beds, and 24 hour emergency services; all services are provided under one organization.

- **ALTCS** (Arizona Long Term Care System) – This program, which is part of the Arizona Health Care Cost Containment System (AHCCCS), provides a full range of home and community care services to the elderly, physically disabled, and developmentally disabled individuals considered at risk for institutionalization.[59] Program contractors provide a full range of services to eligible individuals including home and community based services, alternative institutional settings, nursing facilities, intermediate care facilities for the developmentally disabled, hospice, acute care services, behavioural health, and case management services.

In a separate report, Hollander (2002) provided a description of the British Columbia continuing care system. From 1983 to 1994, the BC Continuing Care Division (which existed under the provincial Ministry of Health) delivered three programs: the Long Term Care Program, which included long term care assessment and case management; the Community Home Care Nursing Program, which provided home nursing services; and the Community Rehabilitation Program, which provided rehabilitation services. These three programs were complementary and offered clients coordinated services. Although regional health authorities currently deliver these health services, the overall model of care is fairly similar to the model in place in 1994. When a potential client is referred to one of the programs, health care professionals in that program determine if the client meets basic need and eligibility requirements. If the requirements are not met, the potential client is informed and, where appropriate, is referred elsewhere. If requirements for the Long Term Care Program are met, a case manager conducts an in-depth assessment of the client's abilities, disabilities, capabilities, and health care needs. As part of this assessment process, both community and facility based long term care clients are categorized into one of five distinct levels of care.

These five models (that is, S/HMO, PACE, CHOICE, ALTCS and the BC Continuing Care System) have a number of common features, including a single point of entry,[60] a comprehensive assessment,[61] ongoing case management[62] and a single administrative structure.[63] In addition, all five models address the three functions of home care: an acute care substitution function, a long term facility/institutional care substitution function and a maintenance and preventive function.

Table 4-1 summarizes difference among the models across a number of relevant dimensions. All the American models (S/HMOs, PACE and the ALTCS) have a single funding

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[59] Although it is thought that all of the other models provide services to all cultural groups, the ALTCS explicitly provides services to Native Americans. Under agreements with AHCCCS, six Native American tribes deliver case management services and provide or arrange for home and community based services for Native Americans who live on reservations. In addition, a Native American Community Health Centre provides case management services to Native American ALTCS members who do not receive case management services from a tribe (Arizona Health Care Cost Containment System, 2001).

[60] A single point of entry provides a focal point so that individuals do not have to speak to multiple sources to find out what services are available and how they can be accessed.

[61] A comprehensive assessment ensures that there is an appropriate determination of need.

[62] Ongoing case management ensures that there is regular monitoring and review of client needs.

[63] A single administrative structure ensures that system efficiencies can be maximized.

envelope through a program of capitation for all component services.[64] The BC model also had a single funding envelope for all continuing care services through a budget process, while the CHOICE model does not. The BC model is the only model of the five reviewed which had one standard care level classification system for all clients served, irregardless of the site of care. As shown in Table 4-2, all of the models provide at least some evidence that integrated care delivery models can be cost-effective.[65] There is no evidence in the literature that splintered and/or disorganized models of care can be cost-effective. Table 4-3 presents key success factors for each of the models.

Table 4-1: Comparison of the Key Characteristics of the Five Models

Model	Type of Context	Type of Client	Key Aspects of Model	Integration into Broader System of Health Care
S/HMO	Primarily metropolitan and urban sites	Elderly population with and without functional deficits	Capitation funding to provide home and community care, facility care, acute care, and primary care	Well integrated as primary care and acute care services are part of S/HMOs
PACE	Multiple metropolitan and urban sites	55 years of age or older and certified eligible for long term care facility placement	Capitation funding to provide home and community care and primary care, and to purchase long term facility care and acute care	Separate programs but integrated through service purchase arrangements for primary care, acute care and long term facility care
ALTCS	State-wide program in Arizona, urban and rural sites	Elderly population, and physically and developmentally disabled who are at risk for institutionalization	Capitation funding for integrated program of primary care, acute care, home care, and facility long term care	Well integrated and is part of the Arizona Health Care Cost Containment System
CHOICE	Metropolitan sites in Alberta	Frail elderly clients	Intensive and expanded adult day service	Fully integrated into region
BC Continuing Care System	Province-wide	Elderly clients and adults with disabilities	Province-wide integrated model incorporating home care, home support, case management, facility care and some acute care	Part of broader provincial system of care

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[64] A single funding envelope provides funding for all relevant programs in one place. In some cases, funding can be transferred between services to maximize system efficiencies. With capitation, a limit is placed on the amount of funding available, based on the overall population served and on client characteristics (such as care level).

[65] As discussed in more detail in the next chapter, a consideration of whether services are cost-effective or not involves a consideration of both costs and outcomes (for example, satisfaction with services). The focus is on more than just costs.

Table 4-2: Comparisons of the Outcomes and Costs of the Five Models[66]

Model	Quality of the Service	Impact on Health Services	Cost-Effectiveness
S/HMO	S/HMO clients had the same levels of satisfaction with access, quality, interpersonal relations and cost-benefits as HMO clients but satisfaction levels were higher for those who remained in the S/HMO compared to those who left.	Many people used the benefit as a home care, hospital replacement service. Only 50% to 75% of people eligible for chronic care benefits used them at any given time because of availability of informal care and home health benefits.	There were problems with the evaluation and, thus it is not clear whether or not S/HMOs are cost-effective.
PACE	Findings were variable across sites but, in general, PACE had a positive effect on frequent attendance at social activities and was related to short-term improvements in quality of life, satisfaction with care, and functional status. In addition, PACE enrollees lived longer and spent more days in the community than individuals who did not participate in the program.	PACE is associated with decreased home nursing visits, admissions to hospital, inpatient hospital days and nursing home days. Reductions in the use of prescription drugs have also been observed.	Studies have concluded that PACE programs result in an overall savings of 14% to 39% compared to fee-for-service models.
ALTCS	The availability of home and community-based services has continued to improve throughout the state. Clients were generally very satisfied with services.	ALTCS clients had fewer inpatient admissions, fewer inpatient days and fewer professional visits in hospital, but used more ambulatory services (such as office visits) and used more prescription drugs than clients in fee-for-service models.	Total costs were, on average, 16% lower for the ALTCS than for a comparable but more traditional Medicaid program.[67] It was also found that home care was a cost-effective substitute for acute care.
CHOICE	Clients rated their overall health status as the same or better after ten weeks in the program. Clients and caregivers reported high satisfaction with care.	Reductions in the use of hospital beds, the total number of hospital days, the number of ambulatory care visits, use of drugs, and use of ambulance services were observed. However, there was increased use of physician services.	Savings of $14.13 per person per day on CHOICE were observed compared to costs before enrollment in the program.
BC Continuing Care System	Fairly high satisfaction with care and quality of life.	Long term reductions in the utilization ratio of facility care services and reductions in the use of hospital services.	Home care was found to be a cost-effective alternative to both facility care and acute care.

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[66] For more information, see Hollander, Miller et al. (2002) and Hollander (2001a, 2001b, 2002).

[67] In the United States, Medicaid is a federal and state system of health insurance for individuals requiring financial assistance, regardless of age. Medicare is a federal system of health insurance for individuals 65 years of age and older.

Table 4-3: Key Success Factors for the Five Programs

Model	Success Factors[68]
S/HMO	• The population was screened in a variety of ways to identify the frail elderly as soon as possible • In-home benefits were flexible • The case managers (resource coordinators) authorized and monitored in-home service and acted as advocates for members with the S/HMO and the community
PACE	• The model has the ability to focus on the frail elderly who are certified for placement in institutions • The team structure facilitates communication and service coordination; physicians working within the team are an important determinant of successful team functioning • Capitation allows for the provision of the most needed services without the restrictions of fee-for-service funding on care • A service commitment for the duration of the life of the enrollee enables the team to develop a detailed knowledge of the service needs of each individual
ALTCS	• A flexible funding arrangement that allows for deviations from constraining regulations • A commitment to deliver quality care at a sustainable cost • The use of controls (such as meeting basic requirements, an emphasis on quality of care, and continuous monitoring) to protect beneficiaries from inadequate care • An investment in data collection and analysis capabilities which are used to evaluate potential health plans and to protect beneficiaries from inadequate care; • Independent state assessors rather than (potentially biased) program contractors determine whether individuals are at risk for institutionalization • Capitation rates include a blend of home and community based services and long term care costs
CHOICE	• The three major components of the program (day program, clinical services, and home care) are integrated and the same staff are involved with all three components; having the same components without the integration would not have the same effect • All basic services are provided under one umbrella and referrals are made for the client and his/her family for services that cannot be provided by the program • The program offers flexible services which meet a variety of client needs • All of the health care services available through the program are provided in one building thus making it easier for clients and family members to access them • The program helps clients stay in the community longer since it offers both short stay convalescent care and long term rehabilitation • The active involvement of physicians in the program is integral to the program’s success

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[68] For more information on these success factors, see Hollander, Miller, et al. (2002) and Hollander (2002).

Model	Success Factors[68]
BC Continuing Care System	• single entry increases overall system efficiency because it minimizes the probability that unnecessary care may be provided; single entry also increases the level of accessibility to the care system • coordinated assessment and placement at the system level increases overall system efficiency as there is a determination of the most appropriate services given the client's care needs and consideration is given as to where the client should receive care services; in addition, the same information can be collected for community and facility based clients on admission to the overall system of care • coordinated, system-level case management increases system efficiency by not allowing clients to deteriorate from lack of regular monitoring to the point where more costly care services may be required • single administration and funding structure increases system efficiency by enabling the transfer of funding between services, the development of policies that consider the total continuing care system, a consideration of how the clinical needs of clients can be met within the overall system of care and planning, and resource allocation on an overall systems basis • a consistent client classification system allows for comparisons of clients across service delivery components by level of care; this allows for comparisons by the level of need across all care services for service planning, projections of future service needs, and determining the most efficient and effective use of available resources

4.2.3 Organizing Continuing Care Services

In 2001, Health Canada initiated a major research project to analyze the strengths and weaknesses of care delivery systems across Canada for four populations of individuals with ongoing, or long term, care needs. Separate studies were conducted on care delivery systems for the frail elderly, individuals with disabilities, individuals with chronic mental health conditions, and children with special needs. Table 4-4 identifies a number of service components that are mandated for continuing care for the general population. The table also includes service components that are currently mandated for First Nations and Inuit under FNIHB's Home and Community Care Program and INAC's Assisted Living Program.

Based on the literature, other existing models and the findings from the study, Hollander and Prince (2002) developed a framework that could be used to organize continuing care service delivery systems.[69] The framework incorporates most of the key aspects of the leading models of continuing care.

As shown in Figure 4-1, there are a number of philosophical and policy prerequisites which constitute the first component of the framework. Unless policy makers, program administrators, and care providers understand, and agree with, these prerequisites it is unlikely that the framework will actually be adopted. The second component of the framework is a set of "best practices" for organizing service delivery systems. The first five relate to administrative aspects and the second five relate to service delivery. The third component addresses issues of coordination and linkage.

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[69] Although the framework is based primarily on research findings involving non-Aboriginals, it is thought that it may also be applicable to First Nations and Inuit.

Table 4-4: Continuing Care Service Components

Type of Service	Seniors	Persons with Disabilities	Mental Health	Children with Special Needs	Services Mandated by FNIHB's and INAC's Continuing Care Programs
Community/Home Based Services					
System Level Case Management[70]	X	X	X	X	
Information/Referral Services	X	X	X	X	X
Meal Programs	X				X
Self-Managed Attendant Services		X			X
In-Home Nursing Care	X	X		X	X
Home/Community Rehabilitation (PT/OT)	X	X	X	X	
Homemakers/Home Support Services/Care Aids/Attendants	X	X	X	X	X
Day Care/Day Support (special and integrated)	X		X	X	X
Group Homes		X	X	X	X
Respite Care	X	X	X	X	X
Palliative Care	X				X
Technical Aids, Equipment & Supplies	X	X		X	X
Supportive Housing	X	X	X		
Life & Social Skills Training & Support Groups	X	X	X	X	
Outpatient/Ambulatory Care Services			X	X	
Primary Care/Family Physicians			X	X	
Day Hospitals	X		X		
Community Emergency Services/Crisis Support	X	X	X	X	
Specialty Transportation Services	X	X	X	X	X
Foster Care	X			X	X
Mental Health Services for Children				X	
Buddy Programs				X	
Summer Camps				X	
Drug Benefits Services	X	X	X	X	
Physician Specialists (psychiatry, pediatrics)	X		X	X	
Institutional Services					
Institutional Services	X	X	X		X
Extended or Chronic Care Facilities	X	X		X	
Specialty Hospital Services (pediatrics, geriatrics, rehab)	X		X	X	
Children's Hospital				X	
Psychiatric Hospital/Beds			X		
Palliative Care	X			X	X
Hospital Based Emergency Services	X		X		
Regular Hospital Services	X	X	X	X	

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[70] As noted earlier, case management is a component of FNIHB's Home and Community Care Program, but does not appear to be present at a broader systems level.

Type of Service	Seniors	Persons with Disabilities	Mental Health	Children with Special Needs	Services Mandated by FNIHB's and INAC's Continuing Care Programs
Respite Care	X	X			X
Educational/Vocational Services					
Special Integrated Preschool Programs				X	
Integrated School Programs				X	
In Home Teachers/Tutors				X	
Vocational Training/Support		X	X	X	
Income Support Programs					
Financial Assistance to Purchase Equipment and Supplies for Home Renovations	X	X		X	
Income Assistance	X	X	X		
Judicial/Criminal Justice Services					
Judicial/Criminal Justice Services				X	

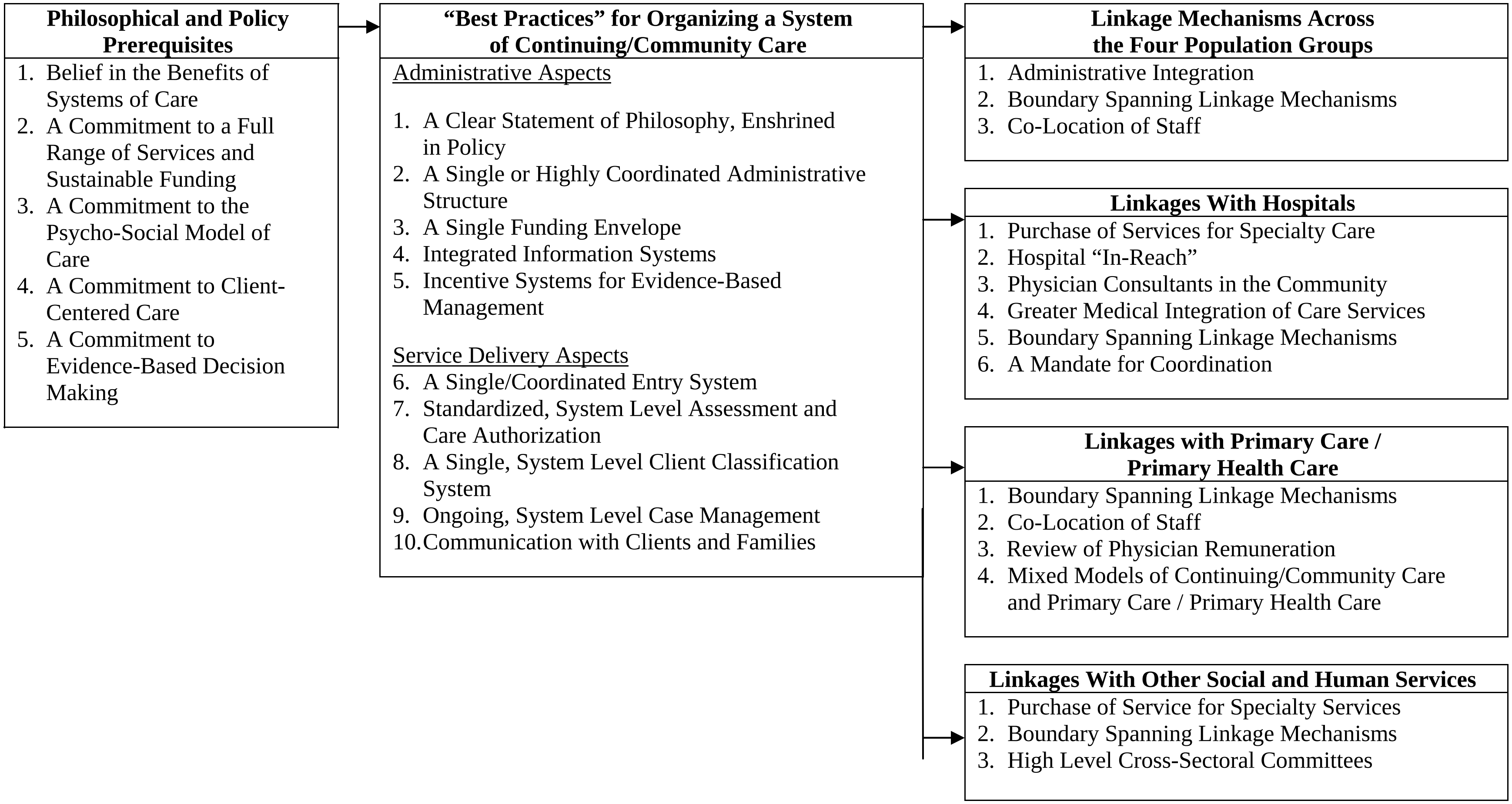
Adapted from Hollander and Prince (2002).

Continuing care combines the best aspects from both integrated health systems (vertical integration) and primary care/primary health care (a broad base of home and community services) and incorporates them into one system. The system has components of primary care, secondary care and tertiary/quaternary care which are linked both horizontally and vertically through case management. Figure 4-2 presents a schematic of the structure of a generic continuing care system that could apply to populations with ongoing care requirements (Hollander & Prince, 2002).

Figure 4-3 shows a simplified schematic of how clients would flow through the system of continuing/community care (Hollander & Prince, 2002). Clients can refer themselves to the system or be referred by family members, professionals or other concerned persons. The referral is made to the local single point of entry organization. There is typically a screen to provide information, ask about care needs and ask about eligibility. If it appears that the client is a potential candidate for care, the client is assessed using a system level assessment tool (preferably with a built-in classification system).

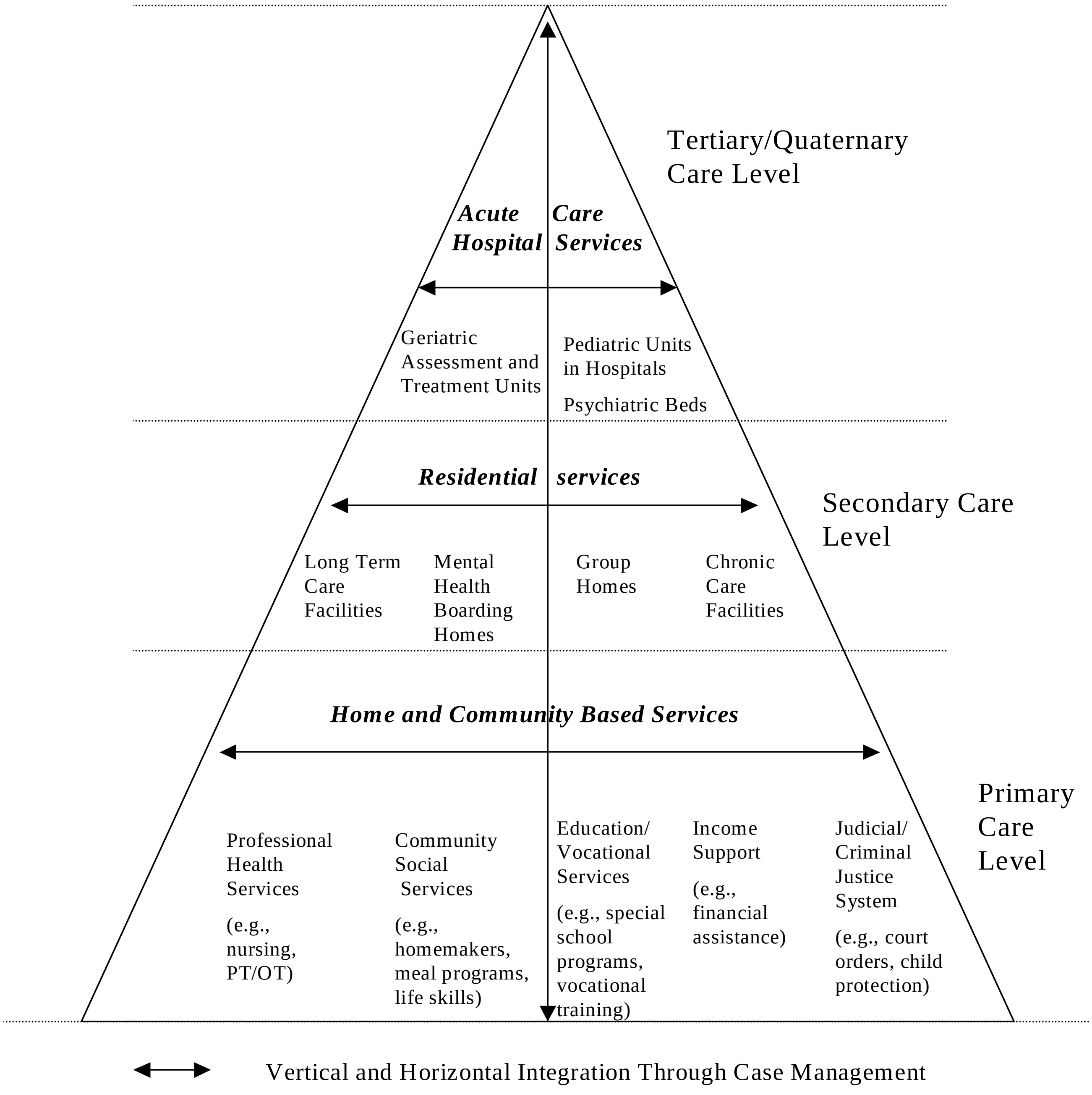
Based on the assessment, on discussions with the client and his or her family, and on discussions with the family physician and/or specialist(s), a care plan is developed. The client then enters the care system. If the client has complex problems, he or she may be seen in a hospital-based specialty service such as a geriatric assessment and treatment unit, or a psychiatric evaluation unit. Once assessed in the specialty unit, the client may be admitted to a hospital based service such as a psychiatric ward or an extended care/chronic care ward in the hospital, or referred to a facility or to care in the community. Clients who do not go to a specialty acute care service may be admitted to a facility or may receive one or more health, social and/or human services in the community.

Figure 4-1: A Framework for Organizing Systems of Continuing/Community Care Services



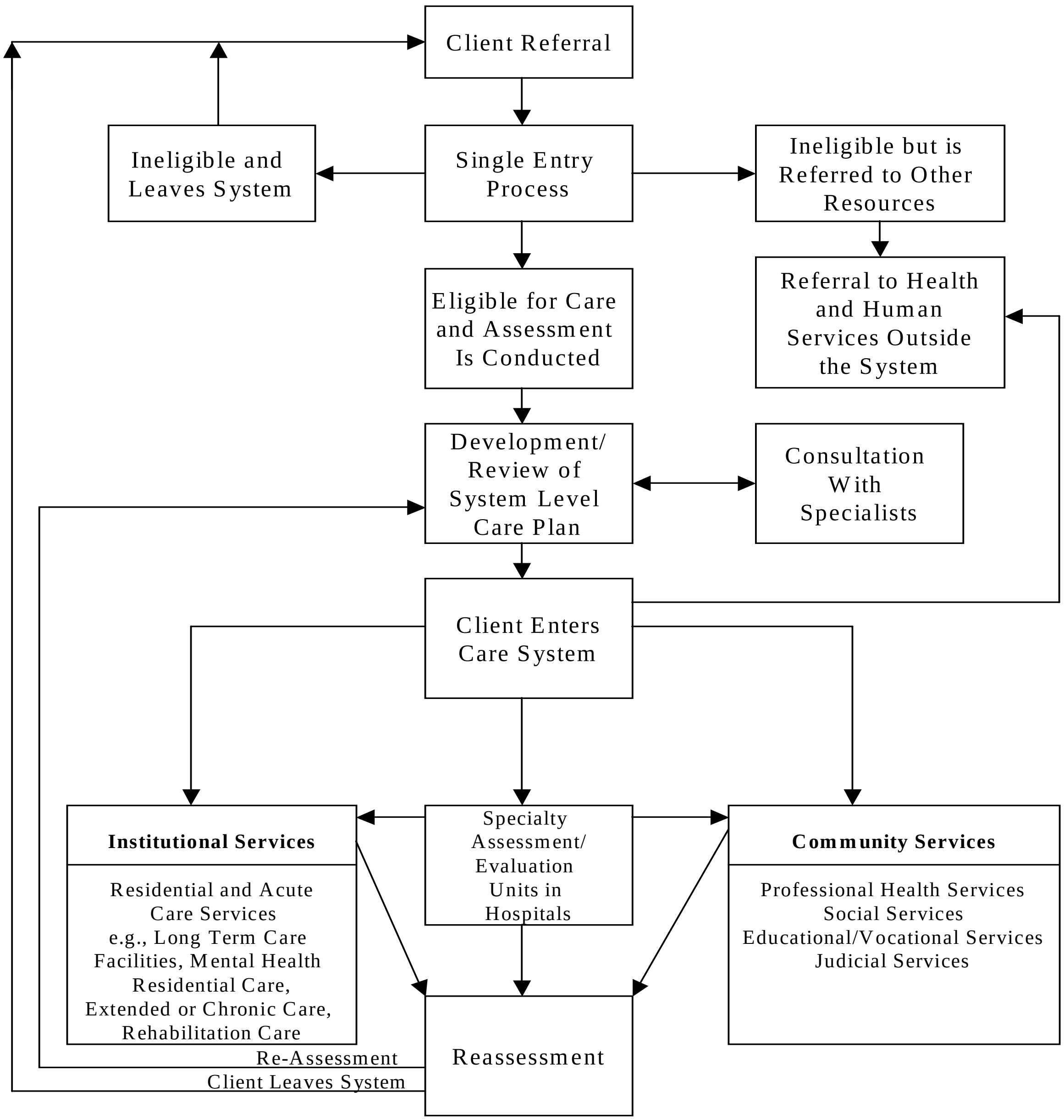
Source: Hollander, M.J. & Prince, M.J. (2002). *Final Report: "The Third Way": A framework for organizing health related services for individuals with ongoing care needs and their families*. Victoria, BC: Hollander Analytical Services Ltd.

Figure 4-2: A Schematic of the Structure of the Continuing/Community Care Service Delivery System



Source: Hollander, M.J. & Prince, M.J. (2002). *Final Report: "The Third Way": A framework for organizing health related services for individuals with ongoing care needs and their families*. Victoria, BC: Hollander Analytical Services Ltd.

Figure 4-3: A Schematic of Client Flow Through the System of Care



Source: Hollander, M.J. & Prince, M.J. (2002). *Final Report: "The Third Way": A framework for organizing health related services for individuals with ongoing care needs and their families*. Victoria, BC: Hollander Analytical Services Ltd.

They may also be referred for additional health and human services outside the system of care. Clients would be re-assessed by their system level case managers on a regular basis and their care plan would be revised, as necessary. Clients may also leave the system but can be referred back to it at any time.

It is believed that the framework presented by Hollander and Prince (2002) offers a way to increase the efficiency and effectiveness of service delivery. As the framework is flexible, it can be adapted to create more specific care delivery models for particular populations, groups, or jurisdictions.

4.3 Aboriginal Integrated Health Systems

4.3.1 Introduction

While examples of integrated continuing care models can be found in the non-Aboriginal literature, this is not the case in the literature on Aboriginal/Indigenous peoples. In the latter case, the emphasis has been on more general integrated health systems. With respect to Aboriginal populations in Canada, an integrated health system can be defined as a health services network which is responsible and accountable for the provision of publicly funded services, including those delivered through federal funding (for example, home and community care, non-insured health benefits) and those currently included under the *Canada Health Act* and funded by provincial or territorial governments (for example, hospital and physician services) (National Aboriginal Health Organization, 2001).

Lemchuk-Favel and Jock (2003; see also Marriott & Mabel, 2003) present a framework for Aboriginal health systems that focuses on governance, system design and financing. They propose that an Aboriginal health system should:

- be organized around multi-disciplinary primary health service delivery and administration and include both a single entry point and case management;
- involve the establishment of a health authority which is accountable to member communities;
- involve practitioners in system planning and governance in order to encourage a sense of ownership in the system;
- define the population to be served by the health authority;
- structure the health authority in such a way as to promote collaboration of the various service partners both within and outside of the system;
- include a broad range of health and health-related services;
- develop community health plans through extensive consultation;
- include a common clinical information system or connected information infrastructure;
- provide practitioners with the necessary skills for multi-disciplinary care; and

- provide funds based on capitation and a rostered population.[71,72]

Integrated Aboriginal health systems have many different forms and include both functional (financial and/or administrative) and clinical models. The following are some Canadian examples of integrated Aboriginal health systems.[73] For examples of integrated systems for indigenous populations in the international literature, see Eby (1998), Nebelkopf and King (2003), Reid, Bartlett and Kozoll, (1981, 1982) and Vizina (1997).

4.3.2 Northwest Territories and Nunavut

In the Northwest Territories and Nunavut, integrated health and social systems are universal, meaning that Inuit, First Nations, Métis and non-status Indians are eligible for all territorial services on the same basis as other residents. However, federal programs that are directed exclusively at the Inuit and First Nations populations (for example, the Non-Insured Health Benefits Program, the Home and Community Care Program) are superimposed on this system. Thus, integration is less than complete with regard to federal programs (Lemchuk-Favel & Jock, 2004; National Aboriginal Health Organization, 2001).

4.3.3 Atlantic Canada: The Eskasoni Primary Care Project

Funded through Health Canada's original Health Transition Fund, The Eskasoni Primary Care Project was developed to deal with high morbidity and mortality rates resulting from substance abuse, diabetes, heart disease and respiratory illness (see Hampton, 2001). Although many health resources were in place, existing health programs were not coordinated, health providers did not collaborate, and health information was not integrated. The purpose of the project was to design, implement and evaluate a holistic model of health service delivery based on a collaborative, multi-disciplinary approach to primary care. The project focused on three areas: prenatal care, diabetes management and prescription drug use.

The project involved a collaborative effort of the Eskasoni First Nation, the federal government, the provincial government, and the Department of Family Medicine at Dalhousie University. Existing federal funding was provided for community health nurses, community health representatives, a part-time prenatal care coordinator, and a diabetes educator. Health Transition Fund funding was used for a nurse clinician, health educator, counselor, project manager and evaluation consultant. Provincial funding was used to make the shift from fee-for-service to salaried physicians. This alternate funding model supported appropriate time spent with patients, collaboration between physicians and other health professionals in carrying out care plans, and a physician lifestyle that was professionally and personally sustainable. The Department of Family Medicine provided the tools necessary to evaluate the impact of the project in changing hospital and physician utilization (see Lemchuk-Favel & Jock, 2004).

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[71] The term "rostered population" refers to a group of individuals who are defined as constituting the population who are in care using specific characteristics, such as age, type of chronic illness, living situation and so on.

[72] The amount of funding would need to be weighted or adjusted to reflect the characteristics of the rostered population. These characteristics would need to include, at a minimum, age and gender, but could also include other characteristics such as geographic location, general health status, and specific health problems (Marriott & Mabel, 2003).

[73] The examples come from a variety of sources. The amount of detail in these sources varies and, as a consequence, the amount of detail provided in the examples varies.

The project included a number of components. A new state of the art health centre was built in the community with sufficient space to house all community health care services. Primary medical care (that is, care provided primarily by physicians) was integrated with community health programs such as public health, home care, prenatal care, and diabetes care services. A collaborative practice model (which included physicians, a primary care nurse, a nutrition educator, a pharmacist, community health nurses, diabetic education staff, community health representatives, home care staff and prenatal care staff) was implemented in the clinic. A telehealth site was also established in the clinic (the only telehealth site in the province not based in a hospital). The telehealth link provided the health care team with access to videoconferencing, referrals with specialists, and continuing medical education. The link also provided patients with access to specialist services thus enabling them to access care without having to travel considerable distances. Health records were integrated through coordination of the paper records used by the health professionals. The integration of community health services required substantial adjustment among staff as well as procedural and administrative adjustments reflecting differences between federally and provincially funded programs.

An internal evaluator conducted a process and outcome evaluation. Pre- and post – implementation surveys were conducted with community representatives (for example, Elders, youth, and representatives from the justice, education and social services sectors), primary care workers (for example, local doctors and staff at the community health centre), regional health care providers (for example, referral agencies and staff at the regional hospital) and patients. Pre-implementation data were gathered as the baseline against which changes over time were compared and analyzed. The outcome evaluation focused on a review and analysis of information related to changes in the utilization of services and in the overall health status of the community. This included a review of hospital, administrative, prescribing and other related data. Key findings from the first year of operation included the following:[74]

- residents accessed a greater range of primary health care services within their own community as a result of an expanded team of local health service providers, visiting services, and telehealth based specialty programs;
- collaboration was achieved with the regional hospital in several key program and service areas;
- the frequency of visits to family physicians decreased from a high of 11 patient visits per year to approximately 4 visits per year;
- 73% of patients reported obtaining an appointment with their family doctor within 24 hours or less and 90% secured an appointment within 48 hours;
- visits by Eskasoni residents to the outpatient/emergency department at the regional hospital declined by 40%;

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[74] Although the report on this health system indicated that pre-implementation data were collected, the time frame over which the information was collected was not always clear. In addition, although the evaluation was conducted in the first year following implementation, information regarding what the situation was like prior to the implementation was not always provided. Thus, it was not always possible to tell *how much* change was observed in the first year following implementation.

- savings of approximately $200,000 were realized in the medical transportation budget;
- 96% of all pregnancies were followed by an Eskasoni doctor and community health nurse from prenatal care through delivery and postnatal care;
- referrals from local family doctors to the team nutritionist/health educator for diabetic management increased by 850%;
- there was more evidence-based prescribing of medications;
- the cost of prescription drugs decreased from $960,000 to $890,000 in three years, a 7% decrease despite a nearly 10% increase in the population and increased costs of prescription drugs averaging 10% to 15% per year;
- all primary care providers reported satisfaction with the primary care model; and
- 89% of patients believed that the quality of health services had improved compared to five years before.

4.3.4 Québec: Kahnawake's Health System

Kahnawake considers health to be essential for nation building and self-determination. As a result, Kahnawake's vision of a health system emphasizes holistic practices and prevention strategies. The health system is quite comprehensive and includes: a community health unit which offers public health services; a medical centre that offers specialty services; a dental clinic; a nationally recognized diabetes education program; a 20-bed Elders lodge; a hospital which provides both in-patient and out-patient care; and a community service centre that provides a wide range of mental health and social services (see Lemchuk-Favel & Jock, 2004).

The Kahnawake Health and Social Services Commission oversees health services and is responsible for planning, coordinating and reviewing all health and social programs. A number of initiatives have been undertaken by the Commission, including the following:

- a single entry point into the mental health and social services system;
- program flexibility from Health Transfer and the budget process in order to increase the efficiency of programs;
- regular meetings with the directors of the various health and social programs to share resources, reduce duplication and participate in long term planning; and
- memorandums of understanding with relevant provincial agencies that define the roles and responsibilities of all concerned.

4.3.5 Québec: Nunavik Regional Health and Social Services Board[75]

Under the James Bay and Northern Québec Agreement, the Nunavik Regional Health and Social Services Board is a locally operated health board supported by the Québec Ministry of Health and Social Services. The board has 100% representation from the 14 communities and two health centres that deliver health and social services in the region. Representation from all communities ensures that a strong grassroots perspective facilitates the development of culturally appropriate health services. The board serves primarily as a resource and support for the health centres and communities (see Lemchuk-Favel & Jock, 2004).

The two health centres provide both general and specialized care, diagnostic services, acute care and long term care. They also provide offer services normally provided by local community service centres (CLSCs), child and youth protection centres and rehabilitation centres for youths with adjustment difficulties. There is a CLSC point of service in each of the communities in the region (Nunavik Regional Board of Health and Social Services, 2003).

Health and social services are not totally integrated at an administrative level. The Board administers five federal programs, including the home and community care and mental health programs. Additional community-based programs, such as home care services, are administered directly by the Québec Ministry of Health and Social Services.

Primarily because of a shortage of physicians, the Board is moving away from a physician-centred primary care model to one that includes nurses in expanded roles. The development of professional resources is a current area of focus. The Board has been successful in establishing management and professional training for Inuit individuals in the health and social services areas.

The development of health technologies, such as telehealth, is considered essential for lowering expenditures and increasing the availability of health and medical specialists in communities.

4.3.6 Ontario: Aboriginal Healing and Wellness Strategy

The Aboriginal Healing and Wellness Strategy (AHWS) is a collaborative effort of the Government of Ontario and Aboriginal organizations designed to promote health and healing among Aboriginal people (see Aboriginal Health and Wellness Strategy, 2003; Lemchuk-Favel & Jock, 2004; Maar, 2004). Four organizations are involved: Ministry of Health and Long Term Care, Ministry of Community and Social Services, the Ontario Native Affairs Secretariat and the Ontario Women's Directorate.

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[75] The Québec region has two other integrated health systems the CLSC Naskapis operates under the James Bay and Northern Québec Agreement and is supported by the Québec Ministry of Health and Social Services. The CLSC provides services to 561 residents on-reserve. The Cree board of Health and Social Services of James Bay also operates under the James Bay and Northern Québec Agreement and is supported by the Québec Ministry of Health and Social Services. The Board has representation from nine communities. The hospital in Chisasibi provides general and specialized care. Two CLSCs and five inland and four coastal communities provide primary care services (personal communication, FNIHB Regional Coordinator for Québec, May 2005).

The AHWS encourages integration of traditional and culturally appropriate approaches to healing and wellness and supports better access to care and services. Programs and services are designed, delivered and managed by Aboriginals. The programs are intended to meet the holistic needs of individuals and, as such, are designed to address multiple needs along a continuum of care and service using health promotion, prevention, curative and rehabilitative approaches. Funding is provided for four types of programs: health centres, maternal and child centres and medical hostels; community workers and health outreach; shelters, healing lodges and treatment centres; and clearing house, translator and advocate services.

The health centres are designed to reflect the needs of the entire Aboriginal population in a geographic area. Although most centres are located off-reserve, many serve on-reserve populations, sometimes through satellite clinics. The centres use a single entry point and a multidisciplinary team. The team generally includes salaried physicians as well as nurses (including nurse practitioners, registered nurses and/or licensed practical nurses). Other professionals may include nutritionists, psychologists, diabetes educators and exercise therapists. Outreach services and street clinics may provide an effective alternative to emergency room visits. The centres may also collaborate with other agencies (including non-Aboriginal ones) to meet the needs of street people.

The health centres are intended to increase accessibility to health services. This seems to have been achieved, at least to some extent. The first phase of a six-year longitudinal evaluation of the health centres found that 87% of urban respondents and 64% of rural respondents stated that their health centre had improved personal access to health care a lot or a great deal. Satisfaction with the full range of services (for example, health promotion, emotional, mental health, and spiritual) was high (Lemchuk-Favel & Jock, 2004).

Implementation of the AHWS has resulted in the creation of more than 650 jobs in Aboriginal communities, the construction of facilities, and the development of management and program planning capacity (Aboriginal Health and Wellness Strategy, 2003).

4.3.7 Manitoba: Aboriginal Health and Wellness Centre

The Aboriginal Health and Wellness Centre is a not-for-profit organization that serves First Nations, Métis, Inuit and non-status Indians in Winnipeg (see Miller, Hollander, Janowitz, Siebold, Gainor, Kosseim, Nurse, Ritter, & Straka, 2003). Operated by a community board, the centre manages six programs: primary care; fetal alcohol syndrome/fetal alcohol effects; Head Start; Children’s Healing; Men’s Healing; and Women’s Healing. The Centre strongly supports community development processes in planning, organizing and delivering its services. Grassroots support and involvement is a major priority for the organization. Centre staff include physicians, nurses, social workers, community health workers, early childhood educators, Elders, traditional healers and administration and support staff. Almost all staff are First Nations, Métis or Inuit.

All programs at the Centre are founded on the philosophy of the medicine wheel, a circular matrix encompassing physical, intellectual, emotional and spiritual needs and aspirations. This framework is used as a health assessment tool and has the capacity to integrate many aspects of the individual’s experience, including individual identity, relationships, support systems and personal expression. The framework supports a holistic, respectful and balanced assessment reflecting overall strengths and challenges, and is used as an alternative to the medical disease model. It is used by the Centre to analyze individual well-being, as well as to assess community population health indicators for social and cultural support programs.

Each program has a separate funding source. Core funding for primary care services and funding for the fetal alcohol syndrome/fetal alcohol effects program are provided by the Manitoba Department of Health. Physicians are paid on a salary basis, and traditional healers receive honoraria. The other four programs receive funding from the federal government through Health Canada, the Federal Crime Prevention Strategy and the Aboriginal Health Foundation.

Evaluations are required on an ongoing basis by the various funders. These are in-house quantitative reports based on statistical records, including program utilization and client satisfaction. The Centre ensures that all evaluations involve a client sample and generally conducts interviews and focus groups as a component of the assessments. The evaluations consistently reveal a high utilization of all programs and a very high level of client satisfaction.

4.3.8 Alberta: The Métis Settlement Health Project

The Métis Settlement Health Project was a collaborative effort of four Métis communities and the Lakeland Regional Health Authority in Alberta. The project was intended to improve the overall health of the four communities by reducing inequities, improving access and strengthening linkages with existing health services (Lakeland Regional Health Authority, 2000).

At the time of the project, many of the community services available in larger communities were available on a part-time, rotating basis, in each of the communities. These services included public health home visits, well baby clinics, oral health services, and home care. Although the public health nurses had provided services to the communities for many years, the majority of the other providers rotated their services throughout the health authority.

As part of the project, half-time nurses were hired to work on site in each of the communities. The position was an addition to, rather than a replacement of, previous staffing. Métis community representatives were actively involved in interviewing and selecting the nurses. The nurses’ role was to enhance the multidisciplinary team providing public health and home care services in the community.

In order to increase residents’ knowledge regarding health issues, the nurses needed to be accepted and trusted by the community and its members. The development of a personal relationship was necessary before the nurses could help residents identify and deal with their health. It took a long time for residents to feel comfortable in approaching the nurses for on-site services. However, once the nurses were able to establish relationships with residents, linkages with other services, agencies and practitioners could be made, thus increasing access.

The project was considered to be very successful and has resulted in permanent funding from the provincial government for on-site nurses who are responsible for both public health and home care.

4.3.9 British Columbia: Nisga'a Valley Health Board

The Nisga'a Nation includes four communities, one of which is remote. The Nisga'a Valley Health Board provides treatment and preventive health services to all residents (approximately 6,000 individuals) within its territory, including non-Aboriginals. The Health Board includes four clinics (one in each community), three physicians, and a staff of approximately 60 (see Lemchuk-Favel & Jock, 2004). Provincial funding is used to pay physicians on a salaried basis.

All of the clinics are able to provide first response treatment. Physician clinics are held in each community on a regular basis. Coverage is provided 24 hours a day, 7 days a week by a diagnostic and treatment centre in one community and by nursing stations. Four major hospitals are located within a 300 km radius.

A strong budgetary system defines the range of services funded and the value for money on a program-specific basis. Benchmarks and goals are set and evaluated regularly. Administrative flexibility is provided through block funding and the ability to change programs to be responsive to community issues. The flexible program base is respectful of culture and community needs and undergoes regular reviews. The block funding can be used to address issues that result from health service changes.

Health and social services are not integrated at an administrative level; health services are provided by an independent, delegated health authority (the Nisga'a Valley Health Board) and social services programs are provided by the Nisga'a Lisims Government and Village Government. However, health and social systems cooperate at an operational level. The Nisga'a Nation's governance is responsible for overall program management and integrated health and social planning.

4.3.10 Discussion

Successful and sustainable client-focused health systems, such as those described above, share many characteristics. These characteristics include (Lemchuk-Favel & Jock, 2004; see also Lemchuk-Favel & Jock, 2002, National Aboriginal Health Organization, 2001):

- **Self-empowerment –** Aboriginal ownership and control of health services contributes to self-empowerment and improves access to supportive, culturally appropriate services.

- **A holistic approach –** The Aboriginal concepts of holism and wellness are incorporated into the design of community programs, from the individual care level to the administrative integration of health and social services.

- **Synergism of traditional and western health philosophies –** Traditional healing practices include physical, spiritual, emotional, social and mental well-being. They may be combined with western medical approaches to develop unique approaches to health services (such as the inclusion of traditional healers on a multi-disciplinary team). Community preferences with regard to traditional and western approaches vary.

- **A focus on primary care –** The health system emphasizes primary care and includes multi-disciplinary teams and linkages to external health resources. The multi-disciplinary teams can include physicians, nurses, nurse practitioners, nutritionists, pharmacists, social workers, traditional healers and so on. One of the key features is that physicians are remunerated on a salary rather than a fee-for-service basis.

- **Collaborations with provincial services** – Provincial governments are the administrators of physician and hospital services. Aboriginal peoples are high users of these services. Collaboration may simply involve establishing effective referral mechanisms and sharing patient information as required.

- **Integrated health services delivery** – Where feasible, partnerships are created among communities to achieve economies of scale.

- **Administrative reform –** The health system is accountable to both the community and the funders. Ideally, the number of funding agreements are reduced so as to allow flexibility in the allocation of resources and a minimization of paperwork.[76]

Despite the development of various integrated Aboriginal health systems, the health inequity gap between Aboriginal individuals and non-Aboriginal individuals still exists. Health care that is delivered or managed within or for First Nations/Inuit/Métis communities is still fragmented with respect to programs and funding. Direct responsibility by Aboriginal communities for funding and organization is generally limited to community and primary care services; secondary, tertiary, and quaternary services are generally accessed outside of communities and are owned and/or funded by external authorities (such as provincial governments and regional health authorities). As a result, there is no continuing care system available in Aboriginal communities, Aboriginal governments and people do not have a "health system" and the desire for substantial control of Aboriginal health services by Aboriginal peoples that serve *their* needs has not been met (Marriott & Mabel, 2003). As NAHO (2001, p. 17) has noted, "A critical gap in Canadian knowledge exists with respect to the impact of the locus of Aboriginal health services control (that is, federal, provincial or Aboriginal) on a population's health status."

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[76] At the present time, 12 federal departments offer programs and services for First Nations, Inuit and Métis (Kirby, 2002). Funding may also come from provincial governments and Aboriginal organizations. The number of reports First Nations and Inuit communities are required to produce to account for funding on a yearly basis is substantial (Lavoie, O'Neil, Sanderson, Elias, Mignone, Bartlett, Forget, Burton, Schmeichel & McNeil, 2004).

5. COST-EFFECTIVENESS OF CONTINUING CARE SERVICES

5.1 Introduction

An important aspect of the Continuing Care Research and Costing Project involves an analysis of the cost-effectiveness (that is, the costs and outcomes) of First Nations and Inuit continuing care services. Cost-effectiveness analysis is often equated with an analysis only of costs for the purpose of determining expenditure reductions. This is *not* what cost-effectiveness analysis is, or should be, all about. Cost-effectiveness analysis is a means by which funders and service providers can analyze how services are being delivered and if, and how, they can be delivered more effectively. It is *not* only about costs; there is an equal weighting on *costs* and *outcomes*. As a result, outcome indicators (such as client and informal caregiver satisfaction with care services and the client's quality of life) are as important as the costs of providing the services. The comparative analysis of costs and outcomes may also reveal new information which can be used to change policies, procedures, and clinical practices, in order to provide more efficient and effective services.[77] An overview of how economic evaluations should be conducted and how they can be used in the continuing care sector is presented in Appendix D.

5.2 The Cost-Effectiveness of Continuing Care Services in the Non-Aboriginal Sector

5.2.1 <u>Introduction</u>

As noted previously, there are three main functions of home care. The first function is to act as a substitute for hospital care. This *acute care substitution* function generally focuses on discharging people from hospital at the end of an acute care phase of their illness. Instead of spending the convalescent part of their illness in hospital, people convalesce at home with the assistance of professional health care providers (such as nurses and/or physiotherapists) and home support workers, as required. The second function of home care is to act as a substitute for long term institutional care. This *long term care substitution* function focuses on the provision of home care to clients who have such high level care needs that, in the absence of home care, they would be admitted to a long term care facility. The third function of home care is to maintain clients at their optimal level of care, preventing or delaying further deterioration, for as long as possible. This *maintenance and preventive* function of home care focuses on preventing or delaying admission to a long term care facility or hospital.

The Continuing Care Research and Costing Project does not address the acute care substitution function. Thus, the literature reviewed in the following sections focuses primarily on the maintenance and preventive and long term care substitution functions of home care. Although some references are made to impacts on hospital care (for example, readmissions to hospitals), the issues relate primarily to the maintenance and preventive function of home care, not the acute care substitution function.

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[77] There are four methods of economic evaluation, namely, cost-minimization, cost-effectiveness, cost-utility, and cost-benefit analysis. The term *cost-effectiveness* is used in this document as a generic term to refer to all four methods.

5.2.2 The Maintenance and Preventive Function of Home Care

5.2.2.1 Introduction

There are generally considered to be the three levels of prevention:

- **Primary Prevention** which focuses on general preventive activities for a population and includes programs such as lifestyle counselling and immunization. Specific activities would include the promotion of regular aerobic exercise, tobacco reduction and safe driving initiatives.
- **Secondary Prevention** which focuses on the identification of individuals at risk through preventive activities related to early detection of subclinical disease by screening or case finding to prevent disability. Examples include screening questionnaires for problem drinking, hearing impairment and diminished visual activity, and regular mammography and clinical examinations for breast cancer.
- **Tertiary Prevention** which focuses on minimizing disability and handicap from established diseases.

(Adapted from Patterson and Chambers, 1995)

The Continuing Care Research and Costing Project focused primarily on tertiary prevention aimed at allowing people to function at their optimal capacity and reducing the rate of deterioration in health and functional status.

Although widely used in Canada, neither the typology of the three functions of home care nor the link between levels of care and preventive activities appear to be used in the international literature. In general, the international studies focused on certain types of preventive programs, rather than on the broader preventive functions of home care *per se*. Even in Canada, there appear to be very few studies on the cost-effectiveness of the maintenance and preventive function of home care.

5.2.2.2 International Studies on Preventive Home Care

Relevant international literature falls into four categories:

- long term substitution of home care for services provided in hospital (for example, Guber, Morris, Chen & Israeli, 2002; Harjai, Mehra, Ventura, Lapayre, Murgo, Stapleton & Smart, 1997);
- case management and hospital related approaches to prevent re-admissions to hospital (for example, Lim, Lambert & Gray, 2003; Rich, Beckham, Wittenberg, Leven, Freeland & Carney, 1995; Stewart, Marley & Horowitz, 1999; Stewart & Horowitz, 2003; and Stuck, Aronow, Steiner, Alessi, Büla, Gold, Yuhas, Nisenbaum, Rubenstein & Beck, 1995);
- community based programs to reduce admissions or readmissions to hospitals and care facilities (for example, Landi, Gambassi, Pola, Tabaccanti, Cavinato, Carbonin & Bernabei, 1999; Landi, Onder, Russo, Tabaccanti, Rollo, Federici, Tua, Cesari, &

Bernabei, 2001, Melin, Håkansson, & Bygren, 1993; Nuñez, Arbruster, Phillips & Gale, 2003; and Townsend, Piper, Frank, Dyer, North & Meade, 1988); and

- other special topics including comprehensive rehabilitation services (for example, Liang, Partridge, Larson, Gall, Taylor, Berkman, Master, Feltin & Taylor, 1984), falls prevention (for example, Rizzo, Baker, McAvay & Tinetti, 1996), and use of assistive technology and environmental interventions in maintaining independence (for example, Mann, Ottenbacher, Fraas, Tomita & Granger, 1999).

Although results are mixed to some extent, the majority of studies seemed to indicate positive and/or cost-effective outcomes for preventive home care initiatives. The following studies are relevant to the current project.

In two Italian studies, Landi, Gambassi et al. (1999) and Landi, Onder et al. (2001) examined the impact of an integrated home care program (which included social and health services) on hospital use. Both studies showed a significant reduction in hospitalizations, hospital days, and costs when data from the same patients were compared before and after the implementation of the integrated home care program. These findings are similar to findings reported in the previous chapter regarding the cost-effectiveness of integrated programs.

As noted earlier, respiratory conditions are common in First Nations and Inuit populations. In an Israeli study, Guber et al. (2002) compared the costs of patients receiving respiratory care at home with the costs of their care in hospital before their transfer home. While the average length of time they received respiratory care at home was over twice what they received in hospital (404 days per patient at home versus 181 days in hospital), the average total cost of respiratory care at home was less than one third of the cost of care provided in hospital ($3,547 versus $11,000).

One of the areas of interest for many First Nations and Inuit communities is the use of hospital liaison workers to make the transition from the community to the hospital and back again as smooth as possible.[78] In an Australian study, Lim et al. (2003) found that patients receiving post-acute care coordination used fewer hospital days in the six months post discharge than patients receiving usual care. This resulted in an average net savings of $1,545 per person for the treatment group.

Another area of interest for First Nations and Inuit is the integration of health promotion and prevention programs with other health related programs. In an American study, Nuñez et al. (2003) examined the impact of a community based, nurse-managed health promotion and chronic disease management program on community-residing older adults. They found that study participants had better health and social functioning, and fewer doctor visits and hospital days per year, than a national comparison group.

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[78] Personal communication, A. Gibbons, February 2005.

5.2.2.3 Canadian Studies on the Maintenance and Preventive Function of Home Care

As noted, there are very few Canadian studies on the maintenance and preventive function of home care. As with the international literature, some studies indicate that home care is not cost-effective while others indicate that it is.

Two Canadian studies found that the maintenance and preventive function of home care was not cost-effective (Contandriopoulos, Tessier & Larouche, 1986; the Saskatchewan Health Services Utilization and Research Commission (HSURC), 2000). The Contandriopoulos et al. (1986) study was designed to determine whether home aid services would decrease the utilization of health care resources by those 65 and over. The researchers compared two different cohorts, one before a home care service was introduced and one after the service was introduced. They found no association between the presence of home aid services and the use of hospitals or other services. However, age and the number of tests or examinations the client had received were significantly related to the use of these services. The HSURC (2000) study examined a cohort of 26,490 seniors over a period of eight years. Approximately 36% of the participants (9,524) received preventive home care and 9% of the participants (2,484) were in seniors housing. The study found that 50% of the individuals receiving preventive home care were more likely to lose their independence or die than those not receiving this service. In addition, costs for clients on preventive home care were three times higher than for clients not receiving this service. The findings need to be interpreted cautiously, however, as there were a number of methodological issues that could have affected the results (HSURC, 2000).

In contrast to the above findings, other Canadian studies have found that preventive home care is cost-effective. For example, Hollander (2001a) examined the impact of a natural experiment which occurred in British Columbia in the mid-1990s. In a one year period, a number of health regions eliminated housecleaning services for people who were at the lowest level of care. Hollander studied the overall costs to the health care system of people who were cut from service in two health regions compared to people who were not cut from service in two similar regions. In the year before the cuts, the average annual cost per client for those who were cut from service was $5,052 and the cost per client for the comparison group was $4,535. In the third year after the cuts were made the comparative costs were $11,903 and $7,808, respectively. Total costs for the three year period following the cuts were $28,240 and $20,543, respectively, for those who were cut from care compared to those who were not cut. Most of the cost differences were from increased use of acute care and long term care facilities.

With regard to Canadian studies of specific program interventions, Darby (1992) found that a Quick Response Team in the Greater Niagara Hospital in Ontario was able to prevent 206 admissions from the Emergency Department to the hospital of frail, elderly adults out of 237 referrals over a 12 month period. While Darby did not provide a cost comparison, he indicated that by being able to send people home with enhanced services, the Quick Response Team was able to free up the equivalent of 8 to 10 beds for a one year period. Larson, Odegard and Brown (1992) conducted a comparative cost analysis of a Respiratory Home Care Program in Alberta for patients on ventilators who were cared for in a long stay unit in the hospital versus those cared for at home. They found that treating patients at home saved about $2.7 million. In a Prince Edward Island study, Robertson and Kayhko (2001) found that an intensive home care follow-up program for first time post-myocardial infarction patients provided a cost-effective alternative to traditional cardiac rehabilitation programs. Detsky, McLaughlin, Abrams, Whittaker, Whitwell, L'Abbé and Jeejeebhoy (1986) conducted an economic evaluation of a home parenteral nutrition program in Toronto. Compared to Total Parenteral Nutrition provided in hospital, the home program resulted in a net savings of $19,232 per patient over a 12 year period.

5.2.3 The Long term Facility/Institutional Care Substitution Function of Home Care

5.2.3.1 International Studies on the Long term Facility/Institutional Care Substitution Function of Home Care

A considerable amount of research has been conducted on studies of home care as a substitute for long term facility/institutional care in the United States. Much of the literature is based on two series of federally funded studies: 14 community care demonstration projects which were funded in the late 1970s and early 1980s, and an additional 10 projects which were funded between 1982 and 1985.

Given the nature of the American continuing care system in the 1980s, it was considered appropriate to study whether or not home care was a cost-effective alternative to facility/institutional care by introducing case management (often with an enhanced home care program) into a community and then randomly assigning eligible clients to existing community services or to the enhanced services. Researchers then studied whether or not the enhanced services led to greater quality of life and client satisfaction, decreased morbidity and mortality, increased functional status, and reduced admissions to long term care facilities and hospitals. Generally, the experimental group had greater satisfaction and quality of life and somewhat reduced costs relative to the control group (Mathematica Policy Research Inc., 1986a; Vertrees, Manton & Adler, 1989). However, when the costs of the enhanced home care program were added into the equation, the overall costs were generally greater for the enhanced services group compared to the group receiving existing community services (Berkeley Planning Associates, May 1985; Mathematica Policy Research Inc., 1986b; Skellie, Favor, Tudor & Strauss, 1984; Weissert, 1985; Weissert Cready & Pawelak, 1988).

Hedrick and Inui (1986) analyzed 12 studies on the cost-effectiveness of home care for chronically ill individuals. They found that home care services appeared to have no impact on mortality, patient functioning or long term care facility placements. They also found that home care had either no effect on hospitalization or tended to increase the number of hospital days. In addition, they found that either the cost of home care was not affected or was increased by up to 15%. Two studies from Taiwan (Chiu, Shyu, & Liu, 2001; Chiu, & Shyu, 2001) also suggest that long term care may be more cost-effective than home care.

While the international research reviewed above suggests that home care is not cost-effective compared to long term care, it generally does not compare the costs of community and home based services versus the costs of long term care directly. Several recent studies have shown that when the costs of community based services are compared directly with the costs of long term care services, home care may be a cost-effective substitute for facility care.

In a Belgian study of people with dementia, Scuvee-Moreau, Kurz, Dresse and the NADES Group (2002) found that the average monthly costs in Belgian francs were 445.50 francs for dementia patients treated at home and 2,301.70 francs for dementia patients in institutions.

Stuart and Weinrich (2001) conducted a broad systems level analysis of the costs of continuing care services in Denmark by comparing cost trends in Denmark and the United States. For many years, Denmark has had an integrated system of care delivery for the elderly and individuals with disabilities which puts a priority on home care. Stuart and Weinrich found that, over a 12 year period, continuing care services for individuals 65 years of age and older increased by 8% in Denmark and 67% in the United States. The savings in Denmark appeared to be due to a 30% reduction in nursing home beds. In the same time period in the United States, there was a 12% increase in nursing home beds.

In an American study of the Arizona Long Term Care System, Weissert, Lesnick, Musliner and Foley (1997) found that the costs of the overall continuing care system were less than they would have been without home care. The researchers suggested that savings probably came from several sources including the use of a payment methodology that encouraged program contractors to place clients in home and community based services rather than risk losing money by using more facility days than their monthly capitated rate allowed.

5.2.3.2 Canadian Studies on the Long Term Facility/Institutional Care Substitution Function of Home Care

In a study of the cost-effectiveness of long term home care, Hollander (2001b) found that for all levels of care needs, on average and over time, home care was significantly less costly than care in a long term care facility. For example, in the mid-to-late 1990s, the average annual costs to the British Columbia government of people with moderate care needs was $9,624 for individuals in home care and $25,742 for people in institutions. For people at the highest level of care, the corresponding costs were $34,859 and $44,233. In a related study, Hollander, Chappell et al. (2002) noted that similar cost differences are seen even when a broader societal perspective is taken in the analysis by including out-of-pocket expenses and care time provided by informal caregivers.

Some Canadian studies have focused on the cost-effectiveness of home care for individuals with cognitive impairments. Using data from the Canadian Study of Health and Aging (CSHA),[79] Østbye and Crosse (1994) used both direct costs (such as home support, physiotherapy, respite care, day centre care) and indirect costs (such as time spent by informal caregivers in assisting clients with activities of daily living) to calculate the net economic costs of dementia. Østbye and Crosse estimated that the annual net cost of providing care for individuals with dementia in the community was $10,100 ($4,970 for direct costs and $5,130 for indirect costs). In contrast, the annual net cost of providing care to individuals with dementia in a facility was estimated to be $19,100. Also using data from the CSHA, Hux, O'Brien, Iskedjian, Goeree, Gagnon and Gauthier (1998) estimated that the annual societal cost was $9,451 per person for individuals with mild Alzheimer's disease and $36,794 per person for individuals with severe Alzheimer's disease. While the authors did not do a direct comparison of all costs for

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[79] The Canadian Study of Health and Aging Working Group (1994) estimated that approximately 8% of the population 65 years of age and older are affected by some form of dementia, and that the prevalence of dementia increases with age, affecting about 35% of those 85 years of age and older. Approximately 50% of those with dementia live in the community. A recent study estimated that 60,150 new cases of dementia are identified each year in Canada (Canadian Study of Health and Aging Working Group, 2000). Alzheimer's disease is the most common form of dementia, accounting for 64% of the individuals with dementia (Canadian Study of Health and Aging Working Group, 1994).

community and residential services, a comparison of the community and facility costs for those with severe Alzheimer's disease indicated that the cost of care in a facility was significantly higher than the cost of care in the community.

5.2.4 Assisted Living

5.2.4.1 The Emergence of a New Sector

Assisted living is a new and emerging component of the care continuum for seniors. Given the relevance of housing issues to First Nations and Inuit, this section presents information on the assisted living component of continuing care.

Currently, there is no agreed upon definition of the term "assisted living". In fact, the term appears to be an umbrella term which incorporates a number of new and previously existing housing arrangements such as group homes, congregate living, group living situations, supportive housing and room and board (to the extent some additional supportive services are included). Nyman (1994) noted that assisted living can be defined in relation to two dimensions: the nature of the commodity and types of services provided; and the care needs of the person receiving the services (see also Murer, 1998). The term "assisted living" may be used somewhat differently by First Nations and Inuit communities, and their funders, than is the case for non-Aboriginal populations. First Nations and Inuit may use the term to refer to long term care facilities which provide care for Type I and Type II clients, that is, clients with relatively lower level care needs.

In a comprehensive review of the expanding concept of home care, Kane (1995) discussed the change in the use of the term home care from meaning "care in the home" to a broader meaning of "care for people living in the community", including in assisted living arrangements. A number of benefits of assisted living include:

- the ability to focus on individualized care;
- greater freedom around schedules, lifestyles, the choice of food and other "independence" factors compared to nursing homes;
- the facilitation of supportive care in a congregate environment through the delegation of professional nursing functions to home support staff or care aides; and
- the possibility that assisted living can provide a cost-effective alternative to nursing homes.

Kane (1995) also identified some potential negative aspects of assisted living including the following:

- people may be forced to move out of assisted living arrangements into care facilities against their will at some point (for example, through policy or legislation);
- there may be issues of legal liability related to the transfer of professional functions to non-professionals; and

- there may be potential liability issues related to health and safety considerations, particularly for residents who require substantially more care services than they did when they first entered the assisted living setting.

Similar issues to those noted above, and cost estimates, are made by other authors (for example, Becker, Stiles & Schonfeld, 2002; Bicknell & Pike, 1993; Bowe, 1993; Chellis, Kelly & Steininger, 1994; Fahrenfort, 1995; Hatton, Emerson, Robertson, Henderson, & Cooper, 1995; Moore, 1991; Moore, 1995; Moore, 1996; Ruchlin & Morris, 1987; Sohng, 1996; Valins, 1995).

5.2.4.2 The Cost-Effectiveness of Assisted Living

Although there are several studies in the international literature that have examined the cost-effectiveness of assisted living, to date there appear to be none in the Canadian literature. Most of the international studies compare the costs, or costs and outcomes, of assisted living with long term facility care.

In a British study, Emerson, Robertson, Gregory, Hatton, Kessissoglou, Hallam, Järbrink, Knapp, Netten and Walsh (2001) compared individuals living in three types of assisted living settings: supported living, small group homes (of 1 to 3 people) and large group homes (of 4 to 6 people). Once adjustments were made for client characteristics, there were no statistically significant differences in service costs among the types of settings.

In a Swedish study, Wimo, Mattson, Krakau, Eriksson, Nelvig, and Karlsson (1995) compared individuals in a group living setting with individuals receiving home care and individuals in an institutional setting. Their overall finding was that the cost per gained quality-adjusted life year was most favourable for the group living alternative.

In an American study, Nyman (1994) reviewed studies of the costs of assisted living arrangements and concluded that, overall, the unit costs of assisted living are lower than the unit costs of residential long term care facilities.

In another American study, Schinka, Francis, Hughes, LaLone and Flynn (1998) compared the costs and outcomes of inpatient care and supportive housing for substance-dependent veterans. Individuals in both groups participated in a three week substance abuse treatment program. The clients in both groups were similar at baseline. While the treatment outcomes for both groups were comparable, the cost for the inpatient group was $9,524, compared to $4,291 for the supportive housing group.

In a third American study, Leon and Moyer (1999) conducted an analysis of the comparative costs of assisted living versus nursing homes for individuals with Alzheimer’s disease. Across all levels of disease severity, the annual costs of assisted living were 13.9% lower than the costs for nursing homes.

5.3 Cost-Effective and Sustainable Aboriginal Health Systems

5.3.1 Introduction

There appear to be four main types of cost drivers in the general health system: inflation; population growth; population aging; and a general category that includes service demand, health need, and system resources. Given the discussion in previous chapters regarding population demographics, health status, geographic issues, health provider issues, program policies and multiple funding sources, it is likely that First Nations and Inuit populations are affected by all of these cost drivers. Given these factors, it is also not unreasonable to expect that health care for First Nations and Inuit may not be as cost-effective as it could be. The non-Aboriginal perspective on health services focuses primarily on economics and efforts to eliminate waste and duplication. In contrast, an Aboriginal perspective holds that health services need to focus on interdependence and that health is not an economic service-based indicator (National Aboriginal Health Organization, 2001). This perspective fits well with the concept that “cost-effectiveness” involves both costs and outcomes.

5.3.2 Cost-effectiveness in Aboriginal Continuing Care Systems

Very few studies, in either the Canadian or international literature, appear to have examined cost-effectiveness in continuing care systems for Aboriginal/Indigenous populations.

Maniapoto and Gribben (2003) examined the Maori Case Management Clinic Project in New Zealand. The project was intended to improve Maori health outcomes through the establishment of low cost, high quality, and culturally appropriate primary care facilities for Maori individuals living in high-need areas. Operated by Maori health providers, the facilities employ a range of staff (including physicians, nurses, and community health workers). Each facility was required to demonstrate traditional models of health care and provide affordable care, with low or zero patient fees. Maniapoto and Gribben reported on the evaluation of one of the three clinics. At this clinic, rapid growth was observed in the initial months after the centre opened and then leveled off after about 10 months. During this time period, enrollment was very high and exceeded expectations; after 10 months, 50% of the total target population was registered. Affordability, cultural acceptability and convenience of location were the three main reasons people accessed the facility. It was estimated that the average cost per visit was $44.79, compared with an average cost of $29.25 at other primary care clinics. The additional $15.54 was allocated for case management. It was felt that with active case management, some of the historical expenditures related to the provision of care to individuals with chronic conditions could be avoided. However, the researchers observed that the provision of care “by Maori for Maori” is difficult to cost and that there are no benchmarks regarding how much providing culturally appropriate models of health care delivery should cost.

As noted previously, the provision of culturally sensitive care is critical for First Nations and Inuit. One of the ways to ensure that care is culturally appropriate is to actively involve care providers from the local aboriginal community. Steele and Hisnanick (1995) found that in fiscal 1991, 1512 Community Health Representatives in the United States had over 4.2 million client contacts, at an estimated cost of $8.50 per visit. Given that the costs of these visits (particularly travel costs) would be substantially less (as well as less disruptive for both the client and the care provider) than traveling between a small community and an urban centre, both the direct and indirect impact of using Community Health Representatives could be substantial.

In addition to some of the models described above in the section on integrated Aboriginal health systems, the Canadian literature on cost-effective Aboriginal systems includes a study by Miles-Tapping (1994) which used interviews with clients and caregivers as well as an analysis of client health records, to evaluate the impact of home care for 16 individuals with chronic obstructive pulmonary disease (COPD) in Iqaluit.[80,81] The study found that home care improved health and reduced the economic impact of COPD by reducing the number of hospital admissions for half of the clients and reducing the average number of days in hospital for each hospitalization episode for almost two thirds of the clients. These reductions resulted in substantial cost savings. For fiscal 1990/1991, the average cost of maintaining a patient in the Baffin Regional Hospital for one day was estimated to be $1344.00. By comparison, the average cost of maintaining a patient in the Iqaluit Home Care Program for one day was estimated to be $10.68. Miles-Tapping estimated that the home care program had potentially saved the health care system 79.6 days in each of the five years it had been operating. In addition, all clients expressed satisfaction with the home care program. It appeared that the program had a substantial impact on clients' quality of life as clients enjoyed being at home with friends and family members, having family members take care of them, and making contributions to their families.

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[80] At the time of the study, Iqaluit was part of the Northwest Territories. It is now part of Nunavut.

[81] Although the sample size is small, individuals with COPD can have a substantial impact on health centres, particularly in the north (Miles-Tapping, 1994).

6. BENCHMARKS AND INDICATORS FOR CONTINUING CARE SERVICES

6.1 Introduction

Nationally, continuing care is not recognized as a major component of the health care system. At the federal, provincial/territorial and regional levels, the focus is generally on component parts (such as home care, facility care, respite care, palliative care and so on) rather than on continuing care as a broad system of care. One of the difficulties with conducting any review of continuing care services is that services have evolved differently over time in different jurisdictions. Table 6-1 provides a breakdown, by jurisdiction, of the types of continuing care services provided in the late 1990s (Hollander, Anderson, Béland, Havens, Keefe, Parent & Ritter, 2000). As can be seen, each jurisdiction provided its own unique mix of continuing care services. Nevertheless, there were certain services such as long term and chronic care facilities, palliative care, respite care, home support services, and professional nursing and rehabilitative services, which were provided in all jurisdictions.

Table 6-1: Services Included in Continuing Care by Type of Service and Jurisdiction

Type of Service	**Jurisdiction**										
	YT	**NT**	**BC**	**AB**	**SK**	**MB**	**ON**	**NB**	**NS**	**PE**	**NF**
Facility Care											
Long Term Care and Chronic Care[82]	X	X	X	X	X	X	X	X	X	X	X
Assessment and Treatment Centres	X	X	X	X	X						X
Subacute Care	X		X	X	X						
Palliative/Respite Care											
Palliative Care	X	X	X	X	X	X	X	X	X	X	X
Respite Care	X	X	X	X	X	X	X	X	X	X	X
Home/Community Care											
Assessment and Case Management	X	X	X	X	X	X	X	X	X	X	X
Homemaker/Personal Care	X	X	X	X	X	X	X	X	X	X	X
Home Care Nursing	X	X	X	X	X	X	X	X	X	X	X
Community Rehabilitation (OT/PT)[83]	X	X	X	X	X	X	X	X	X	X	X
Meal Programs	X	X	X	X	X	X	X	X			X
Adult Day Support	X	X	X	X	X	X	X	X		X	X
Group Homes		X	X	X	X	X		X			X
Equipment and Supplies	X	X		X	X	X	X	X	X		X
Transportation Services					X	X	X	X			X
Congregate Living/Supportive Housing				X	X	X	X				
Quick Response Team			X		X	X	X		X		
Home Maintenance and Repair		X			X		X				X
Self-Managed Care		X	X	X		X	X				X

Note: X = part of continuing care. Findings are only presented for those jurisdictions that provided data.
Source: Hollander, M.J., Anderson, M., Béland, F., Havens, B., Keefe, J., Parent, K., & Ritter, R. (2000). *The Identification and Analysis of Incentives and Disincentives and Cost-Effectiveness of Various Funding Approaches for Continuing Care. Technical Report 5: An Overview of Continuing Care Services in Canada.* Victoria: Hollander Analytical Services Ltd.

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[82] In most jurisdictions, chronic care beds are now considered to be part of the continuing care system. The exceptions are Ontario and British Columbia, but recent steps have moved the chronic care sector closer to continuing care in both jurisdictions.

[83] OT = Occupational Therapy, PT = Physiotherapy

Given the lack of emphasis on continuing care *per se*, it is not surprising that little continuing care data are available. Differences across jurisdictions with respect to terminology, assessment instruments, the mix of services, policies regarding the role of supportive services, and other related factors, have made it difficult to have any degree of consistency across jurisdictions. While there are some benchmarks and indicators for specific service components, there is little consensus on benchmarks and indicators related to continuing care *per se*. This chapter presents *potential* benchmarks and indicators for more integrated systems of continuing care delivery, and for specific services, as appropriate.

6.2 Indicators

6.2.1 Indicators for Home Care

As a result of the focus on component parts rather than on continuing care as a system of care, organizations such as the Canadian Institute for Health Information (CIHI) have focused on developing indicators for specific service components (such as home care).

An early attempt to identify key indicators and benchmarks for home care was conducted by Hollander (1994a). Comparable administrative data for home care services were obtained from Metro Toronto Home Care in Ontario and from the Extra-Mural Hospital in New Brunswick (which provided home care across the province). Table 6-2 presents comparable data on costs and service utilization, overall and by type of provider for three length of stay groupings.

CIHI has completed two phases of indicator development for home care. CIHI groups home care clients into five categories which are defined as follows (CIHI, 2004a):

- **Maintenance Client** – An individual with a stable chronic health condition or functional limitation who requires assistance with personal care, activities of daily living and/or instrumental activities of daily living.
- **Long term Supportive Care Client** - An individual with ongoing multiple and/or complex health conditions, who may be unstable, medically fragile or considered by the case manager/care coordinator to be at risk for institutionalization.
- **Rehabilitation Client** - An individual with temporary or permanent impairments, activity limitations and/or participation restrictions who has the potential for substantial improvement in functional status and/or participation.
- **End-of-Life Client** – An individual with a health condition that is not responsive to curative treatment. The client and/or family have been informed by a physician that the client is expected to live less than six months.
- **Acute Home Care Client** – An individual with acute health or post surgical condition(s) with clearly identified and predictable outcomes or expected recovery.

Table 6-2: Key Indicators and Benchmarks for Home Care for the 1992/1993 Fiscal Year

	Length of Stay					
	Toronto			**New Brunswick**		
	1-28 Days	**29-180 Days**	**181+ Days**	**1-28 Days**	**29-180 Days**	**181+ Days**
Clients (Number)	6,401	10,780	2,008	4,046	5,228	1,413
Clients (Percent)	33.4	56.2	10.5	37.9	48.9	13.2
Average Cost per Case (Dollars)	320.14	1,272.45	3,780.11	*	*	*
Average Hours of Care per Case	9.6	39.5	132.6	5.0	15.6	50.6
Average Number of Visits				7.5	22.8	69.0
Average Length of Stay (Days)	15.5	69.5	413.8	15.2	70.9	499.2
Average Hours of Care Per Week	4.6	4.0	2.8	2.9	1.6	0.9
Average Hours of Care Per Month	N/A	17.4	12.1	N/A	7.0	3.7
Average Hours for Those Receiving						
Nursing Care	8.1	23.7	60.7	4.1	10.6	37.7
Homemaker	11.2	39.9	129.8	14.4	34.1	74.4
Physiotherapist	1.9	1.0	16.7	2.2	5.4	7.0
Occupational Therapy	2.1	7.3	11.1	1.6	3.5	6.4
Social Work	2.1	4.7	7.5	2.1	4.3	8.7
Speech	1.7	7.1	9.6			
Other	*	*	*	1.8	3.7	8.1
Percentage of Clients Receiving						
Nursing Care	95.1	85.1	77.1	94.4	91.8	97.1.
Homemaker	19.7	41.2	57.1	2.8	7.4	9.9
Physiotherapy	0.8	8.7	39.1	4.3	18.0	21.4
Occupational Therapy	5.1	26.4	21.6	4.9	16.0	24.2
Social Work	0.6	3.5	10.1	1.5	5.9	7.5
Speech	0.4	1.7	2.5	*	*	*
Other	*	*	*	30.1	43.9	41.0
Average Cost for People Who Received						
Nursing Care	282.25	827.47	2,122.74	*	*	*
Homemaker	183.61	657.91	2,166.91	119.66	283.37	618.26
Physiotherapy	106.04	393.81	931.69	*	*	*
Occupational Therapy	134.16	460.23	699.79	*	*	*
Social Work	129.89	296.77	475.23	*	*	*
Speech	109.05	443.09	564.78	*	*	*
Other	*	*	*	*	*	*
Percentage of Hours of Care by						
Nursing Care	75.8	35.2	50.5	77.2	62.3	72.7
Homemaker	21.8	55.9	41.2	8.0	16.1	14.6
Physiotherapy	0.2	4.9	1.5	1.8	6.2	2.9
Occupational Therapy	1.1	1.8	4.8	1.5	3.6	3.0
Social Work	0.1	0.6	0.4	0.6	1.6	1.3
Speech	0.1	0.2	0.3	*	*	*
Other	*	*	*	10.8	10.4	6.6

* Asterisks (*) indicate areas where data were not available.

Source: Hollander, M.J. (1994a). *The costs, and cost-effectiveness, of continuing-care services in Canada*, p. 85. Ottawa: Queen's University.

The list of home care indicators developed by CIHI for these five groups is presented in Table 6-3.[84] Findings related to the maintenance and/or long term supportive clients are highlighted in this section.

Table 6-3: CIHI Home Care Indicators

Health Status	**Diagnostic Health Conditions** – The distribution of home care service episodes by the clients' diagnostic health conditions that, at the time of assessment, were monitored or treated by a home care professional.
	Functional Status – Activities of Daily Living – The proportion of home care service episodes in which the clients, at the time of assessment, were dependent on others for, or required extensive assistance with, activities of daily living.
	Cognitive Status – The proportion of home care service episodes in which the clients, at the time of assessment, had a moderate to severe cognitive impairment.
	Behavioural Symptoms – The proportion of home care service episodes in which the clients exhibited behavioural symptoms that caused distress to themselves or that were distressing or disturbing to others with whom the clients lived.
Determinants of Health	**Living Arrangements** – The distribution of admissions to home care by the clients' permanent living arrangements.
	Living Setting – The distribution of admissions to home care by the clients' permanent living setting.
	Availability of Informal Caregivers[85] - The proportion of home care service episodes in which the clients had at least one informal caregiver who provided regular and sustained assistance and/or support.
	Relationship of Primary Informal Caregivers – The distribution of home care service episodes by the relationship of the primary informal caregivers to the clients.
	Living Arrangements of Primary Informal Caregivers – The proportion of home care service episodes in which the primary informal caregiver lived with the client.
	Type of Care Provided by Primary Informal Caregivers – The distribution of home care service episodes by the types of care provided to the clients by their primary informal caregivers.
	Informal Caregiver Burden – The proportion of home care service episodes in which the clients' primary and/or secondary informal caregivers felt unable to continue in their caring activities.
Health System Performance	**Time Waiting for Referral to Service Provision** – The median number of days between the date home care clients were first referred to the home care program and the date of their first service excluding comprehensive assessment.
	Population Access to Home Care – The number of individuals who received publicly funded home care per thousand population.
	Service Goals Met – The proportion of discharges from home care at which the clients had met their expected service goals.
	Disruptive or Intense Daily Pain – The proportion of home care service episodes in which the clients reported having daily intense pain or pain that disrupted their usual activities on a daily basis.
	Inadequately Controlled Pain – The proportion of home care service episodes in which the clients reported pain and that the medications did not adequately control their pain.
	Referral to Other Health Services – The distribution of discharges from home care by the health services clients were referred to after discharge.
	Falls – The proportion of home care service episodes in which the clients had at least one fall in the previous 90 days.
Community and Health System Characteristics	**Utilization Rate** – The number of admissions to publicly funded home care per thousand population.
	Service Intensity – Hours – The average number of service hours received by home care clients per home care service episode.
	Service Intensity – Face-to-Face Visits – The average number of face-to-face visits received by home care clients per home care service episode.
	Service Delivery Settings – The distribution of home care service episodes by the service delivery settings in which the clients received home care.
	Visits to an Emergency Room – The proportion of home care service episodes in which the clients visited a hospital-based emergency room.

Source: Canadian Institute for Health Information. (2004a). *Development of national indicators and reports for home care. Phase 2. Final project report*, Appendix F. Ottawa, ON: Author.

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[84] For more detailed information on these indicators, see the final report of the Home Care Indicators Project (CIHI, 2004a).

[85] Informal Caregivers include family members, friends, neighbours and others who provide support and care to clients without pay.

6.2.2 Indicators for Facility Care

DeCoster, Roos, and Bogdanovic (1995) provided data on key indicators for facility care services in Manitoba for the 1991/1992 fiscal year (see Table 6-4). The data are presented for individuals 75 years of age and older, by region of residence (within Winnipeg or outside of Winnipeg).

Table 6-4: Key Indicators for Facility Care Services In Manitoba for Year 1991/1992

	Winnipeg	**Non-Winnipeg**
Population aged 75 years of age or older	36,488	29,264
Beds/1,000 population aged 75 years of age or older[86]	128	130
Nursing home residents per 1,000 population aged 75 years or older (total)	131.9	136.1
Nursing home residents per 1,000 population aged 75 years or older at Level 1 (lightest care)	4.0	5.8
Nursing home residents per 1,000 population aged 75 years or older at Level 2	42.2	56.1
Nursing home residents per 1,000 population aged 75 years or older at Level 3	48.8	45.3
Nursing home residents per 1,000 population aged 75 years or older at Level 4 (heaviest care)	36.9	28.9
Admissions per 1,000 population aged 75 years of age or older	27.3	28.7
Days of care per resident of region aged 75 years of age or older	38.6	39.4
Estimated annual cost of nursing home care per resident of region aged 75 years of age or older	$3,045	$3,007

Source: DeCoster, C., Roos, N.P., & Bogdanovic, B. (1995). Utilization of nursing home resources. *Medical Care, 33* (12), p. DS77.

6.3 Service Utilization Data

6.3.1 Home Care

CIHI (2004a) noted that service utilization rates were similar for males and females. However, the Canadian Home Care Human Resources Study (2003) found that females used home care more than males (Table 6-5). CIHI (2004a) reported that the utilization of each type of home care increased with age. Similar findings were reported by the Canadian Home Care Human Resources Study (2003; see Table 6-5).

6.3.2 Facility Care

The only comprehensive review of residential long term care facilities in Canada was published by Hollander (1994a) using data from Statistics Canada’s Residential Care Facilities Survey.[87] Statistics Canada and CIHI have published subsequent data that includes all of types of care facilities, including room and board facilities. However, Hollander was able to identify which types of care settings, for each jurisdiction, were actually long term care facilities; non-long term care facilities were excluded from his analyses. Table 6-6 presents data on service utilization ratios for long term care and chronic care facilities from the early 1990s. The rates are unstandardized utilization rates per 1,000 people 65 years of age or older.

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[86] The bed-to-population ratios are crude rates.

[87] This survey uses the federal care level classification system.

Table 6-5: Percentage of People Receiving Home Care in the Past Year by Age Group, Gender and Year for Individuals 20 Years of Age or Older[88]

Age Group	1994 (%)	1996 (%)	1998 (%)
20 – 39 years[89]	.93	.94	.70
40 – 59 years	1.13	1.21	1.39
60 – 69 years	3.40	3.34	2.82
70 – 79 years	9.66	8.02	10.08
80+ years	22.28	23.99	27.99
Less than 65 years	1.07	1.12	1.07
65 years or older	10.31	9.9	11.82
Gender			
Males	1.71	1.69	2.05
Females	3.32	3.34	3.52

Source: Canadian Home Care Human Resources Study (2003). *Home Care Human Resources Study – Synthesis report*, p. 9. Ottawa: Canadian Home Care Human Resources Study.

Table 6-6: Service Utilization Ratios for Long Term Care and Chronic Care Facilities by Province for Individuals 65 Years of Age or Older

Province	Type I and Type II Beds Only	All Long Term Care Beds	Chronic Care Beds	Long Term Care and Chronic Care Beds
British Columbia	30.43	41.70	18.21	59.91
Alberta	57.55	59.14	1.12	60.27
Saskatchewan	39.46	64.68	4.28	68.87
Ontario	38.57	48.82	10.0	58.82
New Brunswick	29.19	63.46	3.89	67.35
Nova Scotia	46.13	56.96	3.74	60.70
Prince Edward Island	35.83	99.53	2.34	101.87
Newfoundland	21.45	63.09	5.19	68.28
All	38.93	51.23	9.56	60.79

Source: Hollander, M.J. (1994a). The costs, and cost-effectiveness, of continuing-care services in Canada , p. 43. Ottawa: Queen’s University.

Figure 6-1 presents comparative data from a recent Manitoba study on the utilization rates of facility care services for persons 75 years of age or older across Canada (Frohlich, DeCoster & Dik, 2002).

DeCoster, et al. (1995) presented data on the expected average length of stay by age group and care level for Manitoba for the early 1990s. As can be seen in Table 6-7, the average expected length of stay in facility care differed by gender, age, and level of care. Females who were under 65 years of age and at Care Level 1 had an expected length of stay of 16.5 years while males 85 years of age and older at Care Level 3 had an average expected length of stay of

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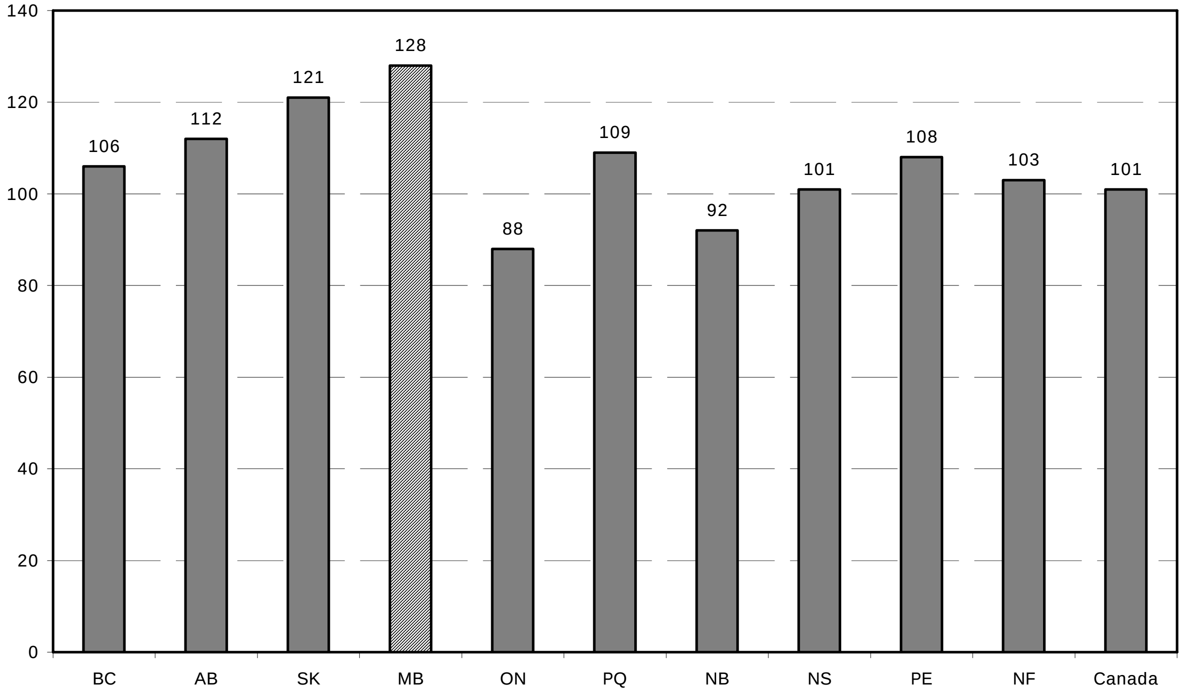
[88] Findings are based on the Statistics Canada National Population Health Surveys for 1994, 1996 and 1998. Comparable data for children are not available in these surveys.

[89] Comparable data are not available for children.

1.8 years. Length of stay is a key variable in determining turnover rates in facility care when one is doing resource planning and/or projecting future bed requirements.

Figure 6-1: Number of Nursing Home Beds per 1,000 Persons Age 75+



Source: Frohlich, N., DeCoster, C., & Dik, N. (2002). *Estimating personal care home bed requirements,* p. 3 Winnipeg: Manitoba Centre for Health Policy.

Table 6-7: Expected Average Length of Stay (in Years) by Age and Care Level at Admission

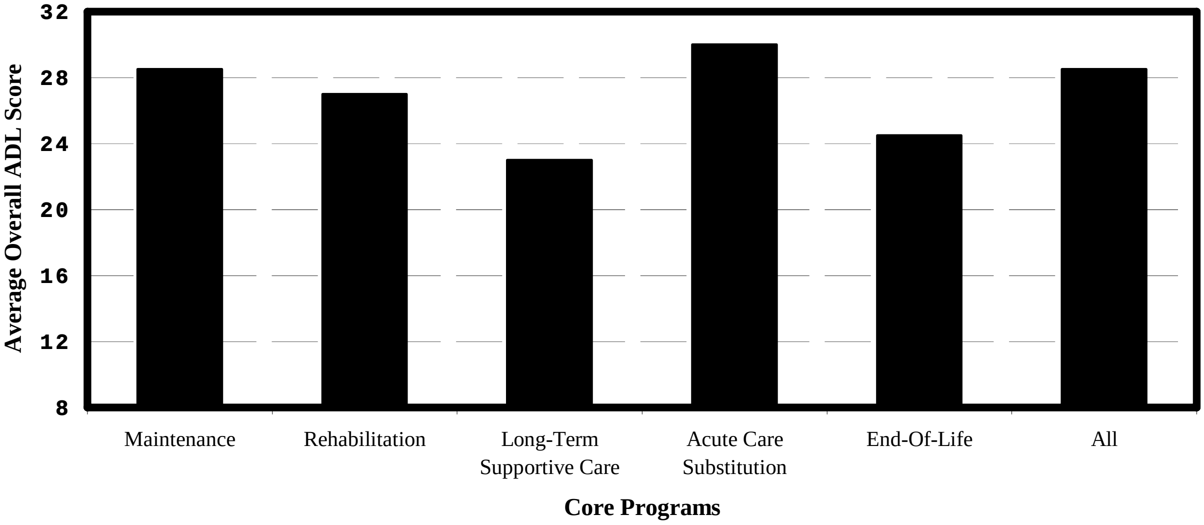
Age (years)	Care Level 1	Care Level 2	Care Level 3
Males			
Less than 65 years of age	14.8	8.2	7.4
65 – 74 years of age	7.2	5.4	3.8
75 – 84 years of age	6.2	3.8	2.7
85 years of age and older	4.5	3.0	1.8
Females			
Less than 65 years of age	16.5	10.3	10.3
65 – 74 years of age	14.7	8.0	5.8
75 – 84 years of age	9.3	6.1	4.4
85 years of age and older	6.3	4.5	3.0

Source: DeCoster, C., Roos, N.P., & Bogdanovic, B. (1995). Utilization of nursing home resources. *Medical Care, 33* (12), p. DS79.

6.4 Data Regarding Functional Status

Activities of daily living are an important measure of the ability of individuals to function independently.[90] Figure 6-2 provides a summary of the level of functional ability for each of the five types of home care based on findings from the Home Care Indicators Project (CIHI, 2004a). The scale is based on the average score of all individuals in each type of home care. The scale ranges from 1 for dependent persons to 4 for independent persons, for eight activities of daily living: eating/drinking, grooming, dressing, bathing, toileting, transferring (for example, from bed to chair or wheelchair and vice versa), indoor locomotion, and outdoor locomotion. Thus, someone who could perform all eight activities independently would score 32 and someone who depended on assistance from others on all activities would score 8. As can be seen in Figure 6-2, the most dependent group, that is those with the highest care needs, were people receiving long term supportive home care. The least dependent (or most independent) group were those in acute care substitution home care.

Figure 6-2: Average Activities of Daily Living Score at Initial Assessment by Type of Home Care Client



Source: Canadian Institute for Health Information. (2004a). *Development of national indicators and reports for home care. Phase 2. Final project report,* p. 54. Ottawa: ON: Author.

Figure 6-3 presents national data on the types of services provided across Canada by home support workers, licensed practical nurses and registered nurses to individuals requiring home care services (Canadian Home Care Human Resources Study, 2003; see also Béland, 1987). The authors caution that the grouping of data in the figure might not reflect important differences that exist by region, province, delivery model, employer type, union status, and so on.

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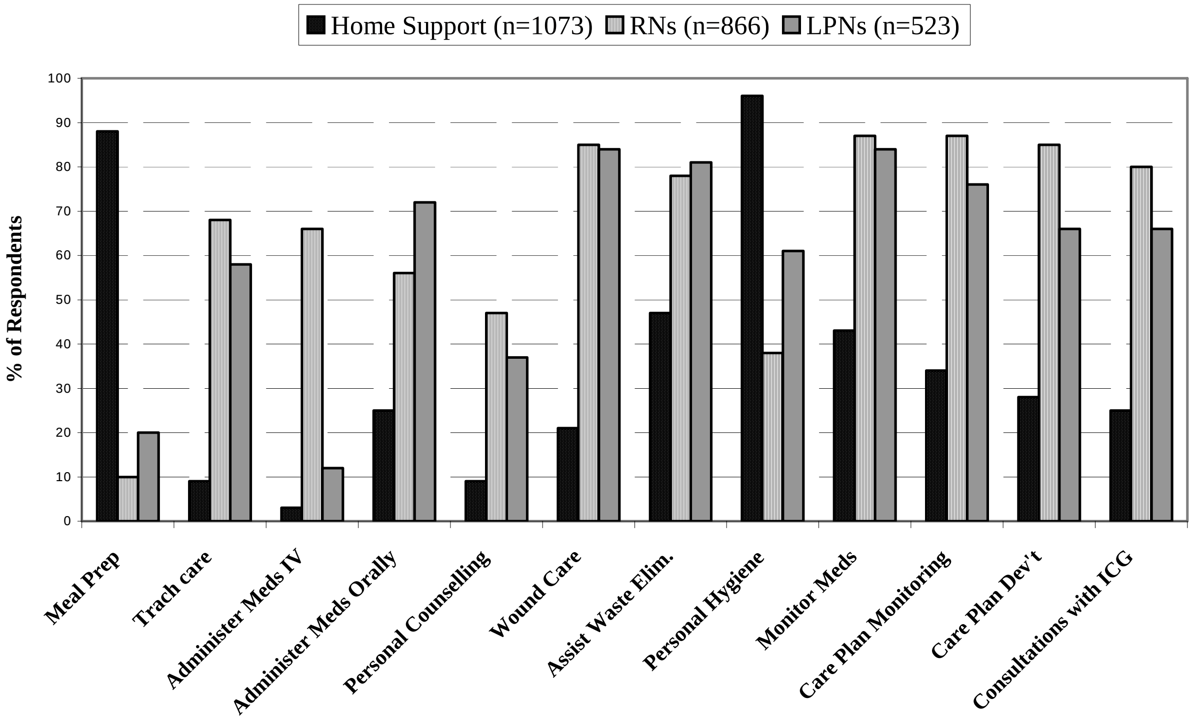
[90] The term *activities of daily living* refers to tasks that healthy individuals often take for granted such as eating, dressing, walking, and bathing.

Figure 6-3: Services Provided by Home Support Workers, Licensed Practical Nurses and Registered Nurses[91]



Source: Canadian Home Care Human Resources Study (2003). *Home Care Human Resources Study – Synthesis report*, p. 23. Ottawa: Author.

6.5 Data on Individuals with Disabilities, People with Chronic Mental Health Conditions and Children with Special Needs

Little continuing care related data on individuals with disabilities and children with special needs was found in the review of the literature. There was data from the national Health and Activity Limitation Survey and the Participation and Activity Limitation Survey, but it was fairly general with respect to disabling conditions and did not clearly separate out adults with physical disabilities or provide utilization and cost data for this population. Dowler and Jordan-Simpson (1990) provide some data on the need for assistance with daily activities by age group (see Table 6-8). However, the data includes a wider range of individuals than those who would typically receive continuing care services.

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[91] Data were not available for Occupational Therapists, Physiotherapists or Social Workers.

Table 6-8: Assistance with Activities Among Disabled Adults in Institutions, 1987

Activity	Age Group				
		15 to 34 years	35 to 54 years	55 to 64 years	64 years plus
	%	%	%	%	%
Helping with shopping	91.0	91.8	85.6	87.1	91.8
- by institution		75.9	64.0	49.9	28.9
- by family/friend		25.0	28.0	43.9	71.3
Helping with personal finance	87.4	90.5	82.1	84.0	87.9
- by institution		74.6	56.2	39.7	18.9
- by family/friend		28.7	43.4	53.3	73.1
Helping with daily personal care	62.4	65.6	52.1	53.2	63.7

Source: Dowler, J.M. & Jordan-Simpson, D.A. (1990). Canada's disabled population in institutions. *Health Reports*, *2*(1), 27-36.

There was, however, some continuing care related data on individuals with chronic mental health conditions. Lesage, Gélinas, Robitaille, Dion, Frezza and Morissette (2003) provide some benchmarks from 1997 related to actual utilization rates and estimates of need for a range of health related services. These data are presented in Table 6-9 and include actual utilization ratios and needs based estimates for a range of services including care in psychiatric wards in hospitals, nursing homes and supervised group homes.

Table 6-9: Actual Utilization Rates and Needs Based Estimates for Individuals with Chronic Mental Health Conditions

	Actual Utilization Rate per 100,000 Inhabitants	Estimated Needs Based on Existing Places Per 100,000 Inhabitants	Estimated Needs for Additional or Fewer Places Based on Acute Care Bed Users	Best Estimate of Needs per 100,000 Inhabitants
Psychiatric Hospital Long Stay Ward	34	15	5	20
Nursing Homes	3	12	8	20
Hostels	21	20	-6	14
Foster Families	40	36	-10	26
Supervised Group Homes	21	27	13	40
Supervised Apartments	31	34	17	51
Total	150	144	27	171

Source: Lesage, A.D., Gélinas, D., Robitaille, D., Dion, E., Frezza, D., & Morissette, R. (2003). Toward benchmarks for tertiary care for adults with severe and persistent mental disorders. *Canadian Journal of Psychiatry*, *48* (7), p. 488.

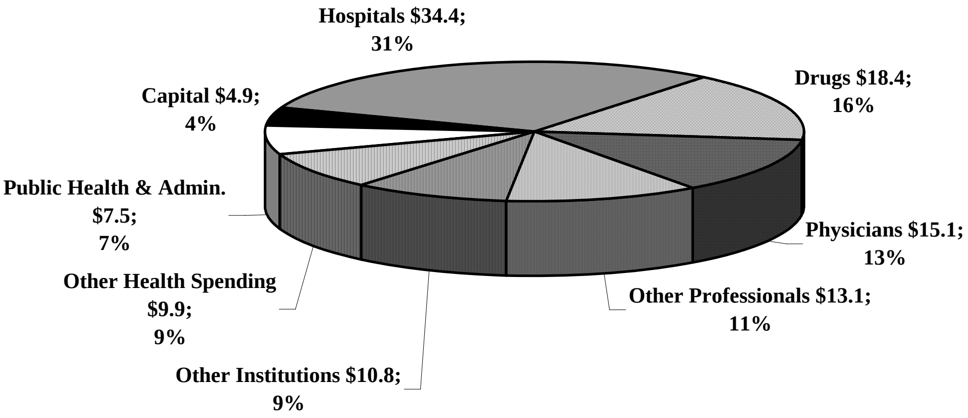
In an Ontario study, Conn, Steingart and Sillerfeld (1992) found that limited psychiatric services were provided to nursing home residents (five hours or less per month per facility). It was estimated that, on average, 30.5% of residents in long term care facilities required psychiatric services. Conn, Ferguson, Mandelman, and Ward (1999) conducted a study in Ontario on psychotropic drug utilization in long term care facilities. They found considerable differences in the use of such drugs both within the same types of institution, and across different types of institutions. For example, 11.8% of clients in retirement homes used neuroleptics compared to 19.8% in nursing homes. Antidepressant use ranged from 12.2% in nursing homes to 24.6% in homes for the aged, while benzodiazepine use ranged from 22.5% in nursing homes to 26.4% in retirement homes.

6.6 Health Expenditure Data

6.6.1 Overall Health Expenditures

As noted earlier, CIHI does not publish data on the continuing care sector *per se*. Figure 6-4 provides a breakdown of overall health expenditures (from both public and private sources) for Canada for 2002 (CIHI, 2004b). As can be seen, hospital services accounted for 31% of expenditures while other institutions, which include long term care facilities, accounted for 9% of total expenditures. Until changes are made such that continuing care, and its component parts are recognized as separate components of the health care system it will not be possible to have accurate national data on the continuing care sector.

Figure 6-4: Total Health Expenditures for Canada in 2002 (in billions of dollars)

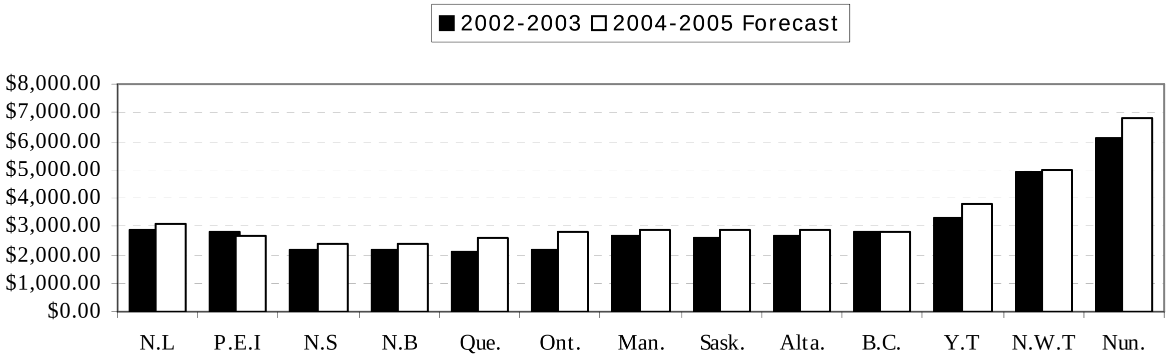


Source: Canadian Institute for Health Information. (2004b). *National health expenditure trends 1975-2004,* p.15.. Ottawa, ON: Author.

6.6.2 Per Capita Health Expenditures

Figure 6-5 presents provincial/territorial government health expenditure data per capita for two fiscal years. As can be seen, for the 2002/2003 fiscal year, per capita expenditures for all provinces were below $3,000, while expenditures for the three territories were above $3,000, with Nunavut exceeding $6,000. The higher costs for the territories are believed to be due to “the higher costs of servicing large areas with relatively small populations” (CIHI, 2004c) Thus, at least for non-urban First Nations and Inuit communities, one would expect that per capita costs would be higher (when all costs are counted) than the Canadian average, and may be up to twice as high, or higher.

Figure 6-5: Provincial/Territorial Government Health Expenditure Per Capita for Fiscal Years 2002/2003 and 2004/2005



Source: Canadian Institute for Health Information. (2004c). *Preliminary Provincial and Territorial Government Health Expenditure Estimates 1974-1975 to 2004-2005*, p. 16. Ottawa: Canadian Institute for Health Information.

6.6.3 Home Care Expenditures

Coyte and McKeever (2001) noted, that in the 1990s, expenditures for home care grew more rapidly on a proportional basis than expenditures for the overall health care system. In 1997, home care expenditures represented less than 5% of health expenditures. More recently, Romanow (2002) found that, on average, across Canada, home care accounted for four percent of overall government health expenditures.

Ballinger, Zhang and Hicks (2001) conducted some preliminary analyses of home care expenditures as input into national health expenditures. Table 6-10 presents data on professional home health care services, home support services and an “unclassified” group of expenditures which could not be broken down between professional and supportive services. As can be seen, over the 11 year period from fiscal year 1988/1989 to fiscal year 1998/1999, there was an overall increased proportion of expenditures for professional services compared to supportive services. It is thought that this trend has continued, particularly because of the current focus on short term home care which involves a high proportion of professional services. Ballinger et al. also provided a breakdown of professional and supportive services by jurisdiction. The western provinces relied more on supportive services than on professional services. This finding is important, as the western provinces generally have more integrated systems of continuing care. Thus, it appears to be possible to use a high level of supportive services in more integrated health systems.

6.6.4 Facility Expenditures

Hollander (1994a) presented data on per diem rates by level of care for facility clients for the 1991/1992 fiscal year. The rates include client co-pay contributions which accounted, on average, for 23.7% of the per diem rate (see Table 6-11).

Table 6-10: Public Sector Home Care Expenditures in Canada, 1988/1989 to 1998/1999

Fiscal Year	Provincial Government Home Care Expenditures						Total ($000)
	Home Health Care		Home Support		Unclassified		
	Amount ($000)	Proportion of Total	Amount ($000)	Proportion of Total	Amount ($000)	Proportion of Total	
1988/89	41,547	7.6	141,007	25.7	365,465	66.7	548,020
1989/90	159,460	19.1	321,573	38.5	354,270	42.4	835,302
1990/91	185,618	19.0	366,900	37.6	422,816	43.4	975,334
1991/92	249,252	21.6	385,350	33.4	520,605	45.1	1,155,207
1992/93	271,134	21.2	462,296	36.2	543,179	42.5	1,276,609
1993/94	902,739	51.8	747,864	42.9	93,468	5.4	1,744,071
1994/95	966,233	50.3	842,547	43.9	111,450	5.8	1,920,229
1995/96	763,060	38.6	1,070,115	54.1	145,575	7.4	1,978,750
1996/97	783,425	37.4	1,146,255	54.8	162,707	7.8	2,092,387
1997/98	876,874	37.2	1,165,232	49.5	313,305	13.3	2,355,411
1998/99	1,092,727	39.9	1,314,816	48.1	327,839	12.0	2,735,383

Source: Ballinger, G., Zhang, J., & Hicks, V. (2001). *Home care estimates in national health expenditures: Feasibility study*. Ottawa, ON: Canadian Institute for Health Information.

Table 6-11: Average Per Diem Rates by Type of Ownership and Level of Care for Fiscal Year 1991/1992

Federal Care Level	Type of Ownership			
	Propriety	Not-For-Profit	Government	All
1	$54.49	$73.44	$86.67	$73.13
2	$75.38	$89.46	$102.66	$89.41
3	$82.56	$96.99	$133.94	$101.52
All	$73.69	$86.34	$103.97	$88.99

Source: Hollander, M.J. (1994a). The costs, and cost-effectiveness, of continuing-care services in Canada, p. 50. Ottawa: Queen’s University.

In a study conducted in Québec, Tousignant, Hébert, Dubuc, Simoneau and Dieleman (2003), provided data on the per diem and annual costs (in 2001 dollars) for residential care services. The costs were stratified across the 14 levels of care which are integrated into the Système de mesure de l’autonomie fonctionnelle (Functional Autonomy Measurement System or SMAF), the functional assessment instrument used in Québec. In any care level classification system, each level of care represents people with similar care needs and/or people who require similar dollar amounts of services. Typically, one would expect a fairly consistent increase in costs, by level of care, as one moves from lower levels of care (representing people with fewer care needs) to higher levels of care (representing people with greater care needs). Table 6-12 provides the data from this study.

Table 6-12: Costs by SMAF Care Level for Public Nursing Homes in Québec (in 2001 dollars)

Care Level	Public Costs Per Day[92]	Annual costs
1	-[93]	-
2	$61.10	$22,300
3	$68.48	$24,994
4	$100.74	$36,771
5	$78.42	$28,624
6	$91.89	$33,541
7	$98.78	$36,053
8	$114.96	$41,962
9	$147.76	$53,933
10	$129.70	$47,342
11	$159.02	$58,043
12	$144.81	$52,856
13	$169.63	$61,914
14	$183.19	$66,863

Source: Tousignant, M., Hébert, R., Dubuc, N., Simoneau, F., & Dieleman, L. (2003). Application of a case-mix classification based on the functional autonomy of the residents for funding long term care facilities. *Age and Ageing, 32*, 60-66.

6.7 Cost Estimates for Continuing Care

6.7.1 Major Expenditure Categories – Facility Care

Hollander (1994a) provided a breakdown of the average per diems for long term facility care into major expenditure categories (see Table 6-13). The importance of Table 6-13 is not the actual dollar amounts but the relative percentages of the major expenditure categories, as it is likely that these percentages would be fairly similar today.

6.7.2 Unit Costs for Home Care and Facility Care

The Institute of Health Economics published a national list of provincial costs for health care for the 1997/1998 fiscal year. While the data would need to be updated, or extrapolated, they can be used to obtain initial cost estimates for continuing care. Table 6-14 provides a summary of unit costs for home care and Table 6-15 provides per diem costs for long term residential care services.

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[92] Does not include infrastructure costs.
[93] No residents were identified for Care Level 1 in this study.

Table 6-13: Expenditure Profile for All Facilities for Fiscal 1991/1992

	Amount	**Percent of Subcomponent**	**Percent of Total**
Overall Per Diem	$87.42	100.00	100.00
Total Salary Expenses	$57.34	65.59	65.59
Care Services Staff	$37.65	65.54	43.06
Registered Nurses	$10.76	28.60	12.32
Registered Nursing Assistants	$ 5.18	13.77	5.93
Therapists	$ 0.57	1.50	0.64
Activity/Recreation Staff	$ 1.64	4.34	1.87
Other	$19.48	51.80	22.29
General Services Staff	$19.70	34.35	22.53
Administration	$ 4.87	24.69	5.57
Dietary Services	$ 7.42	37.60	8.48
Housekeeping/Laundry	$ 5.47	27.80	6.26
Other	$ 1.95	9.90	2.23
Non-Salary Expenses	$30.08	34.40	34.40
Care Services	$ 2.29	7.63	2.63
General Services	$19.75	65.66	22.59
Administration	$ 8.52	43.15	9.75
Dietary Services	$ 5.17	26.18	5.91
Housekeeping/Laundry	$ 1.69	8.54	1.93
Other	$ 4.37	22.13	4.99
Other (Rent, Taxes, etc)	$ 8.03	26.70	9.19

Source: Hollander, M.J. (1994a). The costs, and cost-effectiveness, of continuing-care services in Canada, p. 53. Ottawa: Queen’s University.

Table 6-14: National Unit Costs for Home Care Services

Province	Cost Estimate	Comments
British Columbia	Not available	
Alberta	Professional Nurse - $20.10 per hour Licensed Practical Nurse - $20.10 per hour Physical Therapy/Occupational Therapy – $43.00 per hour	These are fees charged per hour of service. The relation between these fees and costs is unknown.
Saskatchewan	Registered Nurse - $49.00 per hour Physical Therapy - $65.00 per hour Home Support - $25.00 per hour	These are full costs including salaries, supplies, overhead, down-time and support.
Manitoba	Registered Nurse - $24.30 per hour Physical Therapy/Occupational Therapy - $42.72 per hour Licensed Practical Nurse - $21.68 per hour Home Care Attendant - $14.75 per hour Home Support Worker - $12.01 per hour	These are direct salary costs. They do not include overhead costs.
Ontario	Not available	
Québec	Not available	
New Brunswick	Home Health Care - $82.00 per visit Home Support - $68.00 per day	These are full costs. They include supplies and drugs, but do not include general planning and administrative costs.
Nova Scotia	Home Nursing - Registered Nurse - $41.47 per visit - Licensed Practical Nurse - $30.66 per visit Home Support - $15.00 to $20.00 per hour via contracts with non-profit agencies	There are no client fees for visits by Registered Nurses or Licensed Practical Nurses. A sliding client fee scale is used for home support services. For example, there is no fee for clients receiving Old Age Security or Guaranteed Income Supplement. Other clients pay $8.00 per hour to a maximum of $480.00 per month for families with a net annual income of $50,000.
Prince Edward Island	Home Nursing - Registered Nurse - $22.75 per hour - Licensed Practical Nurse - $17.75 per hour Personal Care (bathing, grooming) - $14.87 per hour Home Support (light housekeeping) - $12.50 per hour	These are average fees charged to clients by private agencies.
Newfoundland	Not available	

Source: Institute of Health Economics (2000). *A national list of provincial costs for health care: Canada 1997/8, p. 105.* Edmonton: Author

Table 6-15: National Unit Per Diem Rates for Care Facilities

Province	Cost Estimate	Out-of-Pocket Fee	Comments
British Columbia	Personal Care and Intermediate Care Level 1 - $57.39 per day Intermediate Care Level 2 - $43.85 Intermediate Care Level 3 - $69.20 Extended Care - $99.88		Figures reflect actual costs.
Alberta	A - $28.90 per day B - $36.06 per day C - $47.35 per day D - $54.42 per day E - $73.11 per day F - $88.88 per day G - $147.75 per day	$26.67 per day (average co-payment)	Figures are all inclusive rates, updated for inflation.
Saskatchewan	Level 3 - $96.00 per day Level 4 - $132.00 per day	Resident pays 25%	Figures are all inclusive rates, updated for inflation.
Manitoba	Levels 1 and 2 - $71.45 per day Levels 3 and 4 - $99.35 per day		Figures are per diem rates for private homes in Manitoba. Figure for Levels 3 and 4 do not include pharmaceuticals, rehabilitation services or physician payments.
Ontario	A - $65.06 per day B - $72.43 per day C - $82.32 per day D - $88.44 per day E - $100.25 per day F - $109.58 per day G - $142.65 per day		Figures are adjusted for level of care.
Québec	$124.00 - $163.00 per day		Figures are for all inclusive cost for public homes (level of care not specified).
New Brunswick	Level 1 - $36.00 per day Level 2 - $68.00 per day Level 3 - $105.00 per day Level 4 - $134.00 per day	Varies with income level	Figures are for public homes.
Nova Scotia	Level I - $74.39-$94.69 per day Level II - $90.92-$147.21 per day	Varies with income level ($0 - $360 per month)	Figures are for all inclusive approved rates for public homes.
Prince Edward Island	Self-pay residents in public homes - $107.00 per day Subsidized average rates in private homes - Level III - $86.05 per day - Level IV - $88.05 per day - Level V - $89.05 per day		
Newfoundland	$140.00 per day ($4200 per month)	$33.33 per day ($1000 per month)	Figure is average cost for public units, all inclusive, over all levels of care.

Source: Institute of Health Economics (2000). *A national list of provincial costs for health care: Canada 1997/8, p. 105.* Edmonton: Author

6.7.3 Human Resources

A major study was conducted on human resources issues in the Canadian home care sector in the early 2000s (Canadian Home Care Human Resources Study, 2003). Table 6-16 presents data on the unit costs of home care in the early 2000s, based on an average of costs across Canada.

Table 6-16: Average Hourly Wages by Union Status and Type of Employer

	Gov't/Regional Health Authorities	Private Not-For-Profit	Private for-Profit	Overall
Registered Nurses				
Unionized	$26.41	$23.29	$23.57	$25.36
Non-Unionized	$24.32	$23.13	$21.17	$22.04
Overall	$26.36	$23.23	$21.78	$24.38
Licensed Practical Nurses				
Unionized	$18.37	$18.09	$16.64	$17.91
Non-Unionized	$19.72	$18.10	$16.06	$17.25
Overall	$18.59	$18.09	$16.24	$17.63
Occupational Therapists, Physiotherapists, and Social Workers				
Unionized	$26.78	N/A	$28.63	$26.97
Non-Unionized	$30.25	$25.56	$32.75	$31.81
Overall	$27.04	$25.56	$31.50	$28.17
Home Support Workers				
Unionized	$14.65	$11.74	$13.07	$13.49
Non-Unionized	$13.42	$11.52	$11.79	$11.95
Overall	$14.41	$11.66	$12.04	$12.71

Source: Canadian Home Care Human Resources Study. (2003). *Home Care Human Resources Study – Synthesis report*, p. 25. Ottawa: Author.

There does not appear to be any up-to-date data on facility costs, comparable to the more recent data for home care. However, as part of the process to estimate costs, Hollander (1994a) developed estimated staffing ratios by type of care provider for three federal care levels. These ratios (expressed as full time equivalent staff per bed) are presented in Table 6-17.

Table 6-17: Estimated Staffing Ratios by Type of Care Provider by Federal Care Levels

Type of Staff	Type I	Type II	Type III
Nurses	.070	.090	.103
Other Care Staff	.285	.405	.437
Administration	.050	.049	.049
Dietary Services	.099	.101	.121
Housekeeping	.071	.081	.102
Other	.025	.024	.038
Total	.600	.750	.850

Source: Hollander, M.J. (1994a). The costs, and cost-effectiveness, of continuing-care services in Canada, p. 62. Ottawa: Queen's University.

6.8 Comparative Data for Home Care and Facility Care

British Columbia is relatively unique in that the care level classification system used for continuing care is the same regardless of whether care is provided in a home or in a facility. In addition, the care classification system has been in place since the late 1970s, allowing for analyses of trends over time. This section presents data on potential indicators and benchmarks for both home care and facility care clients for integrated systems of continuing care which provide services for the elderly and adults with physical disabilities.

Table 6-18 presents data on service utilization for each type of continuing care service by age and gender. As can be seen, service utilization ratios differ by both age and gender. For example, there were 0.06 female clients per 1,000 individuals between 0 and 19 years of age in long term care and chronic care beds (total residential beds/clients) in fiscal year 1988/1989 compared to 359.81 female clients per 1,000 individuals 85 years of age or older. The comparative utilization rates for males were 0.05 and 221.48, respectively.

Table 6-18: Actual Utilization Ratios Per 1000 Population for the 1988/1989 Fiscal Year

Type of Service		**Age Groups**					
		0-19	**20-44**	**45-64**	**65-74**	**75-84**	**85+**
Population	Female	386,242	598,342	295,161	127,065	67,636	21,804
	Male	418,955	596,275	298,292	104,729	48,992	10,507
Continuing Care Beds/Clients	Female	0.00	0.07	1.14	10.63	64.52	249.62
	Male	0.00	0.12	1.62	9.39	39.34	157.39
Extended Care Beds/Clients	Female	0.06	0.20	0.98	4.43	22.10	110.19
	Male	0.05	0.25	0.96	3.99	16.28	64.09
Total Residential Beds/Clients	Female	0.06	0.27	2.39	15.06	86.63	359.81
	Male	0.05	0.37	2.58	13.38	55.62	221.48
Homemaker Hours per Month	Female	0.15	15.54	114.14	703.40	1,986.31	2,487.23
	Male	0.23	8.82	43.47	305.55	1,051.58	2,065.12
Homemaker Clients	Female	0.01	1.26	9.30	57.29	161.78	202.55
	Male	0.02	0.72	3.54	24.88	85.65	168.22
Adult Day Care Days per Month	Female	0.00	0.29	2.02	10.87	42.25	66.04
	Male	0.00	0.18	1.30	7.81	26.45	56.06
Adult Day Care Clients	Female	0.00	0.08	0.54	2.90	11.28	17.61
	Male	0.00	0.05	0.35	2.08	7.06	14.98
Group Home Beds/Clients	Female	0.01	0.09	0.04	0.01	0.02	0.04
	Male	0.00	0.16	0.09	0.01	0.00	0.00
Long Term Care Community Clients	Female	0.03	1.43	9.87	60.20	173.08	220.20
	Male	0.02	0.92	3.97	26.97	92.70	183.19
Long Term Care Residential and Community Clients	Female	0.08	1.70	12.26	75.26	259.71	580.01
	Male	0.07	1.29	6.55	40.35	148.32	404.68
Full Time Equivalent Assessor Staff	Female	0.00	0.01	0.04	0.26	0.90	2.02
	Male	0.00	0.00	0.02	0.14	0.52	1.41
Full Time Equivalent Clinical Services Staff	Female	0.02	0.04	0.18	0.66	1.45	2.16
	Male	0.02	0.03	0.14	0.55	1.22	2.11
Clinical Services Clients	Female	0.34	0.70	3.05	11.20	24.71	36.81
	Male	0.35	0.52	2.34	9.48	20.86	35.77
Total Community Clients, Long Term Care and Clinical Services	Female	0.37	2.13	12.93	71.40	197.79	257.01
	Male	0.38	1.44	6.31	36.45	113.56	218.96
Total Residential and Community Clients	Female	0.43	2.40	15.32	86.46	284.41	616.83
	Male	0.42	1.81	8.90	49.83	169.18	440.44

Note: Ratios are based on the number of active clients, on an average day, unless otherwise specified
Source: Hollander, M.J. & Pallan, P. (1995). The British Columbia continuing care system: Service delivery and resource planning. *Aging: Clinical and Experimental Research*, *7*(2), p. 102.

A planning and resource allocation model for all continuing care services for British Columbia was developed in 1989. The model was used to re-allocate resources from facility care to home care services. Table 6-19 presents data on the actual 1998/1999 utilization rates and the 1994/1995 target utilization rates per 1,000 individuals 65 years of age or older for continuing care services.

Table 6-19: A Comparison of Actual and Proposed Utilization Rates in Relation to the 1988/89 Base Year Per 1,000 Individuals 65 Years of Age or Older

Type of Service	1988/89 Actual Utilization Rates	Project 1994/95 Target Rates Adjusted Back to the 1988/89 Population Base
Continuing Care	44 beds	35 beds
Extended Care	19 beds	20 beds
Total Residential	63 beds	55 beds
Homemaker Hours	1169 hours	1519 hours
Adult Day Care Days	25.3 days	33.1 days
Group Home Spaces	0.51 spaces	0.59 spaces
Full Time Equivalent (FTE) Clinical Services Staff	1.37 FTEs	1.76 FTEs
Full Time Equivalent (FTE) Assessor Staff	0.58 Assessors	0.78 Assessors

Source: Hollander, M.J. & Pallan, P. (1995). The British Columbia Continuing Care System: Service delivery and resource planning. *Aging: Clinical and Experimental Research*, *7*(2), p. 103.

Hollander (2001b) conducted an extensive study of the costs to government for continuing care clients. He considered continuing care home care and facility care costs, hospital costs, physician costs and drug costs. The findings indicated that, in general, service utilization and costs increased by level of care. For clients with similar care needs, the costs to government of providing home and community care services were generally substantially less than those for providing services to facility care clients. Table 6-20 presents data on utilization and costs per client for all services included in the study, by level of care.

A major study of costs and outcomes for continuing care clients was conducted by Hollander, Chappell et al. (2002) in Victoria, B.C. and Winnipeg, Manitoba. The study included the costs to the health care system *as well as* the costs to clients and their family members. Thus, this study took a broader societal perspective on costs. Table 6-21 provides a breakdown of costs by level of care designations developed for the study using data from the SMAF.

Total costs for home and community care and for residential care are provided in Table 6-22. Note that, in Table 6-22, total costs for home care and community care are the sum of column 6 (Total Formal Care Cost) and column 11 (Maximum Costs to Client and/or Family Caregiver) in Table 6-21. The total costs for facility care are calculated by adding columns 6 and 11 *and* subtracting column 7 (Purchased Services/Facility User Fees; user fees are already included in the formal care costs included in column 6).

Table 6-20: Average Annual Service Utilization and Costs in 1991/1992 Dollars for Home Care and Facility Care Clients

	Care Level	Utilization		Costs	
		Community	**Facility**	**Community**	**Facility**
Full-Time Equivalent Clients	Intermediate Care 1	1222.53	15.23	1222.53	15.23
	Intermediate Care 2	1201.80	393.90	1201.80	393.90
	Intermediate Care 3	365.41	392.31	365.41	392.31
	Extended Care	163.27	442.04	163.27	442.04
All Costs	Intermediate Care 1	N/A	N/A	$7,690.19	$18,739.03
	Intermediate Care 2	N/A	N/A	$12,677.34	$22,998.64
	Intermediate Care 3	N/A	N/A	$18,665.83	$28,848.59
	Extended Care	N/A	N/A	$26,269.23	$41,296.63
Medical Services Plan (Units/$)	Intermediate Care 1	51.59	49.63	$1,269.03	$1,083.81
	Intermediate Care 2	50.71	44.63	$1,213.60	$1,008.25
	Intermediate Care 3	53.25	45.35	$1,263.88	$1,025.25
	Extended Care	58.20	31.00	$1,390.17	$704.09
Pharmacy (Prescriptions/$)	Intermediate Care 1	20.41	52.59	$639.87	$745.17
	Intermediate Care 2	22.58	46.38	$702.71	$650.56
	Intermediate Care 3	24.14	42.95	$717.74	$587.06
	Extended Care	22.05	12.37	$680.36	$181.60
Hospital Days (Days/$)	Intermediate Care 1	7.22	2.23	$3,070.19	$948.65
	Intermediate Care 2	12.31	4.30	$5,231.52	$1,829.43
	Intermediate Care 3	15.12	4.82	$6,424.77	$2,047.49
	Extended Care	22.26	2.41	$9,458.38	$1,022.51
Direct Care (Visits/$)	Intermediate Care 1	5.50	0.00	$302.77	$0.00
	Intermediate Care 2	9.13	0.00	$502.22	$0.00
	Intermediate Care 3	11.71	0.00	$644.10	$0.00
	Extended Care	22.42	0.00	$1,233.34	$0.00
Homemaker (Hours/$)	Intermediate Care 1	116.85	0.00	$2,007.49	$0.00
	Intermediate Care 2	235.59	0.00	$4,047.49	$0.00
	Intermediate Care 3	485.36	0.00	$8,338.51	$0.00
	Extended Care	768.03	0.00	$13,194.73	$0.00
Adult Day Care (Days/$)	Intermediate Care 1	7.27	0.00	$400.84	$0.00
	Intermediate Care 2	17.78	0.00	$979.79	$0.00
	Intermediate Care 3	23.17	0.00	$1,276.83	$0.00
	Extended Care	5.67	0.00	$312.26	$0.00
All Long Term Care Facility (Days/$)	Intermediate Care 1	0.00	364.00	$0.00	$15,961.40
	Intermediate Care 2	0.00	364.00	$0.00	$19,510.39
	Intermediate Care 3	0.00	364.00	$0.00	$25,188.80
	Extended Care	0.00	364.00	$0.00	$39,388.44

Source: Hollander, M.J. (2001b) *Substudy 1: Final report of the study on the comparative costs analysis of home care and residential care services*. Victoria: National Evaluation of the Cost-Effectiveness of Home Care.

Table 6-21: Mean Annual Costs for Formal and Informal Care Categories (for Clients with 120 Hours per Month or Less of Care Aide Time)[94]

	Care Category										
	1	2	3	4	5	6	7	8	9	10	11
Site, Type, and Level of Care	**Care Staff Costs**[95]	**Support Staff Costs**[96]	**Administrative Costs**[97]	**Continuing Care Costs**[98]	**Physician & Hospital Costs**[99]	**Total Formal Care Costs**[100]	**Purchased Services/ Facility User Fees**[101]	**Out-of-Pocket Expenses**[102]	**Informal Caregiver Time at Minimum Wage**[103]	**Informal Caregiver Time at Replacement Wage**[104]	**Maximum Costs to Client and/or Informal Caregiver**[105]
Victoria Community											
Level A	$10,893.25	-	-	$10,893.25	$1,970.41	$12,863.66	$ 614.46	$1,673.86	$ 1,863.72	$ 5,221.08	$ 7,509.40
Level B	$15,568.99	-	-	$15,568.99	$2,422.39	$17,991.38	$ 803.13	$1,843.70	$ 3,976.59	$11,140.15	$13,786.98
Level C	$13,895.06	-	-	$13,895.06	$1,020.00	$14,915.06	$ 370.50	$3,338.72	$ 4,852.56	$13,594.14	$17,303.36
Level D	$19,886.38	-	-	$19,886.38	$ 434.38	$20,320.76	$ 3,450.00	$6,783.13	$11,249.74	$31,515.42	$41,748.55
Victoria Facility											
Level A	$12,333.33	$ 5,959.37	$15,512.50	$33,805.20	$ 579.17	$34,384.37	$10,291.78	$1,499.18	$ 1,203.63	$ 3,371.89	$15,162.85
Level B	$16,370.46	$ 8,002.44	$15,512.50	$39,885.40	$ 256.67	$40,142.07	$11,000.58	$1,574.46	$ 1,516.26	$ 4,247.70	$16,822.74
Level C	$20,407.08	$10,003.65	$15,512.50	$45,923.23	$ 958.70	$46,881.93	$10,867.00	$1,722.69	$ 1,871.54	$ 5,243.00	$17,832.69
Level D	$26,665.02	$13,180.39	$15,512.50	$55,357.91	$ 379.23	$55,737.14	$11,427.59	$2,356.52	$ 2,932.97	$ 8,216.52	$22,000.63
Winnipeg Community											
Level B	$15,725.32	-	-	$15,725.32	$2,459.29	$18,184.61	$ 204.29	$1,755.42	$ 4,280.30	$ 7,372.99	$ 9,332.70
Level C	$17,062.81	-	-	$17,062.81	$1,062.50	$18,125.31	$ 1,566.00	$1,423.10	$ 5,498.51	$ 9,546.05	$12,535.15
Level D	$14,423.02	-	-	$14,423.02	$1,675.77	$16,098.79	$ 570.77	$2,801.45	$ 7,522.70	$13,374.30	$16,746.52
Level E	$21,859.29	-	-	$21,859.29	$1,956.25	$23,815.54	$ 0.00	$2,628.25	$ 4,805.18	$ 8,669.97	$11,298.22
Winnipeg Facility											
Level B	$20,406.87	$ 9,250.37	$15,512.50	$45,169.74	$ 159.55	$45,329.29	$11,673.70	$ 308.57	$ 1,169.17	$ 1,980.36	$13,962.63
Level C	$20,024.77	$ 9,765.63	$15,512.50	$45,302.90	$ 255.41	$45,558.31	$13,406.55	$ 903.56	$ 1,605.63	$ 2,745.45	$17,055.56
Level D	$17,070.94	$ 8,144.07	$15,512.50	$40,727.51	$ 675.38	$41,402.89	$12,807.15	$1,068.70	$ 1,787.13	$ 3,165.17	$17,041.02
Level E	$20,550.30	$ 9,804.06	$15,512.50	$45,866.86	$ 880.00	$46,746.86	$13,324.14	$1,599.14	$ 1,202.65	$ 2,214.38	$17,137.66

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

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[94] Informal caregiver time and costs refers to the time and funds provided by family members, friends, neighbours, etc.

[95] Care Staff Costs include Home Support Workers, Care Aides, Nursing Staff, and Other Health Professionals.

[96] Support Staff Costs include Dietary, Housekeeping, and Laundry.

[97] Administrative Costs reflect an adjustment made for capital costs, equipment, food, administrative staff and other administrative overhead costs for facility clients.

[98] Continuing Care Costs are the sum of the columns Care Staff Costs, Support Staff Costs and Administrative Costs (includes Purchased Services/Facility User Fees).

[99] Includes Physician and Hospital Services (Purchased Services/Facility User Fees are not applicable).

[100] Total Formal Care Costs is the sum of the columns Continuing Care Costs and Physician and Hospital Costs.

[101] Purchased Services apply only to community clients while User Fees apply only to facility clients.

[102] Out-of-Pocket Expenses are costs paid directly by the client and/or informal caregiver.

[103] Using site-specific data.

[104] Using site-specific data.

[105] Maximum Costs to Client and/or Informal Caregiver is the sum of the columns Purchased Services/Facility User Fees, Out-of-Pocket Expenses and Informal Caregiver Time at Replacement Wage.

Table 6-22: Mean Annual Cost of Continuing Care Services, Physician and Hospital Costs, Out-of-Pocket Expenses, and Informal Caregiver Time Valued at Replacement Wage (for Clients with 120 Hours per Month or Less of Care Aide Time)

Care Level		**Victoria Sample**		**Winnipeg Sample**	
		Community	**Facility**	**Community**	**Facility**
Level A: Somewhat Independent	Mean	$19,758.59	$39,255.44		
	Standard Deviation	$11,590.57	$ 7,594.13		
	Number	37	12		
Level B: Slightly Independent	Mean	$30,975.22	$45,964.23	$27,313.02	$47,618.22
	Standard Deviation	$16,943.63	$12,566.70	$21,219.16	$19,486.61
	Number	23	42	14	11
Level C: Slightly Dependent	Mean	$31,847.92	$53,847.62	$29,094.46	$49,207.31
	Standard Deviation	$13,764.31	$17,417.82	$ 8,851.74	$13,805.44
	Number	12	50	10	37
Level D: Somewhat Dependent	Mean	$58,619.30	$66,310.18	$32,274.54	$45,636.77
	Standard Deviation	$25,473.65	$21,491.15	$ 9,200.12	$15,735.47
	Number	8	26	13	52
Level E: Largely Dependent	Mean			$35,113.75	$50,560.38
	Standard Deviation			$ 6,302.44	$17,196.53
	Number			4	29

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

6.9 Topics Related to the Health and Well-Being of First Nations and Inuit

The previous sections have focused on indicators, data and benchmarks for continuing care services based on primarily non-Aboriginal populations. In any study focusing on the health of First Nations and Inuit, a number of additional topic areas need to be considered in order to address their unique circumstances. The BC Ministry of Health Planning (2001) has identified several topic areas (see Table 6-23).

Table 6-23: Potential Topic Areas for Use with First Nations and Inuit

General Topic Areas	**Specific Topic Areas**
Health Status	Well-being, General health, Health conditions, Deaths
Health Services	Accessibility, Doing the right things right, Culturally appropriate services
Healthy Growth and Development	Healthy child development, Learning opportunities, Healthy choices, Healthy connections
Disease and Injury Prevention	Non-communicable diseases, Communicable diseases, Injuries
Community Environment	Employment, Income, Educational attainment, Participation and social integration
Physical Environment	Housing and infrastructure, Air quality Water quality, Geographic location

7. MEASUREMENT INSTRUMENTS

7.1 Introduction

The issue of conducting cost-effectiveness analyses in the continuing care sector has been a matter of some interest for the continuing care industry and government since the early 1990s. Several initiatives have taken place to identify the type of information required about clients (for example, their characteristics and care needs), costs of care and care outcomes. It has also been recognized that family members, friends, neighbours and others have an important role to play with respect to continuing care clients. A series of initiatives were undertaken by Hollander Analytical Services (see for example, Hollander, Chappell et al., 2001; 2002) to refine what measurement instruments should be used in a major cost-effectiveness study of continuing care.

7.2 Comprehensive Assessment

7.2.1 Introduction

Table 7-1 presents a set of key variables that should be considered as part of a comprehensive assessment of continuing care needs. These variables were identified as part of a study focusing on the need for, and feasibility of, developing a national data base on continuing care (Hollander 1994b). As shown in Table 7-1, these variables include: socio-demographic variables; variables related to client process; information regarding providers; indicators of functional status; indicators of social support; information regarding the ability to care for oneself; information regarding an individual’s ability to communicate; variables related to medical conditions; information regarding nutritional needs; and variables related to psychosocial functioning.

In research studies regarding the continuing care needs of individuals and their families, it is important to collect information regarding three types of variables: socio-demographic variables; variables related to functional status; and variables related to psycho-social functioning, particularly cognitive functioning.

7.2.2 Socio-Demographic Variables

Socio-demographic variables, such as age, gender, education level, and language spoken, are basic variables for any research or analysis in the continuing care area. In addition, some demographic variables such as age and gender are used in identifying service utilization rates.

Table 7-1: Key Variables That Should be Considered as Part of a Comprehensive Examination of Continuing Care Needs

Socio-Demographic Variables	Date of Arrival in Canada
	Date of Birth
	Living Arrangements
	Living Environment
	Marital Status
	Mother Tongue
	Place of Birth
	Receipt of OAS/GIS
	Other Sources of Income
	Gender
Client Process	Admitted From
	Assessor/Case Manager
	Client Identifier
	Date of Admission
	Date of Discharge
	Discharged To
	Provincial Care Level (Actual or Estimated, Including Dates of Changes)
	Service(s) Consumed (RN, HSW, Meals, etc)
Basic Provider Information	Name of Provider
	Location of Provider
	Size of Provider (Beds, Homemaker Hours, Nursing, Visits, etc).
	Type of Ownership
Functional Status Indicators of Activities of Daily Living	Bathing
	Bowel Continence/Ostomy Care
	Dexterity
	Dressing
	Eating
	Locomotion/Ambulation (Indoors, Outdoors, Stairs)
	Potential for Injury to Self or Others
	Toileting
	Transferring (for example, bed to chair or wheelchair and vice versa)
	Urinary Continence/Catheter Care
Social Support Indicators	Capacity of Primary Caregiver
	Availability of Primary Caregiver
	Availability of Other Informal Supporters
Self Care	Cooking
	Financial Management
	Housekeeping (Light and Heavy)
	Medications
	Shopping
	Social Interaction
	Telephone
	Travelling (Walk, Drive, Ride Public Transit)
	Yard Work
Communication	Hearing
	Reading
	Speech
	Understanding
	Vision
	Writing

Medical Variables	Accidents in past 30 days
	Allergies
	Case Mix Grouping (Primary and Secondary)
	Circulation
	Chronic Conditions/Disabilities
	Constipation
	Diarrhea
	Drinking (Alcohol)
	Falls in Past 30 days
	General Frailty
	Height
	Hydration
	ICD-9, ICD-9CM (Primary and Secondary)
	Medications Used (Prescription and Over the Counter)
	Presence of Pain
	Respiration
	Skin Condition
	Smoking
	Weight
	Treatments Required (for example, Dressings)
Nutrition	Ability to Chew and Swallow
	Diet Restrictions
Psycho-Social Variables	Aggression
	Agitation
	Anxiety
	Cognitive Impairment
	Delusion
	Depression
	Emotional Stability
	Evidence of Organic Brain Syndrome
	Expression
	Judgment
	Memory
	Orientation
	Paranoia
	Psychiatric Diagnosis (if any)
	Reality Orientation
	Sexuality
	Spirituality
	Suicidal
	Wandering

Source: Hollander, M.J. (1994b). *Report of the project to review the need for, and the feasibility of, a national data base on continuing care*. Ottawa, ON: Statistics Canada, Health Statistics Division.

7.2.3 Functional Status

Variables regarding functional status (and, to some extent, psychosocial functioning and social support) can be collected using a relatively comprehensive assessment tool of client needs. Assessment tools usually include questions about Activities of Daily Living (ADLs; these include bathing, eating, mobility, and so on) as well as questions about Instrumental Activities of Daily Living (IADLs; these include shopping, vacuuming, use of a phone, and so on). Assessment tools also usually contain items regarding physical health (such as vision) and cognitive/mental health (such as memory) as well as information regarding the availability of family members, friends or other caregivers. Assessment tools are used to obtain a general picture regarding the health of clients, and the supports that are available to them. This information allows the assessor, case manager, or care coordinator, to develop a care plan that is best suited to meet the health and support needs of the client. Major tools currently used for continuing care clients include: two tools developed by the inter RAI international consortium[106] (see for example, Morris, Fries, Bernabei, Steel, Ikegami, Carpenter, Gilgen, DuPasquier, Frijters, Henrar, Hirdes, Belleville-Taylor, 2002); the OASIS[107] (Centre for Health Services and Policy Research, 2000a, 2000b, 2000c, 2000d); and the SMAF (Hébert, Carrier and Bilodeau, 1988).[108] Assessment tools are also used in research related to continuing care clients.

7.2.4 Client Classification Systems

In order to conduct a cost-effectiveness analysis, or develop strategic plans and/or resource allocation models, it is important to be able to categorize clients into a limited number of levels of care based on their continuing care needs. This categorization of clients into groups of individuals with similar care needs is done using a client classification system. Client classification systems can exist separately from an assessment tool (Alberta and Ontario use such systems for clients in long term care facilities). Alternatively, a client classification system may be included within an assessment tool (as is the case for the MDS-Residential Care and the SMAF). Ideally, one would use an assessment tool that could be used for all continuing care clients, regardless of whether they received care at home or in a facility, and which had a client classification system included within it. Of the major assessment instruments currently in use that have been tested for reliability and validity, the SMAF is the only tool which can be used for all clients (regardless of where they receive care) which also contains a client classification system.

7.2.5 Cognitive Status

Another key area for care planning and research relates to the client's psychosocial functioning, particularly his or her cognitive functioning. A tool frequently used to assess cognitive functioning (including the possibility of cognitive impairment and dementia) is the Mini-Mental Status Examination (MMSE; Folstein, Folstein & McHugh, 1975) and a more recent version of this tool, the Modified MMSE (or 3MS; Teng & Chui, 1987). Knowing an

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[106] The two tools are the MDS-Residential Care and the MDS-Home Care.

[107] The OASIS (Outcome and Assessment Information Set) is the officially mandated home care assessment tool in the United States.

[108] The SMAF is used for both home and community care clients and facility clients in Québec.

individual's level of cognitive functioning is critical to care planning as different care responses are required for individuals with different levels of cognitive functioning. It is also important in research, as it will affect whether data can be collected directly from the client or must be obtained from proxies such as family members.

7.3 Care Outcomes

If one is conducting research in continuing care, one should have measures of the outcomes of care. Measures of outcomes of care could include determining: whether care is effective; whether care is helping people; if people are satisfied with the care they are receiving; if people feel they are able to maintain their quality of life; and so on. There are several tools that can be used to obtain information on outcomes. As part of the National Evaluation of the Cost-Effectiveness of Home Care, Hollander, Chappell et al. (2001) identified and pilot tested a set of tools which could be used to conduct a study of the costs and outcomes of home care compared to facility care. After conducting the pilot test, some tools were not considered to be appropriate, others were considered to be appropriate with modifications, and yet others were considered to be appropriate in their original form.

7.4 Costs of Care

If one is doing a study across jurisdictions, it is important to use tools and procedures that can be used across the range of jurisdictions. It is often not possible, within a relatively limited time frame, and because of privacy laws, to access administrative data such as computerized records of hospital use, purchases of prescription drugs, use of physician services, and so on. If timing and other issues can be resolved, access to administrative data is a preferred option as such data identifies formal costs of care (that is, costs to government). However, administrative data do not include information on the informal costs of care (that is, costs borne by clients, family members, and so on). Informal costs of care include out-of-pocket expenses, estimates of caregiver time and similar costs. In order to obtain a more complete picture of the costs of continuing care, it is important to consider both the formal costs of care as well as the informal costs of care. Diaries offer a practical solution to obtaining comprehensive cost data on continuing care services covered through the formal care system, continuing care services provided by family members, friends and neighbours, and out-of-pocket expenses covered by both clients and family members. It is important to point out that questions regarding major, annual, health related expenditures need to be used to supplement the diaries (as diaries may only cover a relatively small period of time).

7.5 Identification and Selection of Tools for the Continuing Care Research and Costing Project

Several potential tools which could be used in a study of the cost-effectiveness of continuing care for home care and facility clients have been identified by Hollander and his colleagues (see for example, Hollander, 1994b; Hollander, Beebe & Stark, 1996; Hollander, Chappell, et al., 2001; and Hollander, Chappell, et al., 2002).

Table 7-2 provides a summary of the tools used by Hollander, Chappell et al. (2002) as part of a study examining the cost-effectiveness of home care and facility care for seniors in two Canadian cities. Together, these tools were used to collect: socio-demographic information on clients and primary family caregivers; physical and cognitive functioning of clients; care outcomes; the impact of providing care on primary family caregivers; and the costs of formal and informal care. While other studies have been conducted on the cost-effectiveness of home care, most have not provided copies of the tools that were used. Where tools have been mentioned, they were generally included in the study conducted by Hollander, Chappell, et al. (2001) that focused on the identification of potential tools for a cost-effectiveness study of continuing care.

The items and tools identified in Table 7-2 were considered for the Continuing Care Research and Costing Project. In addition, consideration was given to including the measure of caregiver burden used by John et al. (2001) in a study of the impact of caregiving on Pueblo family caregivers (see Table 7-3). It was thought that this tool could be used instead of the Montgomery Burden Scale included in Table 7-2. This was the only tool identified as part of the literature review that has been used with First Nations and/or Inuit (although John et al. (2001) identified two other tools that they used, and other authors have identified single items). As well, items included as part of the First Nations Regional Health Survey were considered for the Continuing Care Research and Costing Project. It is noted, however, that the specific tools included in the study was determined in collaboration with the members of the advisory groups for the project.

Table 7-2: Tools Used in a Canadian Study of the Cost-Effectiveness of Home Care and Facility Care

Respondent Category	Topic Area	Specific Items or Tool Used
Client	Demographic Variables – Clients	Gender, age, marital status, primary language, education, ethnic background, occupational background, income, height, weight, weight change, last influenza vaccination
	Social Support and Social Relations	Number of people client lives with, number of people client is close to, number of people client interacts with on a regular basis Social Support Scale (Seeman & Berkman, 1988) – assesses both instrumental support (that is, help with tasks) and emotional support
	Functional Status	SMAF (Hébert et al., 1988) – measures functional abilities in five areas: activities of daily living, mobility, communication, mental functions and instrumental activities of daily living. Also includes some information regarding availability of necessary support
	Health Status	Three questions from the SF-36 (Ware & Sherbourne, 1992) – questions regarding general health, health now compared to one year ago, and the extent to which health interferes with activities
	Cognitive Status	3MS (Teng & Chui, 1987) – measures seven different dimensions of cognitive function: orientation to location and time, registration of information, attention, calculation, short-term memory, written and oral language skills, and visuospatial ability
	Beliefs Related to Health	Rosenberg Self Esteem Scale (Rosenberg, 1965) – assesses feelings of self-worth or self-acceptance
	Use of Health and Social Services	Types of Tasks Provided by Family Caregivers (Hollander, Chappell et al., 2002) – included items related to household maintenance, personal care, physical functioning and finances Health and Social Services Utilization Tool (Browne, Gafni, Roberts, & Hoxby, 1992) – assesses client's use of eight types of health services, and costs of health related supplies and services
	Quality of Life (outcome measure)	Health Related Quality of Life (Interviewer Version) (Hadorn, Sorensen & Holte, 1995) – assesses physical suffering; limits on daily activities; emotional outlook on life; and overall quality of life Terrible-Delightful Scale (Centre on Aging, 1995) - assesses a number of concepts that have been linked to quality of life: health; finances; family relations; friendships; housing; recreation; spirituality; self-esteem; and transportation Satisfaction with Life – single item
	Satisfaction with Care Services (outcome measure)	Satisfaction with Care Related Services (Penning & Chappell, 1996) – assesses client choice, worker characteristics and care concerns

Respondent Category	Topic Area	Specific Items or Tool Used
Family Caregiver	Demographic Variables – family caregivers	Gender, age, marital status, education, ethnic background, occupational background, income and caregiving history
	Caregiving Assistance Required by Client	Types of Assistance Provided by Family Caregivers (Hollander, Chappell et al., 2002) - included items related to household maintenance, personal care, physical functioning and finances; this was similar to a tool used with clients Dementia Behaviour Disturbance Scale (Baumgarten, Becker & Gauthier, 1990) – examines a list of problems an individual with dementia may experience such as physical attacks, wandering, incontinence
	Effects of Caregiving	Montgomery Burden Scale (Montgomery, Gonyea & Hooyman, 1985) – assesses objective burden (such as amount of time caregiver has to him/her self, amount of privacy caregiver has) and subjective burden (such as feelings of stress and anxiety)
	Caregiver Satisfaction with Services	Satisfaction with Care Related Services (Penning & Chappell, 1996) – assesses caregiver's satisfaction with the services the client is receiving; examines client choice, worker characteristics and care concerns
Diaries	Formal Care Costs	Diary Regarding Time and Assistance Provided by Formal Service Providers (Hollander, Chappell, et al., 2001, 2002) – examines the amount of time and the type of services provided by health care professionals; examples include visits to the doctor, home nursing, home support, and visits to an adult day centre
	Assistance Provided by Family Members	Diary Regarding Time and Assistance Provided by Family Members (Hollander, Chappell, et al., 2001, 2002) – examines the amount of time and the type of care and support provided by family members, friends, neighbours, and so on; examples include housekeeping, meal preparation, transportation, assistance with medical equipment and assistance with personal care
	Out-of-Pocket Expenses	Client Expenditures Diary (Hollander, Chappell, et al., 2001, 2002) – examines health-related costs incurred by the client, family members or friends of the client; examples include food for special diets, medical supplies, services of alternative care providers (such as herbalists)

Table 7-3: Caregiver Burden Scale

How often do you feel that [individual] is dependent on you?
How often do you feel that [individual] seems to expect you to take care of him/her as if you were the only one he/she could depend on?
How often do you feel afraid of what the future holds for [individual]?
How often do you feel pulled between caring for [individual] and trying to meet other responsibilities for your family or work?
How often do you feel strained when you are around [individual]?
How often do you feel that because of the time you spend with [individual] that you don’t have enough time for yourself?
How often do you feel that you don’t have enough money to care for [individual] in addition to the rest of your expenses?
How often do you feel that [individual] asks for more help than he/she needs?
How often do you feel you should be doing more for [individual]?
How often do you feel that [individual] currently affects your relationship with other family members or friends in a negative way?
How often do you feel uncertain about what to do about [individual]?
How often do you feel you could do a better job in caring for [individual]?
Overall, how often do you feel burdened in caring for [individual]?
How often do you feel that you do not have as much privacy as you would like because you are caring for [individual]?
How often do you feel that your social life has suffered because you are caring for [individual]?
How often do you feel that you will be unable to take care of [individual] much longer?
How often do you feel angry when you are around [individual]?
How often do you feel your health has suffered because of your involvement with [individual]?
How often do you feel embarrassed over [individual’s] behaviour?
How often do you wish you could just leave the care of [individual] to someone else?
How often do you feel you have lost control of your life since you’ve become a caregiver?
How often do you feel uncomfortable about having friends over because of [individual]?

Source: John , R., Hennessy, C.H., Dyeson, T.B., & Garrett, M.D. (2001). Toward the conceptualization and measurement of caregiver burden among Pueblo Indian family caregivers. *The Gerontologist*, *41* (2), 210-219.

8. DISCUSSION AND CONCLUSIONS

8.1 Introduction

A number of important findings emerged from the review of the literature and existing data sources with respect to continuing care services for both non-Aboriginals and First Nations and Inuit. This chapter discusses these findings.

8.2 Overall Philosophy of Care

First Nations and Inuit have a holistic view of health and well-being. That is, health or wellness is considered to involve physical, mental, spiritual and emotional harmony and balance, rather than simply the absence of disease. This perspective is consistent with the concept of continuing care being used in the Continuing Care Research and Costing Project. Both perspectives require the elimination of artificial stovepipes in the way that health services are funded, delivered and structured in order to focus on the needs of the individual and the most appropriate responses to those needs. Both perspectives also recognize that professional health service (such as those provided by nurses and physiotherapists) are only part of the solution and that such approaches need to be supplemented with various forms of supportive services that assist individuals to maintain their independence for as long as possible. Both perspectives acknowledge the importance of family and community in caring for individuals who require assistance in the longer term and recognize that families and communities need to be supported in their activities. Both perspectives also incorporate the care of the dying into their continuum of care. In addition to the shared similarities, First Nations and Inuit perspectives also include traditional healers, culturally relevant support services and culturally relevant community activities.

8.3 Availability of Data

Policy makers generally do not recognize that continuing care is a major component of the health care delivery system. Therefore, it is not surprising that there is relatively little data on continuing care. With respect to the non-Aboriginal population in Canada, there is little national information on the costs of continuing care, on the comparative sets of services provided across jurisdictions, or on the characteristics and care needs of people receiving care in different continuing care settings.

Although there are some national surveys that shed light on some of these issues, it is often difficult to separate out data that are specifically related to continuing care *per se*. For example, surveys on disability (such as the Participation and Activity Limitation Survey) do not readily allow for sub-analyses to distinguish levels of care needs that would be comparable to continuing care. For individuals with low to medium levels of disability, for example, it is not clear which people would have sufficient care needs to be equivalent to people who would be assessed as being eligible for continuing care. Therefore, it is often difficult to use national surveys to obtain information about people who receive, or would be eligible to receive, continuing care. Similarly, Statistics Canada’s Survey of Residential Care Facilities aggregates data from a range of different types of facilities, and it is not always clear which types of facilities are facilities that would house continuing care clients.

In addition, there is almost no data in the scientific literature which compares different systems of care delivery. The data on the cost-effectiveness of continuing care is still mixed, although recent studies seem to indicate that home care can be a cost-effective alternative to long term care in a facility. Furthermore, it is difficult to compare findings across studies and jurisdictions due to differences in service delivery systems, terminology, funding methods and so on. There are very few jurisdictions in the world that have a standard care level classification system that can be used across sites of care. Without such a system, it is difficult to make comparisons of individuals with similar care needs, across different types of care settings (such as home care versus facility care) for policy and planning purposes.

The lack of information is compounded many times over when it comes to Aboriginal/Indigenous populations. There are almost no published studies, in Canada or internationally, on this topic. There is limited information on how services are organized, what they cost, how effective they are, what types of clients are served and so on. In addition, almost nothing is known about the effectiveness of different approaches to addressing language, cultural issues, and traditions with respect to aboriginal populations. There has been almost no development of measurement instruments that are sensitive to the needs of aboriginal populations for program delivery, policy, planning, and research purposes.

An opportunity to address this lack of data exists in the province of Québec. In Québec, the SMAF is officially designated as the assessment instrument for home care and long term care for both First Nations/Inuit and non-Aboriginal populations. The SMAF has embedded within it a series of care level classification systems. As a result, it should be possible to compare data from the SMAF across different populations, and to compare costs and outcomes for people with similar care needs across different care sites (for example, home and facility).

With respect to the Continuing Care Research and Costing Project it should be possible to make comparisons of client costs and outcomes across different jurisdictions with different continuing care systems and between two different groups (First Nations and Inuit). The Continuing Care Research and Costing Project has the potential to contribute substantial new knowledge not only to First Nations and Inuit in Canada, but also to aboriginal populations around the world.

8.4 Continuing Care Service Delivery Systems

There are several similarities between the organization of non-Aboriginal continuing care services and Aboriginal health services (at least for those discussed in Chapter 4). Single entry is a key component of non-Aboriginal continuing care services. Many First Nations and Inuit communities also have a single point of entry to care through local health centres. The underlying philosophical basis of both systems is also similar in that there is a belief in the benefits of an integrated, client focused, and comprehensive approach to care. Thus, both non-Aboriginal and First Nations/Inuit systems include a wide range of services. There is also a commitment to a psychosocial, rather than strictly medical, model of care, and thus, both recognize the importance of integrating health and social services.

Both non-Aboriginal and First Nations/Inuit systems also face key challenges. In practice, both systems are challenged by: coordinating care with other services (such as physicians and hospitals); human resource issues; gaps in service; and policy and funding stovepipes. These challenges make it difficult to coordinate and/or integrate care services to meet the needs of the individual in care and his/her family. The concept of case management at a broad system of care level is central to the non-Aboriginal continuing care system. However, it appears to be absent from, or quite limited in, the descriptions of the various Aboriginal care systems reviewed for this project.[109] Multiple funding sources, each with their own rules and policies – some of which may contradict each other and/or lead to blockages in the flow of needed care across service delivery components – are a particular challenge for First Nations and Inuit communities.

It appears that there is still a split between health services and social services, at least at the national and regional levels (this may not be the case at the community level). The FNIHB funded Home and Community Care Program provides primarily professional home-based services. The INAC Assisted Living Program funds home support services (in addition to other components). Both the continuing care approach and the comprehensive care approach desired by First Nations and Inuit health systems require close integration of professional health services and a wide range of paid supportive services.

There are a number of service components that are mandated for continuing care for non-Aboriginal populations that are not mandated for First Nations and Inuit. Health Canada, INAC and First Nations and Inuit should review the services currently not mandated to see if the range of services should be expanded. An example of where this may be appropriate is in the area of housing where it may make sense to incorporate certain types of housing options within a broader continuing care framework. Efforts should be made to provide care for individuals with higher care needs in their own communities, thus eliminating the cultural and personal disruption and relocation stress that occurs when people are moved out of their communities.

Continuing care systems in the non-Aboriginal sector have generally been developed for large population areas such as provinces or regional health authorities. Due to the various needs of different groups, it is not possible to integrate all health, social, spiritual, cultural and economic considerations into one care system. Rather, care components related to individuals with ongoing care needs have been integrated, as much as possible, into one care delivery system, referred to as "continuing care". Other components (such as social, spiritual, cultural and economic considerations) are integrated by developing linking mechanisms across major areas. For example, case managers in continuing care play a central role in coordinating service delivery within the continuing care system *and* between the continuing care system and other major components of the health and social services systems. Senior administrators in continuing care also develop linkages with their counterparts in other health and social service organizations to facilitate care delivery. First Nations and Inuit have the advantage of dealing with smaller

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[109] Case management is a component of FNIHB's Home and Community Care Program, but does not appear to be present at a broader systems level.

populations where there can be a greater integration of services into one care system. As a result, the development of continuing care services, and health and social services more generally, in First Nations and Inuit communities has the potential to provide new knowledge about how health and support services can be organized to address the needs of individuals more broadly.

8.5 Effectiveness of Continuing Care Systems

Although there is still relatively little literature on continuing care systems, the evidence that does exist indicates that more integrated service delivery systems are more effective. By integrating services under one administrative umbrella, having one funding envelope, and using case management, a standard assessment instrument and a standard classification system, it may be possible to simultaneously reduce costs *and* provide better care. There is no evidence in the published literature that contradicts the above by documenting that splintered, uncoordinated and fragmented systems save money or result in better care.

There are opportunities to improve the effectiveness of health and social services for First Nations and Inuit. A key prerequisite is to have a high degree of coordination among funders so that there can be one overall funding envelope for continuing care services. When provincial continuing care systems were developed in the 1980s, a typical approach was to identify the social services needed by continuing care clients and to transfer the services to Ministries of Health so that integrated systems of health and supportive care could be developed under one administrative umbrella. A counterpart to this would be to amalgamate all, or most, continuing care related services in Health Canada or INAC. Another option would be to have an inter-departmental coordinating committee at the federal level that would coordinate funding and policies related to continuing care with respect to all of the different branches of government that currently provide funding to First Nations and Inuit. It may also be appropriate to set up a Joint Working Group, which includes federal, provincial/territorial, and First Nations/Inuit/Métis representatives to facilitate and coordinate service delivery between federal, provincial/territorial, and aboriginal health care systems.

8.6 Key Points for Future Consideration

Several key points need to be considered with the respect to the future funding and provision of continuing care services in First Nations and Inuit communities. These include the following:

- The provision of continuing care services in First Nations and Inuit communities should focus on the needs of the individual and his/her family and the most appropriate responses to those needs.
- Professional health services need to be supplemented with various forms of supportive services that assist individuals to maintain their independence for as long as possible.
- The use of traditional healers, culturally relevant support services and culturally relevant community activities needs to be explicitly supported.

- Families and communities caring for individuals with continuing care needs should be supported.
- Although palliative care is not a focus of the Continuing Care Research and Costing Project, consideration needs to be given to the provision of care to individuals who are dying.
- Artificial stovepipes in the way health services are funded, structured and delivered should be eliminated.
- Jurisdictional issues among federal, provincial/territorial, and First Nations/Inuit governments need to be resolved. The identification of roles and responsibilities at each level may contribute to this process.
- Steps need to be taken to better integrate the programs and services offered by various governments.
- The active involvement of First Nations and Inuit in the development of programs and policies and the determination of realistic funding requirements with regard to the provision of continuing care services and related issues (such as the training of First Nations and Inuit health care providers) is critical.

8.7 Conclusions

In conclusion, there appear to be several areas in which improvements could be made to enhance the funding and delivery of continuing care services for First Nations and Inuit. Such improvements could streamline service delivery and free up some existing resources to be used to enhance care delivery for First Nations and Inuit requiring continuing care services. The potential for improvement clearly exists. It is hoped that the Continuing Care Research and Costing Project can contribute to the process.

GLOSSARY

Assisted living – This is an umbrella term which currently appears to include a number of new and previously existing housing arrangements such as group homes, congregate living, group living situations, supportive housing and room and board. The term may be used differently in First Nations and Inuit communities.

Capitation - With capitation, a limit is placed on the amount of funding available, based the overall population to be served, for example a rostered population (see below).

Comprehensive assessment – A comprehensive assessment ensures that there is an appropriate determination of need and that an initial care plan is developed which most closely suits the needs of the client.

Continuing care – Continuing care refers to a complex system of service delivery. The system has a number of components and is integrated conceptually, as well as in practice, through a "continuum of care". As used in this project, the term 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, including elderly individuals, 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.

Cost-effectiveness analysis – Cost-effectiveness analysis is a means by which funders and service providers can analyze how services are being delivered and if, and how, they can be delivered more effectively. There is an equal weighting on *costs* and *outcomes*.

Facility – This term refers to a range of housing options, outside of a private home, where continuing care services may be provided. It includes, but is not limited to, supportive living settings, group homes and personal care homes.

Formal care – Refers to a service that is provided by a paid health care provider (such as a home support worker, a community health nurse, or a care attendant in a facility).

Home care - Historically, this term was used to describe home based services provided primarily by health professionals, such as nurses. Currently, the term is used to describe both professional health services and supportive services provided to individuals living at home.

Home support – Supportive services (such as homemaker services and meal services) that are provided to individuals in their home. May be included as part of home care.

Informal care – Refers to a health care service that is provided by a family member, friend, neighbour or similar individual. The individual usually does not receive payment for providing the service. An alternative term is "care provided by family caregivers."

Integrated service delivery system – An integrated service delivery system involves more than collaboration or networking. Services are organized and funded in such a way that people can move easily along a continuum of care. Policies support the integration.

Long term care – Historically, this term was used to describe a range of facility services, primarily for the care of the elderly, but may now include a type of facility.

Ongoing system level case management – Ongoing case management ensures that there is regular monitoring and review of client needs and that, as needs change, care plans are adjusted to ensure that there is a continuing match between the needs of the client and the range of care services available.

Rostered population – A group of individuals who are defined using a defined geographic area or specific characteristics, such as age, type of chronic illness, type of living situation and so on. For example, services could be provided for frail elderly living in the community.

Single administrative structure - An administrative structure that ensures that system efficiencies are maximized. Funding can be readily transferred between services, policy issues are viewed in the context of the total system (not just one sector) and care staff have an understanding of how the needs of the client can best be met within the overall care system.

Single funding envelope – A single funding envelope provides funding for all relevant programs in one place. In some cases, funding can be transferred between services to maximize system efficiencies.

Single point of entry - A single point of entry provides a consistent screening mechanism that ensures that only individuals with appropriate needs are given services. In addition, single entry provides a focal point so that individuals do not have to speak to multiple sources to find out what services are available and how they can be accessed.

Stovepipe - A term used to refer to a structural, policy, financial and/or program entity that functions separately from other, sometimes related, entities. The term “silo” is sometimes used for the same concept.

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Appendix A:

Federal Care Levels

FEDERAL CARE LEVELS[1]

Type I - residential care for individuals requiring primarily supervision and assistance with daily living activities and social and recreational services

Type II - extended care for individuals requiring availability of personal care on a 24 hour basis under medical and nursing supervision

Type III - chronic care for individuals who require a range of therapeutic services, medical management and skilled nursing care

Type IV - rehabilitative care to restore or improve functional ability; this may require psychiatric treatment along with physical restoration

Type V - acute care for people who present a need for investigation, diagnosis or treatment and who are critically, acutely or seriously ill or convalescing

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[1] From the Request for Proposal for *An Assessment of Continuing Care Requirements in First Nations and Inuit Communities* (South of 60 degrees latitude), dated December 17, 2003 (p. 4).

Appendix B:

Literature Search Strategy

LITERATURE SEARCH STRATEGY

An extensive electronic literature search was carried out for this project. First, numerous components were identified which could be merged as needed to identify different articles. These components were:

- Continuing Care
    - Home care
    - Facility care
    - Integrated systems
- Models of Care
- Service Demand
- Health Status
- Measurement Instruments
- Caregivers
- Cost
- Methods
- Evaluation
- First Nations and Inuit
- Canada

A number of search terms were identified for each component. Search terms were a combination of Medical Subject Headings (MeSH terms) and Keywords for the Medline database. The detailed list of MeSH terms and keywords for the search are presented in Table 1.

Several literature searchers were conducted in accordance with topic areas identified in the Phase 1: Literature Scan and Review section of the initial proposal for this study.[110] The searches were limited to articles dating from between 1980 and 2004. Each search required that at least one term (Medical Subject Heading or keyword) for each component be present in the title, abstract, or medical subject headings of the articles. Table 2 describes the searches and their results.

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[110] See the document *Technical proposal in response to the request for proposal for an assessment of continuing care requirements in First Nations and Inuit communities (south of 60°L)* prepared by Hollander Analytical Services Ltd. (February 4, 2004).

Table 1: Components, Search Terms and Keywords

Component		**MeSH Terms**	**Keywords**
Continuing Care	**Home Care**	Home care services Home nursing Homemaker services	Home health care Community long term care
	Facility Care	Nursing homes Homes for the aged Intermediate care facilities Skilled nursing facilities Long term care	Chronic care Extended care
	Integrated Systems	Delivery of health care, integrated Continuity of patient care Comprehensive health care Managed care programs	Integrated care SHMO Program of All-Inclusive Care for the Elderly Continuing care Continuum of care
Models of Care		Models, organizational Pilot projects	Model$ Model$ of care
Service Demand		Health services needs and demand Benchmarking	Service demand$ Utilization Benchmark$
Health Status		Health status Health status indicators Quality of life	Health status Health indicator$ Quality of life
Measurement Instruments		Questionnaires Outcome assessment (health care) Data collection Health surveys Workload Activities of daily living Patient satisfaction Consumer satisfaction	Measurement tool$ Survey$ Questionnaire$ Functional abilit$ Cognitive ability$ Cognitive functioning Workload Satisfaction with services
Caregivers		Caregivers Cost of illness	Informal caregiver$ Family caregiver$ Formal caregiver$ Paid caregiver$ Unpaid caregiver$ Caregiver$ Care provider$

Component	MeSH Terms	Keywords
Cost	Cost allocation Cost-benefit analysis Costs & cost analysis Health care costs Cost control Cost savings Cost of illness Deductibles & Coinsurance Quality adjusted life years	
Methods	Methods/	Method$
Evaluation	Program evaluation Evaluation studies	Evaluation$
First Nations & Inuit	Indians, North American Inuit Health Services, Indigenous Arctic Regions	Aboriginal people$ American Indian$ Band council$ Eskimo$ First Nation$ First people$ Indian$ Indigenous$ Innu$ Inuvialuit Inuit$ Metis$ Native$ Native American$ Reservation$ Reserve$ Tribal council$ Tribe$ Circumpolar$ Aboriginal$

Component	MeSH Terms	Keywords
Canada	Canada British Columbia Alberta Saskatchewan Manitoba Ontario Quebec Prince Edward Island Nova Scotia New Brunswick Newfoundland Northwest Territories Yukon Territory Nunavut	Canadian$ Victoria Vancouver Calgary Edmonton Regina Saskatoon Winnipeg Toronto Ottawa London Montréal Quebec City Sherbrooke Charlottetown St. John’s Halifax Fredericton Hamilton Kingston University of Alberta University of Calgary University of British Columbia University of Manitoba Memorial University of Newfoundland Dalhousie University McMaster University Queen’s University University of Western Ontario University of Ottawa University of Toronto Laval University (Université Laval) McGill University Université de Montréal Université de Sherbrooke University of Saskatchewan

Table 2: Results from Literature Searches

Search	Topic Area	Combination of Lit Search Components	Geographic Area	Articles Identified	Articles Selected
Search 1	General indicators of demand for continuing care services	Continuing Care AND Service Demand	International *(review articles only)*	381	40
			Canada	211	33
Search 2	Continuing care service options	Continuing Care AND Models of Care	International *(review articles only)*	720	41
			Canada	333	33
Search 3	Canadian data on the demand for continuing care services and the provision of actual services	*Covered in 1 (Canada only).*	*Same as Search 1 (Canada only)*		
Search 4	Canadian continuing care services benchmarks and costs	Continuing Care AND Service Demand AND (Cost OR Evaluation)	International *(review articles only)*	111	5
			Canada	38	3
Search 5	First Nations, Inuit and other indigenous perspectives on continuing care and service options	Continuing Care AND Models of Care AND Service Demand AND First Nations & Inuit	International	5	0
			Canada	0	-
Search 6	First Nations/Inuit and Canadian health status data for indicators relevant to continuing care	Continuing Care AND Models of Care AND Service Demand AND First Nations & Inuit AND Health Status	International	1	0
			Canada	0	-
Search 7	First Nations/Inuit and Canadian service utilization data relevant to continuing care	Continuing Care AND Service Demand AND First Nations & Inuit AND Health Status	International	2	0
			Canada	0	-
Search 8	Studies which quantitatively assess continuing care needs and services in indigenous and non-indigenous populations	Continuing Care AND Service Demand AND First Nations & Inuit AND (Health Status OR Evaluation)	International	4	2
			Canada	0	-

Search	Topic Area	Combination of Lit Search Components	Geographic Area	Articles Identified	Articles Selected
Search 9	Culturally neutral or culturally appropriate data collection tools which could be used to assess continuing care needs, physical and cognitive functioning, perceptions of health status and quality of life, and satisfaction with health care services for the elderly, adults with disabilities, adults with mental health needs and children with disabilities in both indigenous and non-indigenous populations	First Nations & Inuit AND Continuing Care AND Measurement Instruments	International	52	17
			Canada	4	4
Search 10	Culturally neutral or culturally appropriate data collection tools which could be used to assess the impact of caregiving, satisfaction with health care services, workload, and costs related to caregiving for caregivers of individuals in the above four groups in both indigenous and non-indigenous populations	First Nations & Inuit AND Continuing Care AND Measurement Instruments AND Caregivers	International	9	6
			Canada	1	0
Search 11	Options for continuing care services in indigenous and non-indigenous populations and conclusions on cost-effectiveness of different services	Continuing Care AND First Nations & Inuit AND Cost	International	34	2
			Canada	1	0
Search 12	Methodologies used to cost continuing care options/services and published costs of continuing care services.	Continuing Care AND Cost AND Methods	International *(review articles only)*	73	16
			Canada	40	13
Search 13	Continuing Care and First Nations/Inuit – A broad search	Continuing Care AND First Nations & Inuit	International	455	72

Appendix C:

Review of National Health Data Sources

REVIEW OF NATIONAL HEALTH DATA SOURCES

1. Introduction

A review of Canadian national health and social survey data bases was conducted in order to identify reliable information regarding the health status of Aboriginal peoples. The focus was on health status relative to chronic conditions, disability, and functional limitations, as these health problems result in the need for continuing care.

Information was obtained from Statistics Canada, Health Canada, Indian and Northern Affairs Canada, the Canadian Institute for Health Information, the Assembly of First Nations, the National Aboriginal Health Organization, and the University of Toronto's government documents library. A search of each source was performed using the key words: First Nations and Inuit health information; national health surveys; and Aboriginal health surveys. The search was restricted to Canadian data sets. When necessary, data sources were contacted by telephone or e-mail to obtain additional information. A brief description of each of the various data sources examined is presented below.

2. Statistics Canada Data Sources

2.1 2001 Census of Population

2.1.1 Purpose

The purpose of the Canadian Census of Population is to maintain a statistical portrait of Canada and its people. The census is conducted every five years; the most recent census was conducted on May 15, 2001. The census provides the population and dwelling counts for Canada, for each province and territory, and for smaller geographic units such as cities or districts within cities. It also provides information about the demographic, social and economic characteristics of Canadians.

2.1.2 Methods of Data Collection

The Census is a household enumeration survey which involves six different survey forms. In 2001, 98% of householders were self-enumerated, while 2% received visits from a canvasser who completed a questionnaire for the household by interview. The canvasser method of data collection is normally used in remote and northern areas and on most First Nations reserves.[111] Eighty percent of households used the short form of the questionnaire and the remainder used the long form or special forms designed for use in collective dwellings or for members of a household who wanted to be enumerated separately. All census data are self-reported.

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[111] Statistics Canada (nd). *Census technical reports and user guides. 1. Data collection and coverage.* Available on-line at www12.statcan.ca/English/census01. Note that the technical reports do not include any information on Aboriginal data collection.

2.1.3 Identification of Aboriginal Peoples

The 2001 Census is able to identify Aboriginal peoples by their self-identification with at least one Aboriginal group (North American Indian, Métis, or Inuit) and/or who reported being a Treaty Indian or registered Indian as defined by the *Indian Act of Canada*, and/or who reported being a member of a First Nation or Indian band. Multiple responses were recorded. The 2001 Census is the first census to publish results by Aboriginal identity rather than by ethnic origin.

There were some data collection problems that affected the accuracy of the Aboriginal data to some extent. In 30 communities, data collection was either not permitted or was interrupted.

2.1.4 Health Content

The questions in the census change over time.[112] There is very little health information contained in the census. In 2001, the only health questions asked were about disability: limitations in daily activities; activity reductions at home, at school, or work; and limitations with other activities. These questions were included as screening questions for other surveys. The “Yes” category was split into “Yes, often” and “Yes, sometimes”. Instructions told respondents that these questions referred to conditions or health problems that had lasted or were expected to last six months or more. Activity limitations could be due to physical, mental or health problems.

The disability data for the Aboriginal population are available only by special request. The 2001 Census Handbook warns that disability data should be used with caution and have been subjected to minimal edits.[113]

2.1.5 Results

A set of Highlight Tables describe the 2001 census data about total Aboriginal population by province and territory.[114] According to the 2001 Census there are 638,915 American Indians, 292,310 Métis and 45,075 Inuit in Canada for a total Aboriginal population of 976,300 individuals (3.29% of the total Canadian population).

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[112] See Statistics Canada’s (2003d) *2001 Census handbook* for a history of modifications to census questions. Available on-line at www12.statcan.ca/English/census01.

[113] Statistics Canada. (2003d). *2001 Census handbook* . Catalogue No. 92-379-X1E. Available on-line at www12.statcan.ca/English/census01.

[114] Statistics Canada. (2003a). *Aboriginal Peoples of Canada. Highlight tables.* Available on-line at www12.statcan.ca/English/census01.

2.2 2001 Aboriginal Peoples Survey

2.2.1 Purpose

The purpose of the Aboriginal Peoples Survey is to improve the availability of demographic, health and lifestyle information about Canada's Aboriginal Peoples (North American Indians, Métis and Inuit).

2.2.2 Methods of Data Collection

The Aboriginal Peoples Survey is a post-censual survey based on Aboriginal self-identification from the Census of Population. Face-to face interviews are used to collect the data. The 2001 Aboriginal Peoples Survey included items regarding health, employment, schooling, housing, technology and the use of Aboriginal languages. A number of Aboriginal organizations participated in the development of the survey. Approximately 117,000 individuals participated; the sample is representative of the 700,000 Aboriginal people who do not live on reserve. The size of the sample allows researchers to distinguish among the North American Indians, Métis and Inuit groups.

2.2.3 Identification of Aboriginal Peoples

In 2001, some reserves did not participate in the Census of Population and thus their residents could not be included in the Aboriginal Peoples Survey. In addition, most First Nations reserves have not been participating in the Aboriginal Peoples Survey. In 2001, 123 reserves out of 1,000 participated in the survey. In the Northwest Territory, the total Aboriginal population is included.

The 2001 Aboriginal Peoples Survey thus describes the health status of Aboriginal peoples who do not live on First Nations reserves. The sample was drawn from respondents on the 2001 Census questionnaire who had indicated that they:

- had Aboriginal origins, or
- were North American Indian, Métis, and/or Inuit, and/or
- had registered Indian status, and/or
- had Band membership.

If an individual indicated more than one form of identity, they were included in tables for as many groups as they identified with but were counted only once in the total Aboriginal identify population.[115]

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[115] Statistics Canada. (2003b). *Aboriginal Peoples Survey 2001. Initial findings: Well-being of the non-reserve Aboriginal Population.* Catalogue No. 89-589-XIE. Available at www.statcan.ca.

2.2.4 Health Content

The Aboriginal Peoples Survey contains modules on education, language, labour activity, income, health, communication technology, mobility and housing. The adult core health content includes general health status, contact with health professionals and traditional healers, chronic conditions (including diabetes, tuberculosis, heart disease and cancer), height and weight, smoking, drinking, social support, and social problems in the community. The Children and Youth questionnaire includes information on general health, health care utilization, activities of daily living and medical conditions, physical injuries, dental care, nutrition, education, social activities and relationships, language, child care arrangements and general household information.

There were two supplements to the core questionnaire. The Métis self-identified population was asked supplemental questions about family background, household information, cultural background and health. The health component included physical check-up, testing for diabetes, high blood pressure, PAP smear test, mammogram, leisure activities, depression, spirituality and health care use. The Artic supplement included household and harvesting activities, personal wellness, community wellness and social participation.

2.2.5 Results

In 2003, Statistics Canada published initial findings from the 2001 Aboriginal Peoples Survey.[116]

2.3 <u>Participation and Activity Limitation Survey</u>

2.3.1 Purpose

The Participation and Activity Limitation Survey was conducted after the 2001 Census. of Population. The Participation and Activity Limitation Survey identifies Canadians with an activity limitation, and examines the impact of these limitations on their lives and barriers to participating fully in Canadian life. The Participation and Activity Limitation Survey is the primary source of disability data for 2001.

The Participation and Activity Limitation Survey followed the groundwork laid by the Health and Activity Limitation Survey that was conducted by Statistics Canada in 1986 and 1991. Because of differences in the sample and the questions, it is not possible to compare the results of the 2001 Participation and Activity Limitation Survey with the 1986 and 1991 Health and Activity Limitation Survey.

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[116] Statistics Canada. (2003c). Aboriginal Peoples Survey: Well-being of the non-reserve Aboriginal population. *The Daily*, September 24. See also *Aboriginal Peoples Survey 2001. Initial findings: Well-being of the non-reserve Aboriginal population.* Catalogue No. 89-589-XIE available at www.statcan.ca

2.3.2 Methods of Data Collection

The survey frame for the Participation and Activity Limitation Survey was provided by the answers to two questions regarding disability (questions 7 and 8) on the 2001 Census of Population questionnaire. The 2001 Participation and Activity Limitation Survey respondents were selected through the use of census information on age, geography and the responses to these questions. Participation and Activity Limitation Survey data were collected through telephone interviews using pen and paper questionnaires. Approximately 35,000 adults and 8,000 children living in the provinces were interviewed in 2001. The overall response rate was 82%.

2.3.3 Identification of Aboriginal Peoples

The population living in Aboriginal communities covered by the Aboriginal Peoples Survey, including all First Nations reserves and those in the three northern territories, were excluded. Thus, there are no data from this survey for First Nations and Inuit peoples.

2.3.4 Health Content

The first report of the 2001 Participation and Activity Limitation Survey titled *A Profile of Disability in Canada in 2001* contains findings on the number of individuals with disabilities as well as the type and severity of disability by age and gender.[117]

2.3.5 Results

An estimated 3.4 million Canadians reported some degree of disability in 2001 – 1.1 million reported mild levels of disabilities, 855,000 reported moderate levels and 1.4 million reported severe or very severe levels. Individuals with disabilities represented 14.6% of the adult population. Approximately 33% of adults and 43% of children reported severe or very severe difficulties. In general, disability levels are higher among women. Mobility problems affected 80% of adults with disabilities.[118]

2.4 Canadian Community Health Survey

2.4.1 Purpose

The goal of the Canadian Community Health Survey, which began in 2000, is to provide regular and timely cross-sectional estimates of health determinants, health status and health system utilization for 136 health regions across the country.

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[117] Available on-line at www.statcan.ca

[118] Statistics Canada. (2002a). Participation and Activity Limitation Survey: A profile of disability in Canada. *The Daily*, December 3, 2002.

2.4.2 Methods of Data Collection

Each two-year cycle of data collection includes two distinct surveys: a health region level survey in the first year with a total sample of 130,000 and a provincial level survey in the second year with a total sample of 30,000. Sample sizes in any particular cycle may increase or decrease depending on provincial buy-in. Data are collected using computer-assisted and telephone surveys.

The health region survey consists of a 45 minute interview, 30 minutes of which are devoted to common content asked of all sample units. Ten minutes consist of optional content determined by the health region from a predefined set of questionnaire modules. Socio-economic and demographic content complete the interview.

The provincial level survey lasts about 60 minutes and consists of some common content and one focus area per cycle. Focus areas can include mental health, nutrition and social support. In 2002, the focus area was mental health.

2.4.3 Identification of Aboriginal Peoples

The target population includes residents of all provinces and territories. Populations living on First Nations reserves, on Canadian Forces Bases, and in some remote areas are excluded.

2.4.4 Health Content

The 2000 survey concentrated on stress and mental health, social support, chronic conditions, accidents and injuries, alcohol and tobacco use, medications, and demographic and employment information. In 2000, the common health content included: administration; alcohol; alcohol dependence/abuse; blood pressure check; breastfeeding; chronic conditions; contacts with mental health professionals; exposure to second hand smoke; food insecurity; fruit and vegetable consumption; general health; health care utilization; Health Utility Index; height and weight; household records variables; income; injuries; labour force; mammography; Pap smear test; patient satisfaction; physical activities; PSA test; restriction of activities; smoking; socio-demographic characteristics; tobacco alternatives; and two week disability. The optional content included: breast examinations; breast self examinations; changes made to improve health; dental visits; depression; distress; driving under the influence; drug use; eye examinations; flu shots; home care; mastery; mood; physical check up; sedentary activities; self-esteem; sexual behaviours; smoking cessation aids; social support; spirituality; suicidal thoughts and attempts; use of protective equipment; and work stress.

2.4.5 Results

There have been no releases of general survey data specific to the Aboriginal population. However, Statistics Canada has made available selected results for Aboriginal individuals for Canada and the provinces and territories. Variables include: self-rated health; body mass index; presence of arthritis, diabetes, asthma, and high blood pressure; presence of pain that affects activities; severity of pain; risk of depression; injuries; functional health status; two-week disability days; activity limitations; smoking initiation; smoking; drinking frequency; leisure-time physical activity; dietary practices; life stress; exposure to second hand smoke; influenza; immunization; mammogram; Pap smear; contact with alternate providers; contact with medical doctors; contact with health professionals regarding mental health; and contact with dental professionals.

2.5 Health Services Access Survey

2.5.1 Purpose

The Health Services Access Survey was designed to collect information regarding waiting times for key diagnostic and treatment services, and access to 24/7 first contact health services (Statistics Canada, 2004c).

2.5.2 Methods of Data Collection

The Health Services Access Survey was administered in 2001 and 2003. Data were collected using telephone access to respondents and computer-assisted interviews.

The target population was a sample of individuals 15 years of age and older, living in private dwellings in the ten provinces. The target group was drawn as a sub-sample of the Canadian Community Health Survey. In 2001, 17,616 individuals (one per household) were interviewed. In 2003, the survey was administered as a supplement to the Canadian Community Health Survey; the sample size was 32,000 individuals.

2.5.3 Identification of Aboriginal Peoples

In 2001, the target population included residents in all provinces and territories. In 2003, residents in the territories were excluded. In both surveys, individuals living on First Nations reserves, on Canadian Forces Bases, and in some remote areas were excluded.

2.5.4 Health Content

The survey includes data on respondents’ experience in getting: immediate care for minor health problems (such as fever, headache, sprained ankle, vomiting, unexplained rash, etc.); health care services in general; and health information or advice. Respondents were asked about their use of first contact services at different times of the day, difficulties accessing services, and where services were obtained. They were also asked about: their access to specialized services, such as a cardiologist, allergist, etc. to obtain a diagnosis of a new condition; their experience in obtaining non-emergency surgery such as joint surgery, cardiac surgery, etc.; and their experience in accessing selected diagnostic tests such as MRIs, CT scans, and angiographies. They were asked about waiting times, acceptability of the waiting time, and the impact of the wait on the respondent.

2.5.5 Results

There are no data available on-line for Aboriginal individuals. With respect to the non-Aboriginal population, the 2003 survey found that between 13% of respondents (for non-emergency surgery) and 21% of respondents (for specialist visits) who accessed specialized services reported they had encountered difficulties. Among those who waited for a specialist visit, 29% reported that the wait time was unacceptable.[119] There is no content specific to continuing care in this survey.

2.6 National Population Health Survey

2.6.1 Purpose

Initially, the purpose of the National Population Health Survey was to provide cross-sectional estimates and examine changes in health and health behaviours over time. The survey had the potential to link to outcome data in the future. Now, the National Population Health survey is a longitudinal survey, with cycles planned every two years for up to 20 years. The cross sectional content is collected in the Canadian Community Health Survey (see Section 2.4 above). The National Population Health Survey started in 1994.

2.6.2 Methods of Data Collection

The National Population Health Survey is a longitudinal household-based survey. The target population is household residents of all ages in all provinces and territories. For operational reasons, separate surveys are conducted for the territories.

Data may be collected through telephone or face-to-face interviews. Both longitudinal and cross-sectional data are collected in the survey. In the past few cycles, the sample size has been about 20,000 households.

2.6.3 Identification of Aboriginal Peoples

Individuals living on First Nations reserves, on Canadian Forces Bases or in some remote areas of Ontario and Québec are excluded from the survey. The sample size is too small to permit reliable analysis of the data regarding the Aboriginal population.

2.6.4 Health Content

The core content of the National Population Health Survey includes: health status; two-week disability; health care utilization; chronic conditions; preventive health practices; alcohol and tobacco use; physical activity; weight; height; sleep; injuries; legal drug use; mental health; and social support.

In Cycle 5 (2002-2003), the household survey included the following variables: general health; sleep; height and weight; nutrition; preventive health; health care utilization; restriction of

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[119] Statistics Canada. (2004c). Health Services Access Survey. *The Daily*, June 30, 2004. Available on-line.

activities; chronic conditions; insurance; health status; physical activities; UV exposure; repetitive strain; injuries; stress; medication use; smoking; alcohol; alcohol dependence; mental health; social support; residence history; language; education; labour force; income; provincial health number; and administration.

2.6.5 Results

Several publications have described findings from the National Population Health Survey. There have been no releases on the health of the Aboriginal population from this survey (see the note above regarding the sample size).

2.7 General Social Survey

2.7.1 Purpose

The purposes of the General Social Survey are to monitor changes in the living conditions and well-being of Canadians over time, and to provide immediate information on specific policy issues of current or emerging interest.

2.7.2 Methods of Data Collection

Until 1997, the General Social Survey was an annual survey that repeated its core content every five years. The General Social survey now occurs every two years; the most recent General Social Survey was conducted in 2003.

The health content has now been replaced with social and community support content. Data are collected through telephone interviews. Each interview takes approximately 30 to 45 minutes and contains a core topic, a focus or exploratory questions and a standard set of socio-demographic questions used for classification.

The target population is adults (aged 15 and over). The sample is selected across the ten provinces; the base sample size is 25,000 individuals. In 2003, the response rate was 78%.

2.7.3 Identification of Aboriginal Peoples

The sample size is not large enough to produce reliable data on Aboriginal peoples.[120]

2.7.4 Health Content

Health data are no longer collected as part of the General Social Survey.

Cycle 1 (1985) and Cycle 6 (1991) of the survey had health as their core content. Health information has not been collected since 1991. Social support is now a core area of the General Social Survey and was the core topic of Cycle 11 (1996). Cycle 11 focused on help given or

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[120] Statistics Canada. (2004b). *The General Social Survey An overview*. Available online at http://www.statcan.ca/cgi-bin/downpub/freepub.cgi

received during either temporarily difficult times or out of necessity due to long-term health or physical limitations in daily activities either inside or outside the home. Cycle 16 (2002) collected information on social support for the senior population. This cycle collected information on help provided to and received by older people. It also collected information on transitions to retirement, retirement planning and other topics targeted to older people. Cycle 16 is the only cycle whose sample is comprised of individuals 45 years of age and older. Cycle 17 (2003) is the first cycle to examine social engagement. This cycle examined such topics as well-being, social participation, civic participation, trust and values.

2.7.5 Results

Statistics Canada has produced a number of reports over the years detailing selected findings from the General Social Survey.[121] There is no content specific to the Aboriginal population.

2.8 Residential Care Facilities Survey

2.8.1 Purpose

The Residential Care Facilities Survey collects data from care facilities across Canada. The data are used by government agencies, health organizations and others, for program analysis, policy development, planning and research purposes.

2.8.2 Methods of Data Collection

The target population for the survey is all residential care facilities in Canada. Provincial and territorial ministries of health and/or social services are requested to update the inventory of residential care facilities annually.

The term "residential care facilities" includes all facilities which have four beds or more and which are approved, funded, or licensed by provincial/territorial departments of health and/or social services. The facilities include homes for: elderly individuals; individuals with physical disabilities; individuals with developmental delays; individuals with psychiatric disabilities; individuals with alcohol and drug problems; emotionally disturbed children; and others (Statistics Canada, 2000b).

The Residential Care Facilities Survey is a census with a longitudinal design. Under the Statistics Act, facilities must respond to the survey. Facilities are asked to report totals for personnel (both direct care services and general services) and expenses (direct care services, general services and other expenses). Data are collected from survey respondents and administrative files.

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[121] A list of the reports can be found in *The General Social Survey: An overview* Catalogue No. 89F0115XIE, which is available from Statistics Canada (Statistics Canada, 2004b).

2.8.3 Identification of Aboriginal Peoples

No information is available specifically on facilities operated by Aboriginal organizations or on the cultural background of individuals in the facilities.

2.8.4 Health Content

Data are collected regarding health care personnel and expenditures related to direct care services. However, no data regarding the health of clients are collected.

2.8.5 Results

Information about individual facilities is not released. No data were released for 1994-1995 and 1995-1996.

2.9 Canadian Cancer Registry

2.9.1 Purpose

The purpose of the Canadian Cancer Registry is to provide a large database to study cancer patterns and trends and to monitor differences in cancer risks among different populations. Information about cancer incidence and survival in Canada is generated by the Canadian Cancer Registry.

2.9.2 Methods of Data Collection

The Canadian Cancer Registry includes administrative data submitted to Statistics Canada by the provinces and territories. The data are in the form of patient records and tumour information. Each year, about 145,000 new tumour records are entered into the national database.

2.9.3 Identification of Aboriginal Peoples

Information regarding Aboriginal peoples is not available on a national basis. The western provinces are the only ones that identify First Nations and Inuit individuals in their databases.

2.9.4 Health Content

The following tumours should be reported to the national database although not all provinces are able to submit all of them: in situ/intraepithelial/non-infiltrating/non-invasive carcinomas; primary benign tumours of the brain and central nervous system; and borderline malignancies.

2.9.5 Results

There are no results specific to the Aboriginal population.

2.10 Canadian Health Measures Survey

2.10.1 Purpose

The purpose of this new survey is to estimate the number of Canadians with selected diseases and risk factors. The survey will also serve to ascertain relations among disease factors, health protection practices and health status based on direct measures.

2.10.2 Methods of Data Collection

The first round of data for this survey will be collected in 2006. Data will be collected through interviews and physical measurements. There has been no detailed information related to the sample composition although it will be a random, nationally representative sample of 6,000 to 8,000 individuals.

2.10.3 Identification of Aboriginal Peoples

There will be no data collection on First Nations reserves. The chances of collecting information from a substantial number of Aboriginal peoples are slight, given the relatively small size of the total sample.

2.10.4 Health Content

The health content is not finalized. However, a major focus of the survey is on the risk of chronic diseases such as diabetes, cancer, asthma, etc.

2.10.5 Results

Results are expected to be available in 2007.

3. Health Canada Data Sources

3.1 Partnerships

Health Canada partners with Statistics Canada for the collection of Canadian health information. The major health surveys included in the partnership are described above.

3.2 Berger Population Health Monitor

3.2.1 Purpose

The Berger Population Health Monitor focuses on health issues. The Berger Health Monitor is conducted on behalf of Health Canada.

3.2.2 Methods of Data Collection

The Berger Population Health Monitor is a semi-annual, random sample, telephone survey of 2,500 individuals 15 years of age and older. Data are collected by private polling firms in association with the Hay Health Care Consulting Group under the Direction of Earl Berger.

3.2.3 Identification of Aboriginal Peoples

The sample is too small to allow identification of Aboriginal peoples.

3.2.4 Health Content

The health content varies with each survey.

3.2.5 Results

The results are available only to subscribers (including Health Canada).

3.3 Administrative Datasets Held by Health Canada

The First Nations and Inuit Health Branch (FNIHB) within Health Canada collects data from the 600 Aboriginal communities for which the Branch provides primary care, public health and health promotion services. Mandatory reporting includes information on communicable disease control and environmental health. Non-mandatory reporting includes vital statistics and chronic diseases. Variability exists in the collection and reporting of the non-mandatory information.[122]

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[122] Health Canada, First Nations and Inuit Health Branch. (no date). *A Statistical Profile on the Health of First Nations in Canada*. Health Canada. Available on-line at www.hc-gc.gc.ca/fnihb-dgspni/fribh/sppa/hia/publications/statistical_profile.pdf

3.4 The Maternal Mortality and Fetal/Infant Mortality Studies

These studies are expected to provide accurate information about the occurrence of maternal and infant mortality among the Aboriginal population. Data will be linked from the national Maternal Mortality database and the Infant Birth-Death database to the Indian Register Population to identify maternal and infant deaths in the First Nation population.

4. Indian and Northern Affairs Canada Data Sources

The Ministry of Indian and Northern Affairs does not collect health information.

5. Other Data Sources

5.1 The First Nations Regional Longitudinal Health Survey

5.1.1 Purpose

The purpose of the First Nations Regional Longitudinal Health Survey is to provide a longitudinal database about health, wellness, health determinants and the concerns and issues of First Nations peoples across Canada. The study began in 1997. A second wave was conducted in 2002-2003.

5.1.2 Methods of Data Collection

In the 1997 study, the survey was implemented in nine regions (British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia and Labrador). The Regional Health Survey was conducted again in 2002–2003 in 10 regions as the first cycle of a longitudinal survey that will be repeated in 2006 and 2010. The target sample size was 28,405 First Nations individuals living on reserve and in some non-reserve communities in the Territories.

Survey data are collected in face-to-face interviews, using computer-assisted technology. Interviews regarding adults require approximately 44 minutes to complete, interviews regarding adolescents require approximately 35 minutes, and interviews regarding children require approximately 24 minutes.

5.1.3 Identification of Aboriginal Peoples

The survey contains information on First Nations peoples living on participating reserves and in some non-reserve communities in the Territories. Inuit communities participated in the 1997 cycle of the survey only. This Quebec sample in 1997 did not include the James Bay Cree or the Inuit. The Labrador sample included the Inuit Peoples of Labrador.

5.1.4 Health Content

Three surveys (adult, adolescent, and child) were developed for the 2002-2003 cycle. The adult questionnaire includes items regarding: demographics; language; education; employment; income and sources; household composition; housing condition; water quality; height and weight; general health; 28 health conditions (duration, treatment and effects); diabetes (type, treatment and effects); physical injuries; disability limitations; dental care; home care (need and use); health services (use and access); food and nutrition; physical activity; smoking; alcohol use; drugs (use, cessation and treatment); sexuality; consultation with a traditional healer; preventive health practices; residential school impact; culture; spirituality; religion; supports and mental health; suicidal ideation and attempts; and community wellness.

The adolescent questionnaire includes items regarding: demographics; language; education; household composition; housing condition; general health; height and weight; 19 health conditions (duration, treatment and effects); diabetes (type and treatment); physical injuries; dental care; health care utilization; food and nutrition; physical activity; smoking; alcohol use; drug use; sexuality; leisure activity; residential school impact; culture; spirituality; supports and mental health; and suicidal ideation and attempts.

The child questionnaire includes items regarding: demographics (of child and parents/guardians); language; education; household composition; housing condition; height and weight; general health; 19 health conditions (duration, treatment and effects; diabetes (type); physical injuries; disability limitations; dental care; access to health services; food and nutrition; physical activity; emotional and social well-being; residential school impact; culture; and child care arrangements.

5.1.5 Results

Findings from the 1997 First Nations and Inuit Regional Health Survey have been released in a comprehensive report entitled *First Nations and Inuit Regional Health Survey. Summary from the 1997 National Health Survey of First Nations and Labrador Inuit Communities*.[123] Published information from the 2002-2003 is expected to be released in 2006. Some preliminary information is available at the present time (January 2006).

5.2 Canadian Institute for Health Information

The administrative records provided by the provinces to the Canadian Institute for Health Information contain information about health utilization by First Nations and Inuit peoples. However, most provinces do not identify Aboriginal peoples in the databases. As a result, national information about health utilization that is routinely provided for the Canadian population is not available for First Nations and Inuit peoples.

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[123] First Nations and Inuit Regional Health Survey National Steering Committee. (nd). *First Nations and Inuit Regional Health Survey. Summary from the 1997 National Health Survey of First Nations and Labrador Inuit Communities*. Available on-line at www.hc-sc.gc.ca/fnihb/aboriginalhealth/reports.

The Canadian Institute for Health Information has a small continuing care database but it is limited to facility-based data from Ontario at this time. The Canadian Institute for Health Information is also in the process of developing a home care program database.

5.3 Provincial Administrative Datasets

The provinces of British Columbia, Alberta, Saskatchewan and Manitoba use a variety of mechanisms ranging from self-report and address (Saskatchewan) to use of unique health numbers (British Columbia, Alberta and Manitoba) to identify First Nations clients in their health databases. In Manitoba, the identification system does not include up to 30% of the First Nations population in the province. The Pacific Regional Office of Health Canada is the only source of administrative data (hospital utilization) in annual reports.[124]

5.4 2002 Joint Canada/United States Survey of Health

This survey was not included in the review of national surveys and databases as it was a one-time survey with a sample size that was too small (3,500) to identify Aboriginal peoples.

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[124] Health Canada, First Nations and Inuit Health Branch. (no date). *A Statistical Profile on the Health of First Nations in Canada*. Health Canada. Available on-line at www.hc-gc.gc.ca/fnihb-dgspni/fribh/sppa/hia/publications/ statistical_profile.pdf

Appendix D:

An Overview of Economic Evaluation and Its Application to Continuing Care

AN OVERVIEW OF ECONOMIC EVALUATION AND ITS APPLICATION TO CONTINUING CARE

1. Introduction

A number of excellent books and articles have been published on the techniques of economic analysis in health care (Donaldson, 1990; Drummond, O'Brien, Stoddart and Torrance, 1997; Drummond, Stoddart and Torrance, 1987; Eisenberg, 1989; Ganiats and Schneiderman, 1988; Stoddart and Drummond, 1984a, 1984b; Weinstein, 1990). Drummond et al. (1987) noted that economic analysis deals with two aspects: the inputs and outputs, or costs and consequences, of activities; and, choices between alternatives. They developed a typology for the different types of economic analysis based on these two aspects – dimensions of inputs and outputs, and choices about alternatives (see Figure D1). The primary area of interest for the Continuing Care Research and Costing Project is box 4 in Figure D1, full economic evaluation, particularly cost-minimization and cost-effectiveness analysis. It is important to note that cost-effectiveness analysis is not only about costs; equal weight is given to the outcomes or consequences of the services in question. Outcomes may include satisfaction with care and the quality of the life of the client from the perspectives of both clients and caregivers.

2. The Techniques of Economic Evaluation

2.1 Design Issues

Methodologically, most of the more advanced techniques of economic analysis have similar characteristics to quasi-experimental research, clinical trials and outcome evaluation. All of these approaches have certain common elements. Some type of program or experimental condition is introduced and applied to a group of individuals, and the consequence of this act is analyzed to determine the outcome of introducing the program or experimental condition. There is a temporal dimension to this approach such that the intervention is typically done at one point in time and the consequences of that action are studied over time. Programs receiving the experimental condition are usually compared to control groups or alternative programs.

2.2 Perspective

One of the most important aspects of an economic analysis is the perspective inherent in the question being asked. Ideally, the widest range of costs and benefits should be considered in doing an economic analysis. However, this is often not done in actual studies. Rather, costs and benefits are often considered from a more restrictive perspective, for example, the government, the agency, or the client. Even within a government or funder perspective, one may only consider a given agency, or type of service, rather than the whole system of care. By adopting a restrictive rather than comprehensive perspective one may come to erroneous conclusions.

Figure D1: Types of Economic Evaluation

Is there a comparison of two or more alternatives?	Are both costs (inputs) and consequences (outputs) of the alternatives examined?		
	NO		YES
	Examines only consequences	Examines only costs	
NO	1A PARTIAL EVALUATION Outcome description	1B Cost Description	2 PARTIAL EVALUATION Cost-outcome description
YES	3A PARTIAL EVALUATION Efficacy or effectiveness evaluation	3B Cost Analysis	**4 FULL ECONOMIC EVALUATION** **Cost-minimization analysis** **Cost-effectiveness analysis** **Cost-utility analysis** **Cost-benefit analysis**

(Source: Adapted from Drummond et al., 1987, p. 8)

The types of evaluations noted in the above schematic are as follows:

- **Outcome Description**: A description of the program or service provided.
- **Cost Description**: A description of the cost components of the service provided.
- **Cost-Outcome Description**: A description of both the costs and outcomes of a single service.
- **Efficacy or Effectiveness Evaluation**: An analysis in which only the consequences of the alternatives are compared.
- **Cost Analysis**: An analysis in which only the costs of the alternatives are compared.
- **Cost-Minimization Analysis**: An analysis in which the costs of the alternatives are compared and the consequences of service are deemed to be equivalent, for example, a search for the lowest cost alternative.
- **Cost-Effectiveness Analysis**: An analysis in which the costs and consequences of programs are measured in comparable, appropriate, natural physical units, for example, costs are related to a single effect which may differ in magnitude across alternatives.
- **Cost-Utility Analysis**: An analysis in which the costs and consequences of programs are measured in time units adjusted by health utility weights, for example, costs are related to one or more effects, which are not necessarily common to each alternative, by a standardized utility measure such as quality-adjusted life years.
- **Cost-Benefit Analysis**: An analysis in which the costs and consequences of programs are both valued in monetary terms, for example, costs are related to one or more effects, which are not necessarily common to each alternative, by the standardized measure of money.

For example, consider: 1) clients who pay a user fee for homemaker services but who pay no fee for home nursing care services; 2) a government which wishes to reduce costs; and 3) a home care agency which wants to maximize profits. Government may ask for an economic analysis of a new program where certain functions typically provided by nurses are transferred to homemakers through a transfer of function agreement.

An economic analysis is conducted, from the government perspective, which shows that 20% of the volume of work can be transferred and that homemakers are paid half as much as home care nurses. This finding tells government that it can save 10% of the costs of its home nursing care program by instituting the transfer of function program. The client sees it differently. Clients who are affected may pay more for the added homemaker service (for which they may pay a user fee) than they would if nurses (for which no user fee is required) continue to provide the service. The position of the agency in this scenario is determined by its comparative profit margins for nurses versus homemakers. The result of adopting the program, when all matters are considered together, could be: no actual change but a cost-shift from government to clients and/or agencies; an actual overall saving, but less than projected from the government perspective alone; or, an actual increase in overall costs, particularly if homemakers take longer to provide the service than nurses.

There is also a fourth group which could be affected, that is, informal caregivers (for example, family members). Homemakers may provide care to the client but may not teach family members how to care for the client in a correct and efficient manner. To the extent that nurses do so, there could be a differential impact on the amount of time and resources family members would have to devote to caring for the client. Time may constitute real direct costs to family members if they take non-paid leave from work. Thus, the decision to transfer nursing functions to homemakers may have economic impacts not only on the government, the agency, and the client, but on the client's family as well.

2.3 Determining Costs

As noted, one must properly consider what is the appropriate range of costs and benefits to be included in a given study. Table D1 presents definitions for a number of different types of costs used in economic analysis. An important issue in costing is how to assign costs for non-market goods such as the time of family members. Four possible approaches have been suggested (see Drummond et al., 1987). These are: what clients are willing to pay to obtain the necessary services; what policy makers are willing to pay for clients to obtain the services; what the current market rates are for similar services; and what rates practitioners or professionals would assign for the services.

Table D1: Types of Costs

Name	Definitions
Total Costs	Costs of producing a particular quantity of output
Fixed Costs	Costs that do not vary with the quantity of output in the short run (about one year). These include rent, equipment lease payments, some wages and salaries. These are costs that vary over time, rather than quantity.
Variable Costs	Costs that may vary with the level of output (for example supplies, food, fees for services, salaries and wages for non-core staff).
Capital Costs	Costs related to the purchase of the major capital assets required by an agency such as land, buildings and equipment. To the extent that consistent payments are made on an annual basis, capital costs are a subset of fixed costs.
Operating Costs	Costs that are not capital costs.
Overhead Costs	An accounting term for resources that serve many different departments or programs (for example, hospital administration, central laundry, medical records, cleaning, electricity/power).
Average Costs	The average cost per unit of output.
Marginal Costs	The additional or extra cost of producing one extra unit of output.
Per Diem Costs	The average cost per client per day. Per diem rates can be calculated for total costs but are more typically calculated for operating costs as capital costs are often handled separately.
Opportunity Costs	The value of foregone benefits because the resource is not available for its best alternative use. In efficient markets the opportunity cost is the market price.
Non-Market/Indirect Costs	Costs that do not have an existing, or direct, market value (for example, volunteer time, family time, leisure time).

Source: Adapted from Drummond et al., 1987.

3. Determining Benefits

It is usually difficult in a health related cost-benefit study to value the outputs of health care interventions in strictly monetary terms. One can try to ascribe costs to a life saved but determining the cost of a human life is controversial and analysts who have attempted to do so typically come up with a wide range of costs. One can also attempt to assign dollar values to foregone income or the willingness to pay for avoiding some condition. Currently, there appears to be little substantive consensus on the valuation of the benefits of health interventions in monetary terms.

The outcomes in cost-utility analysis are measured in Quality Adjusted Life Years (QALYs). This is an advance over cost-effectiveness analysis in that one can incorporate the quality of the life years saved into the analysis. QALY scores can be determined in a number of ways. One may wish to adopt values already published in the literature, conduct studies of persons with a given condition to obtain their utility scores for given conditions, ask experts such as physicians to assign values to different conditions, or ask informed members of the general public to assign values. Any given set of QALY scores should be subjected to extensive sensitivity analysis and to analyses of their validity and reliability.

In cost-effectiveness analysis, no attempt is made to place a monetary value on the quality of outcomes. The outcomes are measured in appropriate natural or physical units such as years of life gained. Thus, the result of a cost-effectiveness analysis is a determination of the relative cost per unit (for example, cost per year of life gained). Totally different interventions, for different groups of people, can thus be compared to determine where one can have the most impact, for example, maximize the number of life years saved for a given cost. In cost-minimization analysis, the benefits are assumed to be equivalent. Therefore, no valuation is required except for the valuation of the costs of two or more programs.

4. Sensitivity Analysis

A sensitivity analysis allows an investigator to determine the extent to which the results of a study differ when different values, or assumptions, are used for certain key aspects of the analysis; for example, how different the outcomes of a study are if one varies the calculation of the costs of care provided by family members from costs based on minimum wage to costs based on market rates for similar work.

Drummond et al. (1987) note that the steps to be taken in conducting a sensitivity analysis are as follows:

- Consider which of the estimates made in the analysis are subject to debate because:
  - no estimates were available and informed guesses were made (for example, the effectiveness of new and unproven medical procedures);
  - of known imprecision in the estimation procedure (for example, hospitalization costs based on average *per diem* figures); and/or
  - of methodological controversy or have the potential for different value judgements.
- Set upper and lower bounds on the possible range of estimates. Depending upon the source of uncertainty or debate surrounding the estimations, this might be done by:
  - considering empirical evidence from other research studies;
  - considering current practice in the literature; and/or
  - soliciting judgements from those who will be making decisions based on the cost-effectiveness study.
  - Calculate study results based on combinations of the "best guess", "most conservative" and "least conservative" estimates of the variables concerned.

5. The Appropriate Use of Cost-Effectiveness Analysis

Avron (1984) noted that cost-effectiveness analysis, as opposed to cost-benefit analysis and cost-utility analysis can be a potentially valuable tool if used to compare the relative efficacy of different means, or programs, for achieving a particular goal. Cost-effectiveness analysis and cost-minimization analysis are simpler models and do not rely to the same extent on the detailed quantification of benefits. Emery and Schneiderman (1989) present a number of situations in which cost-effectiveness analysis can be used as an appropriate technique. These are:

- **Comparing alternative treatments for an identical goal -** If outcomes are truly comparable, then cost-effectiveness analysis serves to find the most frugal way to attain an established goal.[125]
- **Determining the most effective utilization of funds earmarked for a specific population -** As long as there is a clear target population, cost-effectiveness analysis can help to determine which one, of a set of alternative programs, provides the most of the outcome desired for a given funding envelope.
- **Providing empirical support for the adoption of previously under-funded medical programs -** Demonstrating that existing and exciting, but underfunded, programs are particularly cost-effective.
- **Exposing noncostworthy care -** Noncostworthy care can be identified through cost-effectiveness analysis. Examples of noncostworthy care include: care that is relatively inefficient when compared to alternative therapies for the same goal; care that, though inexpensive, provides no benefits; and, care that provides definite benefits but at a great expense.

The most appropriate form of economic analysis for much of the continuing care sector may be cost-minimization analysis, at least until there are substantial improvements in methodology. Providing appropriate care is an equivalent activity, or consequence, for persons at the same level of care, across different settings (for example, care in the home versus care in a facility). Thus, the only matter of interest is the relative cost of each form of care. If outcomes such as satisfaction with care or differential rates of deterioration in different settings can be quantified, one could engage in other forms of economic analysis, such as cost-effectiveness analysis. If outcomes are not equal, but are quantifiable, cost-effectiveness analysis is the appropriate approach as one is able to, for example, conduct a comparison of the relative cost-effectiveness of a more expensive program with better outcomes compared to a less expensive program where the outcomes are not as good. It would be desirable to do more sophisticated types of economic analysis but further methodological development is required in the continuing care sector before this can readily be done.

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[125] Some writers would refer to this as cost-minimization analysis.