An evaluation of institutional long-term care in the St. John's Region and implications for policy

by

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ABSTRACT

Introduction: Restructuring of the institutional long-term care (LTC) sector in the St. John's health region has occurred during the past two decades. A single entry system has improved the efficiency of placement and the appropriateness of nursing home (NH) bed utilization, and provision of more supervised care (SC) beds and downsizing of NH has been undertaken. 1) To assess the impact of restructuring of institutional LTC in the St. John's region, the annual incidence of clients, defined by disability, was determined. 2) Also, the efficiency and appropriateness of placement over a 10 year period was examined using three incident cohorts of clients seeking placement through the single entry system.

Results: Incidence rates of clients seeking institutional placement increased from 21.7 to 30.8 per 1000 ≥ 65 years of age. Appropriateness of placement was better in 2005/6 in that 8.7% of clients recommended for NH had no indicators for NH compared to 20.3% in 1995/6, and all SC clients had low Alberta Resident Classification scores compared to 91.7% in 1995/6. Time to placement from 1995-2006 improved over time for both SC (from 26 to 7 days) and NH (from 76 to 42 days). Median survival following assessment was significantly longer in 2005/6 (27.6 vs. 37.7 months; p=0.003) with the major increase occurring in those referred to SC. This difference in survival was independent of age, gender and degree of disability.

The optimal configuration of the LTC sector for the region in 2014 was assessed using predictions derived from the 1999/00 incident cohort and the 2005/6 incident cohort. Beds required for appropriate housing increased by 65%, supervised care bed need increased by 21%, specialized care for the cognitively impaired increased by 107% and NH bed need increased by 41 %.

The major policy issues in LTC in the region were discussed with 3 decision makers. The major policy issues in Newfoundland and Labrador and 3 provinces of similar population size were explored. Policy options for the St. John's region and for the government of NL include an integrated approach to LTC, more resources in home care, support of the private sector to provide more SC, building of facilities specifically for those with cognitive impairment and restructuring of NH. However, supply induced demand may create further need for each component of the LTC system.

Conclusions: Consequently, monitoring the match between need based on disability and client placement, together with the annual incidence rates by degree of disability will be necessary to facilitate planning and evaluation.

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
ARCS	Alberta Resident Classification System
AH	Alternative/Appropriate Housing
AUROC	Area under the Receiver Operating Characteristic
ALF	Assisted Living Facilities
LTC	Long-term Care
MDS	Minimum Data Set
NL	Newfoundland and Labrador
NH	Nursing Home
PCH	Personal Care Home
QOL	Quality of Life
ROC	Receiver Operating Characteristic
RHA	Regional Health Authority
RAI	Resident Assessment Instrument
RUGs-III	Resource Utilization Groups Version III
SES	Single-entry System
SC	Supervised Care

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Chapter 1 Introduction

In almost every developed country, the proportion of people aged over 65 years is growing faster than any other age group, as a result of both longer life expectancy and declining fertility rates (1). Population ageing can be seen as a success story for public health policies and for socioeconomic development, but it also challenges society to adapt in order to maximize the health and functional capacity of older people as well as their social participation and security (1). Meeting this challenge requires a multi-pronged approach and includes establishing a sustainable long-term care (LTC) system. In 1996, 12.2% of the Canadian population was 65 years and older (2). By 2011 this group represented 14.8% of the population. The proportion of this age group will continue to increase in the future. By 2036 it is predicted they will represent 23% of the population and 25% by 2061 (3). In Canada, the federal and provincial governments will be forced to remodel the health care system in response to this dramatic demographic change.

1.1 Background

1.1.1 Ageing Population in Newfoundland. While the Canadian population is ageing, Newfoundland and Labrador's (NL) population is ageing more rapidly. In 1996, 10.8% of NL's population was ≥ 65 years of age (2). By 2006, this had increased to 13.9% and by 2011 this age group represented 16.0% of the population (4). This population will continue to rise in the future as it is projected to represent 32% of the population by 2036 (3). This is partly due to the province having the lowest fertility rate in the country. In 2007 the rate of children per woman was 1.46 compared to the national average of 1.66, and in 2011 these rate dropped to 1.45 and 1.61 respectively (5). Fertility rates and birth rates leveled off in Canada, similar to other

industrialized countries, around the late 1970s to early 1980s but NL did not experience a similar trend. Fertility rates in the province continued to decline well into the 1990s. Also, a steady negative interprovincial net out migration of younger people, mostly seen in rural areas, over the past 35 years has occurred. These two demographic changes were associated with a period of widespread economic decline in many parts of the province caused by the collapse of the cod fishery, government restraint measures, and Employment Insurance (EI) reforms (6). Also, selective outmigration of the young left many rural communities old with more older people few youth available to support family members informally or as part of the formal care system. These factors combined with increased longevity have made the province the "oldest" in Canada with a median age of 44.2 years (7). As the 'baby boomer' population approaches 65 in the present decade and care needs become increasingly complex as people age, it is clear that more people will require some form of support as they become more disabled (8).

1.1.2 Long-term Care. People who need LTC often depend on others to assist them with instrumental activities of daily living (ADL) such as preparing meals, performing housework, taking medications and doing errands. They might also need assistance with basic ADL such as eating, dressing and bathing. Some people need assistance with both categories of activity. LTC differs from acute or rehabilitation care, in that it tends to be required for an extended period of time and is often associated with increasing dependency and needs over time as opposed to the opposite with acute and rehab (9). Components of LTC service delivery include institutional care, community-based services and home-based services. The types and mix of services vary between provinces and territories in Canada (10).

Institutional care can be divided into two main types: chronic care units/hospitals and LTC facilities. Chronic care units and hospitals provide care to persons who, because of chronic

illness and marked functional disability, require long-term institutional care but do not require all the resources of an acute, rehabilitation, or psychiatric hospital. Twenty-four hour coverage by professional nursing staff and on-call physician care is provided, as well as care by professional staff from a variety of other health and social specialties. Only people who have been appropriately assessed and who are under a physician's care are admitted (10). LTC facilities which include nursing homes (NH) and personal care homes (PCH) provide living accommodation for people who require on-site delivery of 24 hour, 7 days a week supervised care (SC), including professional health services, personal care and services such as meals, laundry and housekeeping (11). Clients may have moderate to severe care needs that can no longer be safely or consistently met in the community (10). Across Canada, these facilities are referred to as NH, personal care facilities and residential care facilities. The level or type of care offered, its measurement, governance and ownership also varies (11).

Home and community care is an integral part of health care systems in Canada, and the demand for such services is expected to grow dramatically over the coming years (12). Home and community care services help people to receive care at home, rather than in a hospital or a LTC facility, and to live as independently as possible in the community. Home and community care is delivered by regulated health care professionals (e.g., nurses), non-regulated workers, volunteers, friends and family caregivers. The goals of home and community care are to help people maintain or improve their health status and quality of life (QOL), assist people in remaining as independent as possible, support families in coping with a family member's need for care, help people stay at or return home and receive needed treatment, rehabilitation and palliative care. (13). Home care can be provided by professionals such as nurses and allied health workers or by non-professional care givers. Home services can include housekeeping tasks, or

nursing services providing comprehensive care which can be curative, palliative or supportive. In addition Allied Health services, for example physiotherapy and occupational therapy, provide assessment and treatment in order to rehabilitate or relieve pain. Community-based care programs include adult day care, respite services, day hospitals and palliative care. These programs provide short-term assistance and support to seniors and their families. Other programs include meal programs and transportation services. Volunteers are utilized for friendly visiting and doing errands, like shopping. Group homes or family care homes help persons with physical and/or mental disabilities (10).

1.2 Significance of the Study

This study builds on previous published work in this area. The first study conducted in 1995/6 analyzed the newly administered single-entry system (SES) in the St. John's region, and found that clients were inappropriately placed in NHs and investment into alternatives to NH care was suggested (14). The second study determined the impact of the SES on appropriateness of NH bed utilization by examining panel placement changes between 1997 and 2003 in prevalent residents (15). The SES improved appropriateness of placement in LTC facilities, however there was still a need for alternative options of institutional care for clients. A third study that analyzed institutional LTC across the province recommended that the St. John's region build more SC beds in the city and downsize the NH sector (16). This thesis provides a more recent evaluation of clients entering institutional LTC in the St. John's region and outlines a plan to address the estimated future need based on this analysis.

1.3 Purpose of the Study

The NL population is aging therefore future planning is necessary. Recommendations were made to restructure the system by providing more SC beds, new specialized facilities for

the cognitively impaired, and fewer nursing home beds, however there are still few alternative options for institutional care besides SC and NH care. Past studies have demonstrated the need for alternative care (14-16), and predictions have been made for future need based on assumptions of future care (15). However there has been no research on the stability of assumptions made and how the region had changed over time.

The rationale for this thesis was to test the assumptions used to predict future need and assess the St. John's region LTC utilization a decade after SES initiation. It was also to develop a plan on how to best proceed for future planning. In order to achieve this rationale, a quantitative and qualitative approach was taken. The quantitative approach included analyzing a third incident cohort of clients applying to the SES in 2005/6, ten years after the original incident cohort was studied in 1995. The qualitative approach involved interviewing stakeholders that worked in planning LTC in NL and other jurisdictions across the country about the current structure and future needs with open-ended questions.

Together these analyses will answer whether predicting bed need is a stable method for future planning, how the client population entering LTC differs from when the SES was developed in 1995, and combine the results with stakeholder vision to develop a future path for LTC in the St. John's region.

1.3.1 Objectives. The objectives of this study are:

1. To compare demographics and disability across three separate incident cohorts in 1995/6, 1999/2000, and 2005/6.
2. To determine the rates of placement of clients and clients by disability per year

3. To determine the theoretical demand for placement in various facility types (Appropriate Housing. SC for the Cognitively Impaired, SC and NH) over time using an optimal placement decision tree.
4. To determine optimal bed needs for 2014 using various assumptions and determine whether these assumptions are stable.
5. To determine predictors of short (6 months) and long (4 years) term survival for clients presenting to institutional LTC.
6. To develop a mortality risk score for clients presenting to institutional LTC.
7. To determine the change over a ten year period in rates of clients by degree of disability, rates of beds available compared to beds needed, and survival for those placed in institutional care
8. To integrate the health care policy implications of the results from this thesis into the plans envisaged by key stake holders involved in LTC in NL and other provincial jurisdictions in Canada.

The study was designed to answer the following research questions:

1. What changes have occurred within the placement rate of clients, the disability rates of clients, the efficiency of placement and the survival of clients over a 10-year period in institutional LTC in the St. John's region?
2. Is there a difference in the number of optimal beds determined for 2014, when comparing data used from the 1999/00 cohort to data used from the 2005/6 cohort?

The secondary research question addressed by this study was:

1. Can a plan be developed using the health care policy implications of the results from this research and the plans envisaged by key stakeholders of LTC in NL and other provincial jurisdictions in Canada?

Chapter 2 Literature Review

"As the population ages and care needs become more increasingly complex, it is clear that more people will require some form of support. A system that provides quality service within the province's fiscal reality will ensure services are available into the future. Therefore, new and enhanced services must be cost effective and sustainable."(8)

2.1 Introduction

The following literature reviews several topics that are relevant to the study and vision for the document. The first section examines how an ageing population will affect the health care system. The next provide sections overview the Canadian Health Care system, the organization of LTC in Canada, NL, and specifically the St. John's region which is the geographic area of interest in this thesis. More specifically, these sections examine the financing of LTC in Canada and NL and how disability in clients is defined for institutional placement. The next two sections examine the methods of predicting future need of LTC services and predicting mortality. These tools can be very useful for planning purposes. Finally the last sections examine possible solutions for LTC in the St. John's region. The first overviews an integrated care model and then reviews models that have been attempted in other jurisdictions. The last reviews other institutional facility options that have been proven to be successful in other jurisdictions.

2.2 The Impact of an Ageing Population

Generally it is expected that the ageing process will be an important driver of health and LTC expenditure in the coming decades (17). The following studies describe the potential impact that an ageing population, increased longevity, and increased prevalence of the population entering LTC can have on the healthcare system.

Schulz and colleagues projected what impact effect the ageing population would have on both hospital and LTC in Germany (17). They developed two different possible scenarios, one where all determinants of current utilization of healthcare and mortality were held constant, and a second where all determinants were held constant except mortality. This scenario would show the impact of ageing with further increases in life expectancy. For LTC, scenario 1 saw a rise from 1.93 million persons (current prevalence) receiving care in 1999 to 2.9 million in 2050. Scenario 2 on the other hand saw a rise from 1.93 million to 4.73 million in 2050. It should be noted that the growth was found in higher levels of disability therefore it is likely that the demand for institutional care will increase more than for home care (17).

Spillman and Lubitz set out to determine the contribution of the ageing population to health care costs in the US by estimating total expenditures for Medicare covered services, NH care, and other services from the age of 65 years until death and in the last two years of life (18). Medicaid and Medicare ate two governmental programs that provide medical and health-related services to specific groups of people in the US. Medicaid is program for families with low incomes, while Medicare is for seniors and the disabled. Total expenditures from the age of 65 years until death increase substantially with longevity, from $31,181 for persons who die at the age of 65 years to more than $200, 000 for those who die at the age of 90. This was, in part, due to steep increases in NH expenditures for very old persons. It was found that expenditures for NH care increase at an accelerated rate for persons who die at the age of 65 with an average cost of $1,751 compared to those who die at the age of 90 that had an average cost of $64,665. NH care at the end of life (Last 2 years) also increased with age from less than $6,000 for those who die at the age of 75 to about $32,000 for those who die at the age of 95 (18).

Yang and colleagues investigated the relative contributions of both age and time to death to health care expenditures for elderly Medicare beneficiaries in the US (19). Results showed that monthly health care expenditures increase with age from $500 per month at age 65 to more than $2,000 per month at age 97. Average monthly health care expenditures start to increase about 24 months before death and increase faster in the last 6 months of life up through the last calendar month of life. Healthcare by service type show that monthly inpatient expenditures do not increase much with age, and home health care expenditures only increase slightly with age. However, monthly NH expenditures steadily increase after the age of 75, regardless of whether people are in their last year of life or not. Average NH expenditures for those over the age of 85 are close to $2,000 per month just before death, which is about three times higher than those aged 65-74. This is due to the fact that the main payers of NH care are Medicaid and out-of-pocket. Therefore, as people age, they use more NH and health care, but not substantially more inpatient care (19).

McGrail et al. assessed the effects of age and proximity to death on costs of both acute medical care (hospital, pharmaceutical and physician) and nursing and social care in British Columbia, as well as whether this relationship was stable in a time of rapid change in health care expenditures (20). Results showed that medical care, along with social and nursing care costs increased with age. The costs for those who died, decreased with age for medical care, but increased for social and nursing care. It was concluded that not age but proximity to death was a decisive factor in cost (20).

The ageing population is a growing issue. The prevalence of health problems increases sharply with age as do associated costs for medical care, social services, and LTC. Even in developing countries people are living longer, resulting in a rapid increase in the oldest sector of

their populations. Therefore, health trends in the oldest sector are of particular interest when estimating need for future care resources (21). The cost of health care increases with age, mostly due to the LTC costs. The impact of the demographic change on the need for LTC will become increasingly difficult to cope with (17). Health policy makers must find new approaches and alternatives to institutional care that include community-based care and preventative measures.

2.3 Canadian Health Care and Financing Long-term Care

Canada's publicly funded health care system is best described as an interlocking set of ten provincial and three territorial health insurance plans, known to Canadians as "medicare"(22). The system provides access to universal comprehensive coverage for medically necessary hospital and physician services. Health Canada state that "Primary health care involves providing services, through teams of health professionals, to individuals, families and communities. It also involves a proactive approach to preventing health problems and ensuring better management and follow-up once a health problem has occurred. These services are publicly funded from general tax revenues without direct charges to the patient (22). The provincial and territorial governments fund health care services with assistance from the federal government (23).

LTC does not fall under the umbrella of the Canada Health Act, the legislation that governs Medicare. These services are considered non-insured and thus provinces and territories are responsible for the design, delivery, and administration of LTC services to all their residents. While the overall responsibility for LTC falls under provincial/territorial health departments, regional health authorities (RHAs) usually deliver services and programming on their behalf (24).

While the provisions of the Canada Health Act apply to certain aspects of long-term residential care such as NH, intermediate care and adult residential care services (25), the financing of LTC is a patchwork. While LTC is publicly subsidized in most provinces, there is also a user-pay component for both residential and home-based LTC. Out-of-pocket expenses are usually income-tested and vary considerably across the country. Total expenditures on NH and residential care facilities for Canada in 2006 was estimated at $15.5 billion of which about $3.8 billion was from private sources (26). For institutional care, in 2008, maximum annual charges for standard accommodation for non-married seniors were $12,157 in Quebec, compared with $33,600 in NL (9).

2.4 Long-Term Care in Newfoundland and Labrador

The LTC and community support services system in NL offers an array of programs and support services designed to provide individuals with the opportunity to live as independently as possible within the services provided (8). The main options include home support, and institutional care options in PCH and NH (now called LTC facilities). There are variations in delivery and access to these services because each RHA is responsible for assessment and placement in PCHs, NHs and home care.

Home support is for eligible individuals of all ages in the community. Individuals have the option to purchase these services from an agency or hire their own workers to assist them at home. These services consist of respite, assistance with personal care, meal preparation and household management. Shared living arrangements can be set up with individuals who require home support and choose to share the cost of a living arrangement and home support staff with another person (8). As of 2012, there were a total of 6,501 caseloads, 3,442 of them being for

seniors (65 years and older) and the remaining 3,059 for adults under the age of 65 who had chronic health conditions or disability issues (27).

PCHs are private, for-profit, residential settings primarily for seniors. These residences provide accommodations and personal care for those persons who are ambulatory and require minimal care and/or supervision. They may receive assistance with ADLs or personal care, and have access to social recreational activities. Supportive services, such as meals and housekeeping, are also provided and aim to provide a home-like environment. PCH's are monitored and licensed by RHA's and provide subsidies for dependent residents. As of 2012, there were a total of 95 PCHs with 4,370 licensed PCH beds. 3,040 of the beds were occupied by clients, with 786 of them being private paying residents and 2, 254 being subsidized residents. From 2006/7 to 2012/3, there has been an increase in subsides of 45%, with the majority being added to the Eastern Health Region (28).

NHs are publicly-funded facilities operated by RHAs that provide care and accommodation primarily to seniors who require a higher level of care. They provide many services including medical, nursing, social services, pharmacy, dietetics, recreation, pastoral care and physiotherapy. Most residents require professional care supervised by nurses. The level of service provided depends upon funding, resource availability and client needs (29). As of 2012, there were a total of 38 NHs with a total of 2,814 beds. Within these facilities there were 2,347 clients who were subsidized and 312 private paying residents (30).

2.5 Financing Long-term Care in Newfoundland and Labrador

From 2012, the Home Support Program spends more than $165 million annually, as to deliver services to clients (27). In addition, government has invested more than $138 million

since 2006 to enhance the program for such initiatives as: increasing the hourly subsidized rate, increasing the rate for a home care worker to $2.25 above minimum wage; funding the significant growth in active cases; introduction of the income test financial assessment; and increasing the monthly financial ceiling, which means the amount of money subsidized for a client is increased. The Department of Health and Community Services has improved access to the Home Support Program through improvements to the financial assessment process and now considers a potential client's liquid assets along with ones fixed assets. Due to these improvements, approximately 2,000 more individuals are receiving services in 2013 compared to 2009. These changes have also had a significant reduction in the amount a client contributes towards home support costs with an average decrease of $291 per month since 2009 (27).

Prior to implementation of the SES, the government provided "fixed" subsidies in PCHs meaning only certain beds were available for subsidized clients. High demand for beds provided a viable business opportunity for private industry. Licensing and capacity controls were later discontinued and new operators entered the industry in competition with previously licensed homes where the 'fixed' subsidies were retained. This caused complications, by 2000, there was a demand for an increase in the number of subsidized beds because eligible clients were restricted in their choices, particularly as the newer homes had few subsidies and older homes without subsidies were unable to modernize due to less business. A new policy was adopted which expanded the subsidy pool and introduced 'portable' subsidy rates which meant clients could carry their subsidy to their preferred home, either a previously licensed home or new home built under the deregulated environment. The number of portable subsidies and the subsidy rate amount increased yearly for five years, starting in 2000. In 2003/04, a total of 477 portable subsidies had been added to the system and the rate was $1,138.00 per month, increased from

$923.00 in 2000 (31). Clients in subsidized beds with low income are given a "comfort" allowance of $125.00 per month (31). As of 2011/2, there were a total of 2,537 subsidies available to clients at a monthly rate of $1800, a rate increase of 20% since 2006, giving a total expenditure by government of $24 million per annum.

In 2001, the NL provincial government estimated that the average cost of care in a NH was $4,200 per month (32). Clients are charged up to $2800.00 per month regardless of their disability, with the remaining balance paid by government subsidy. The cost of board and lodging for clients is based on a financial assessment completed by the RHAs. Private paying clients having with a monthly income exceeding $2,925 or liquid assets exceeding $5,000 ($10,000 for a couple) pay the universal rate of board and lodging ($2,800). Subsidized clients include those with a monthly income less than $2,925 and assets less than $5,000 single ($10,000 for a couple) (31). The government pays the difference between the client's income and the cost of the NH, leaving $115-$125/month for the client as spending money (33). Most NHs in the province received these government subsidies, with the exception of privately owned and operated homes. In 2011/2, the NL provincial government estimated that the average cost of care in a NH bed was $9,200 per month, more than double the estimate from 2001. However, clients are still charged a maximum of $2800 a month regardless of the level of care required and the amount of money they have. All residents who receive a subsidy retain a $150 comfort allowance. For instance a resident with an income of $1200 gives the RHA $1050 and the government subsidizes the remainder. The total expenditures for NH in 2011/2 were $308 million.

2.6 The St. John's Region

NL is divided into four Regional Health Authorities: Eastern, Central, Western and Labrador-Grenfell. Within the Eastern Health Region, the St. John's area had a population of 185,905 in 2006, approximately 37% of the total population of the province. Of those, 100,650 lived in metropolitan St. John's, 24,670 in the contiguous city of Mount Pearl, and the remainder in the growing communities of Paradise (12,585), Conception Bay South (21,965) or in more rural areas (26,035) (34) (Fig.3.1). A boundary change occurred in 2005 which increased the catchment area for Eastern Health.

In 1995, a SES was implemented in the region to decrease inappropriate NH care. In this system, a client requests institutional LTC placement. The client is assessed by a multi-disciplinary panel and it recommends placement to a NH or PCH. For clients eligible for provincial subsidization, the panel considers this information when determining the services to be provided. A client may express a preference for placement in a particular facility and may not be required to accept an earlier placement if their choice of facility is not currently available. There is one exception to this in the St. John's region. Clients waiting in an acute care bed for institutional LTC are transferred to a transitional unit, and if the facility of choice is not available during this time, the client is transferred to the first available facility that can provide the care they require. Prior to 1995, entry into these facilities was negotiated separately with each institution.

In 1996, Long-Term institutional care in the region was delivered through six publicly funded NHs and multiple private PCHs. The NHs were in the city of St. John's and included a small number of beds for clients with modest disability, who did not require the professional

services of a NH. PCHs were located largely outside the city of St. John's. Incident cohorts for the region were studied (in 1995/6 and 1999/00, (14-16) and recommendations were made to build more SC beds and new specialized facilities for the cognitively impaired, and to provide fewer NH beds. As a result, SC beds were built in the city of St. John's, NH beds were downsized, and planning commenced for the provision of specialized care for the cognitively impaired.

2.7 Defining Disability

2.7.1 Resident Assessment Instrument (RAI). The Institute of Medicine in the US conducted a study that found the need for a uniform assessment tool to improve the quality of care in NH. As a result, the Nursing Home Reform Act of 1987 was put into effect and made recommendations that all NHs implement a comprehensive, standardized assessment tool for residents (35-37). As part of the reform the RAI to manage the regulation of NH care was implemented (35). The RAI`s main use was to be clinical and to view the 'whole' person and guide care, along with facilitating communication amongst caregivers (35). Residents are assessed on admission, annually and at any significant change in health status (35). The RAI consisted of three components, the first being the Minimum Data Set (MDS), which contains the essentials to conduct a comprehensive assessment of a NH resident (37). The MDS incorporates 12 indicative measures of physical health, functional status, psychosocial well-being, dietary status, comprehension, vision, hearing, communication skills, activity preferences, potential for self-care improvement, and indicators of QOL (37). The MDS 2.0 is used nationally and internationally in Canada, UK, Holland, Japan, and other countries across Europe (35, 38). The inter-rater reliability was considered sufficient for clinical use. The validity of the MDS has been investigated in several studies (38). The MDS are grouped in to domains such as

cognitions, ADL, mood and behavior. To investigate, these domains were compared with other valid instruments of the same measure (38). Validity had been found to be good for ADL's and cognition, however appears less valid in domains such as mood and behavior.

The second component of the RAI is the Resident Assessment Protocol, which guides the assessor to a care plan for the common issues attributed to the elderly (39). The third is a classification system based on the MDS to estimate resources used by an individual client (39). This is the Resource Utilization Groups (RUGs-III) and it is one of the assessment tools that is utilized in this thesis.

2.7.2 Resource Utilization Groups III (RUGs-III). In response to changes in practice methods and client characteristics (40) and as a result of widespread concern about quality and escalating cost of care in NHs in the US the RUGs III system was developed after re-evaluation of prior RUG systems (RUG II & RUF T18) (41). The new version would be based on the MDS which is implemented across the US to improve care planning (40). The new version is improved by identifying measurements for impaired cognition, additional ADL's and "high-tech" residents (42).

The RUGs-III system integrates three dimensions when assessing a client. The first comprises a hierarchy of seven major types of clients ranked by cost. They include rehabilitation, extensive services, special care, clinically complex, impaired cognition, behavior problems, and reduced physical function (41-42). The second is an ADL index which combines the score from four measures that include toileting, eating, bed-to-chair transfer, and bed mobility. The third incorporates special types of care such as rehabilitation and other problems such as the presence or absence of depression (41-42).

The classification system has been an attractive tool that has been tested in a variety of settings and countries across the Globe (41). A study examining staff time relationships between RUGs-III groups that include the USA, England, Wales, Japan, and Sweden showed that the total average time spent on a client per day varied widely. However, when examining the relationship between individual RUGs groups (eg. Cognitive Impairment, Special Care) it was found to be very similar between all countries (41). The Czech Republic found it to be a "suitable" case-mix system for institutional LTC because of its usefulness for resource and facility management, quality assurance process and for comparing on a national and international stage (43). The RUGs-III system was also found to be quite effective in explaining the variance in cost amongst those with intellectual disability in NHs and may also provide useful information for specialized facilities designated for those with an intellectual disability (44).

2.7.3 Alberta Resident Classification System. In 1982, the Alberta Home Review Panel made recommendations to improve LTC care and eliminate the care and service differences that existed between NHs and chronic care hospitals (45). Based on these recommendations the Alberta Resident Classification System (ARCS) was created (1988) (45) and has been in use since 1991 (46). The purpose of this classification system was to provide means of grouping LTC clients according to care needs and to case-mix data for funding purposes. It is also perceived that the ARCS may be useful for policy and planning purposes (45).

This classification system is based on seven categories ranging from A-G, where A represents the most independent and G the most dependent. The categories are derived by the combinations of four indicators of ADLs which include the need for assistance with eating, toileting, dressing, and transferring; two indicators of Behaviors of Daily Living (BDLs) which

include coping and the potential for harm or risk to themselves or others, and continuing care (CCLs) which consist of urinary incontinence and fecal incontinence (45).

It has been suggested that the Alberta RCS is insensitive to clients with clinical complexities (46). Also, it does not deal competently with regard to resource utilization and was not homogenous in grouping client resource requirements. Thus it was therefore recommended that the Province of Ontario switch to the MDS to measure RUGs-III utilization. (46). A combination of these two disability classification tools (ARCS and RUGs) is utilized in this thesis.

2.8 Predicting Future Need

The ageing of society will have a great impact on the long-term care sector. Many questions are asked when this issue is raised such as, how many people will require LTC services? How much will it cost? Projecting future LTC needs is of great importance for policy and planning as this information will inform the restructuring of the institutional LTC sector in order to ensure sustainability of the healthcare system so therefore projecting the needs is of great importance for policy and planning (47-49). The following studies have all attempted to predict future needs and/or cost for LTC in the future.

Wittenberg et al. make projections in three particular areas by using specific assumptions about future trends in England (47). The areas consist of the number of older people ($\geq$ 65 years of age) with levels of dependency, levels of LTC services demanded, and expenditure on LTC services. The numbers aged $\geq$ 65 years are projected to grow from 7.8 million in 1996 to 12.4 million in 2031, which is an increase of 60%. Residential places (in residential care establishments, NH and hospitals) would need to expand from approximately 400,000 in 1996 to

670,000 in 2031, an increase of around 65%. The number of home care hours would need to increase from just below 2 million per week in 1996 to approximately 2.9 million per week in 2031, an increase of around 48%. LTC expenditure would need to rise by around 148%. This would mean an overall increase in expenditure from around £9.8 billion in 1996 to £24.3 billion in 2031. These projections of future demand for LTC services are sensitive to the projected numbers of older people and future dependency rates (per 1000 ≥ 65 that need LTC services). Also future LTC expenditure is highly sensitive to assumed real rises in the unit costs of care (47).

Kunkel et al. estimated the changes in prevalence over time in long-term disability in the US by using four different mortality/disability scenarios (48). The Projections for 1986-2040 showed: 1) Constant Mortality/Constant Disability Scenario, 2.6-7.2 million people with moderate disability and 2.5-7.6 million with severe disability; 2) Longer Life/Lower Disability Scenario, 2.6-7.5 million with moderate disability and 2.5-8.5 million with severe; 3) Longer Life/Higher Disability Scenario, 2.3-10.6 million with moderate disability and 2.5-12.0 million with severe and; 4) Longer Life/Moderate Disability Scenario (Best Guess), 2.6-7.9 million with moderate disability and 2.5-8.4 million with severe. Estimates of the over-65 population expected to have a long-term disability in 2040 range from 14.8 to 22.6 million people, compared to approximately 5.1 million older people experiencing a long-term disability in 1986 (an increase ranging from 190 to 343%) (48). The wide range between these estimations of clients entering LTC could make future planning difficult.

The third study was conducted by Comas-Herrera et al (49). They presented projections for the next 25 years of future numbers of older people with cognitive impairment in England, their demand for LTC services and associated expenditure under a range of assumptions. The

assumptions relate to factors that affect LTC expenditure, projections of the number of older people, prevalence rates of cognitive impairment, household composition, care patterns (formal and informal),and cost. Under the base case assumptions, between 2002 and 2031, the numbers of people with cognitive impairment would rise by 83%, the number of hours of home care provided would need to rise by 91%, and the numbers of people with cognitive impairment in institutional care would rise by 88%. The expenditures on LTC for older people with cognitive impairment are projected to rise from £5.4 in 2002 to £16.7 billion in 2031 (49).

In summary studies projecting LTC services all state that with current trends of ageing and disability the system`s needs will dramatically increase. It is emphasized that without proper policy and planning and frequent review of trends, the future of the LTC system will not be sustainable.

2.9 Predicting Survival

Not only is age at death important in predicting LTC needs but survival following admission to LTC is important, particularly as incidence multiplied by survival will determine the number of beds required for LTC. Other potential uses include its value to physicians and clients/family for proper care management and end-of life planning. It is also valuable to policymakers for planning and comparing the quality of care between different healthcare facilities (50-53). The following studies have attempted to predict short and long-term mortality in the elderly using various methods and variables.

Diagnostic and prognostic or predictive models serve different purposes. Whereas diagnostic models are usually used for classification, prognostic models incorporate the dimension of time (54). A prognostic model should not enter clinical practice unless it has been

demonstrated that it performs a useful role (55). There are two fundamental aspects of evaluating and validating model performance: discrimination and calibration (55).

Discrimination is the ability of the model to correctly separate the subjects into different groups, e.g. being in various prognostic groups (54, 56). The most popular measure of discrimination is a plot of sensitivity of a test, which refers to the ability to identify persons with the disease, vs. 1-specificity, which refers to the ability to identify persons without a disease (57). This is also known as the Receiver Operating Characteristic (ROC) curve. The performance of the variable can be quantified by calculating the area under the ROC curve (AUROC) (58), which is also known as the c-statistic or c index. The AUROC curve can range anywhere from 0-0.5 (no predictive ability) to 1.0, which represents perfect accuracy or discrimination (54, 57).

Calibration is the ability to correctly estimate the risk (probability) of a future event or the degree of correspondence between the estimated probability produced by the prognostic model and the actual observed probability (54, 56). The observed risk or scores can only be estimated within groups of individuals, such as 'low risk', 'intermediate/moderate risk', and 'high risk' categories, e.g. studies of predicting early death in renal disease patients starting dialysis conducted by Barrett et al. (59) and predicting death in Chagas heart disease conducted by Rassi et al. (60). Carey et al. question whether a database of elderly people enrolled in the Program of All-Inclusive Care for the Elderly (PACE), a program designed to keep NH eligible seniors in the community, could be used to develop an accurate, easy-to-use prognostic index for community-living frail elderly people with LTC needs (50). They divided the database into a developmental cohort to produce a prediction model and then tested it in a validation cohort. Using Cox regression analysis, the developmental cohort model found eight independent risk

factors for survival consisting of age, sex, ADL, and various clinical issues to be significant. Each variable was designated a score and applied to all participants. To determine the discrimination and predictability of the score index, the AUROC was calculated. For the developmental cohort the AUC was 0.66 and 0.69 for the validation (50). To determine calibration, subjects were divided into risk groups of equal size based on their risk score. The predicted mortality from the development cohort was then compared to the observed mortality from the validation cohort at both 1 and 3 year periods.

Flacker and colleagues wanted to determine whether available MDS information can identify factors associated with 1-year mortality and use these factors to estimate the risk of 1-year mortality in newly admitted and long-stay NH residents (51). The study was a retrospective cohort study with developmental and validation cohorts. Logistic regression analysis was performed to identify factors associated with 1-year mortality. For newly admitted residents, a total of 11 variables were found to be independent predictors. To stratify residents a score was developed from the final model and applied to residents. The model showed good performance in the developmental cohort with an AUROC of 0.73. Long-stay residents showed similar results with 11 variables being significant and an AUROC curve of 0.71 (51). Although calibration was not mentioned in the methodology, each score in the development cohort was compared to the validation cohort, to examine the percentage of mortality in each group (51).

The purpose of the Kiely et al. study was to examine whether higher levels of social engagement were associated with longer survival in NH facilities, independent of recognized factors associated with mortality (61). Cox Regression analysis was performed and results showed that for each increase in the Social Engagement scale, residents were 6% (95% CI 0.92-0.95) less likely to die during the follow-up period (61).

The purpose of the Porock et al's. study was to identify the MDS indicators that best predict 6-month mortality in NH residents (53). A total of 43,510 residents completed the data set with 75% designated to the developmental cohort and the remaining 25% to the validation cohort. Using sub-analysis of about 11,000 residents (to avoid having too much power), logistic regression found 17 predictors including demographics (age and sex), cognitive ability, and clinical complexities to be significant predictors of 6-month mortality. Each variable was assigned a score based on their β regression coefficients, and then a risk score was calculated for each individual. The c-statistic (AUC) was high at 0.75 (53).

In summary, the studies described are representative of the papers that were analyzed for the purpose of this thesis. Although there were different settings and variables used in the analysis the methods proved to be very similar. Predicting mortality for LTC clients can prove to be a very useful prognostic tool whether used for clinical use to assist with physicians care plans or to, give useful information to clients and families for end-of-life planning or for healthcare facility planning.

2.10 Integrated Care

2.10.1 Introduction to Integrated Care. The word 'integration' is mostly used to express the bringing together or merging of elements or components that were formerly separate (62). All organizations are, to some extent hierarchical structures that are comprised of separate but interconnected components. These components are supposed to play complementary roles in order to accomplish their joint tasks. Health system and health care institutions are among the most complex and interdependent entities known to society (63). Without integration at various levels, all aspects of health care performance suffer. Patients get lost in the system, needed

services fail to be delivered, or are delayed, quality and patient satisfaction decline, and the potential for cost-effectiveness diminishes (62).

For some time health system policy-makers and some providers have been concerned with two-related issues: poor quality of care for those with chronic conditions and the continued sustainability of the publicly funded health care system (64). These issues are related because those with chronic conditions are the most frequent users of health care services, and inefficient use of resources in the treatment of chronic conditions contributes to higher health care spending (64). Improving the ability of health care systems to respond to demands of older people is among the greatest challenges of our time (65). With growing numbers of those over the age of 65, they utilize a disproportionate amount of both acute hospital and NH care with frequent transitions between them (66).

Integrated models of care for the elderly date back to as early as the 1970's (On Lok)(67). In San Francisco's Chinatown a project was undertaken to maintain the frail elderly in the community for as long as possible to avoid premature institutionalization (67). Since then, various models have been created across the globe including Canada, United Kingdom, Italy, and the United States. The target population was the frail elderly who are at risk of institutionalization. The primary objective of these models was to improve the coordination of health and social services to the elderly, and to avoid unnecessary institutionalization (67). They were structured in a variety of ways but at a minimum typically included a system-level case management; a single administrative structure, a single funding envelope, and a range of services appropriate to the care of seniors such as home care, home support, supportive housing/assisted living, LTC facilities and specialty geriatric units in hospitals (68).

Based on an international review of these models, common features of an effective integrated system of care were a single entry point system, case management, geriatric assessment, involvement of a multidisciplinary team, and use of financial incentives to promote downward substitution of services from institutionalization to community-based care (67). It was concluded that focused community-based care can impact favorably on rates of institutionalization and costs.

One of the more successful countries implementing this system is Denmark. In the early 1980's, in response to policy direction from the government, municipalities started to expand home care services as an alternative to NH (69). They expanded care options to assisted living instead of new NH construction. By the mid 90's the Danish adopted the integrated model by amalgamating NH and home care organizations where they were previously separated and fragmented. The system involves a revolving door. In the town of Skaevinge, when an individual becomes ill and requires closer supervision that cannot be provided at home, they are transferred to an Assisted Living facility (ALF) until well enough to go home. Similarly, someone who has been hospitalized may be discharged to an ALF until able to go home. After 12 years of implementing integrated systems for home and community-based services, growth in the Danish LTC expenditures has leveled off and expenditures for the over 80 population have decreased. It was concluded that focused community-based care can impact favorably on rates of institutionalizations and costs (69).

2.10.2 Randomized Trials of Integrated Care Models. The System of Integrated Care for Older Persons (SIPA) program is a community-based primary system based on a patient-focused model designed to meet the needs of the frail elderly and to assure comprehensive care, integration of all available services and continuity of care by all professionals and institutions

involved (70). Its distinguishing features are community-based multidisciplinary teams with full clinical responsibility for delivering integrated care through the provision of community health and social services and the coordination of hospital and NH care, all within a publicly managed and funded system (71). A randomized controlled trial was conducted to assess whether the model would change service configuration by decreasing hospital and NH stays. They compared the elderly persons assigned to the SIPA program to those receiving usual care. Primary outcomes were differences between SIPA and control for admissions, service utilization, and public costs of healthcare services. Results showed that there was increased accessibility for health and social home care. There was a 50% reduction in hospital and alternate level stays ("bed blockers") but no significant differences in utilization and costs of emergency department, hospital acute inpatient, and NH stays. It was concluded that integrated systems appear to be feasible and have potential to reduce hospital and NH utilization without increasing costs.

In the 1990's, the health agency of Rovereto, a town in northern Italy, created a broad array of health services for the elderly (65). However, no coordination of these components or integration with social services was conducted. Therefore, a randomized trial was conducted to evaluate the impact of an integrated program with the primary outcomes being admissions to institutions, use and costs of health services and functional variations in the frail elderly. A total of 200 subjects were randomly allocated to receive either, primary and community care with the conventional and fragmented organization of services (n=100) or case management and care planning by the community geriatric evaluation unit and general practitioners (n=100). Results showed that admission to hospital or NH in the intervention group occurred later and was less common than in controls (HR 0.69, 95% CI 0.53-0.91). Health services were used to the same extent, but control subjects received more frequent home visits by General Practitioners. In the

intervention group the estimated financial savings were in the order of $1800 per year of follow up. The intervention group had improved physical function (ADL's) ($p<0.001$). Decline of cognitive status was also reduced ($p<0.05$). It was concluded that integrated care may provide a cost effective approach to reduce admission to institutions and functional decline in older people living in the community (65).

The Hospital Admission Risk Program (HARP) projects in Australia aimed to provide an integrated system of care that would ensure patients were linked to all the existing acute and community services they required (72). They also facilitated the coordination between the services through ensuring effective communication and exchange of relevant information. The four key components of the model were: a "gateway system" for recruitment of the right population; assessment of needs; care coordination and facilitation; and a suite of services. People over the age of 55 years with complex health needs, who had made three or more presentations to a hospital emergency department (ED) in the past 12 months or who were identified as being at risk of frequent visits were recruited. Each participant was assigned a care facilitator who provided guidance through identifying and accessing the required health care services. A comparator group was formed from patients who were eligible to participate and had been offered the opportunity but had declined. Because the comparator groups were of those who declined to be in the study there is a participation bias. However, baseline characteristics show that there was no difference in mean age, sex, pre-ED rates (presentations/patients/day), pre admission rates (admission/patient/day), and pre-bed-day rates (bed-days/patient/day). The objective of this study was to reduce patient's use of acute hospital services through the new model. A total of 316 patients were analyzed (HARP n=231, comparator n=85). There was a 20.8% reduction in ED presentations, a 27.9% reduction in hospital admissions and a 19.2%

reduction in bed-days. The comparator group showed a 5.2% increase in ED presentations, a 4.4% reduction in hospital admissions, and a 15.3% increase in inpatient bed-days. A cost-savings analysis showed a possible annual savings of $1 million. It was concluded that the integrated model of care HARP is useful for reducing utilization of acute health care facilities for older patients that have frequent presentation to the ED (72).

The Social Health Maintenance Organization (HMO) is a community-based LTC program that originally operated in 4 sites in the Unites States (73). Fischer et al compared the experience of a site that withdrew from the program to another that continued to examine whether community-based care reduced the probability of institutional placement for at-risk elderly. A total of 18,143 participants were studied (Study Group n=7667, Comparator n=10,746) for a 4.5-year period from January 1995 to June 1999, which immediately followed the closure of the comparator site's Social HMO program. Results showed approximately a 40% increase in long-term institutional placement associated with the termination of the Social HMO program (OR 1.43, 95% CI 1.15-1.79). It was concluded that the community-based services program appears to help delay institutional placement in at-risk elderly (73).

The Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) in Quebec considers itself a different model of coordination-based integrated care (74). As opposed to fully integrated systems, this model uses all the public, private, or voluntary health and social service organizations involved in caring for older people in a given area. Every organization keeps its own structure but agrees to participate under an umbrella system and to adapt its operations and resources to the agreed requirements and processes. Hébert et al. used a population-based quasi-experimental design with pretest, multiple posttests and a comparison group. The three experimental areas in Eastern Quebec were matched with three comparison

areas in the same region. A total of 1501 persons identified as at risk of functional decline were randomly selected (experimental n=728, comparison n=773). Participants were assessed over a 4-year period for disabilities, unmet needs, satisfaction with services, and empowerment. In the fourth year of the study, the annual incidence of functional decline was lower by 137 cases per 1000 in the experimental group, whereas the prevalence of unmet needs in the comparison region was nearly double the prevalence observed in the experimental region. Health services utilization, a lower number of visits to emergency rooms and hospitalizations than expected was observed in the experimental group. Based on the positive PRISMA experiment, the Quebec Ministry of Health and Social Services decided to generalize the model to the entire province (74).

2.10.3 Frameworks for Integrated Care. The Care and Management of Services for Older People in Europe Network (CARMEN) developed the 'Policy Framework for Integrated Care for Older People' as a guideline for European nations to implement (75). The framework does not attempt to address all the policy measures related to living well in later years but focuses on the challenges of integrating services and care processes for older people with complex needs. However, the approaches that it promotes reinforce policies on active ageing, emphasizing control by individual older people and the concept of interdependence, in which older people give as well as receive. It states that integrated care for older people is at the heart of three objectives in national policies on health care and care for older people which are accessibility, quality and financial sustainability. The policy framework addresses the following items: clarifying the vision; underpinning principles and values; criteria for operational success; coherence with other policies; active promotion and incentives for integrated care; evaluation and monitoring; regulation and inspection; and support to implement policy (75).

Kodner and Spreeuwenberg's discussion paper on integrated care examined practical applications and implications for integrated care models (62). The applications are organized into five important interlocking domains that consist of funding, administrative, organizational, service delivery, and clinical. Funding affects every aspect of integrated care because it determines how health and social care are structured. Suggested strategies include pooling of funds and prepaid capitation; Sufficient administrative structuring allows for a more discernable health system and proper resource management can be achieved through consolidation and inter-sectoral planning; having seamless integrated care means being very organized. "Working both vertically and horizontally and through formal and informal means is a major method to improve how organizations work together". Methods to improve the organization for integrated care include co-location of services, inter-agency planning and jointly managed programs and services; service delivery, meaning how health care professionals, management and other staff are trained and perform the abilities are a crucial feature for integrated care. Some strategies include joint training, centralized information/data, case management, and interdisciplinary teamwork. Finally the clinical aspect of patient care in an essential ingredient in integrated care. Strategies include joint care planning, shared clinical records and continuous patient monitoring (62).

Kodner and Spreeuwenberg discuss the implications of such a model of care and make five points which stood out. First it includes the need for specific details for delivering care to certain groups, such as the frail elderly, and how they can benefit from such a design. Second, there is a need to have a better understanding of the possible barriers that may affect integrated care. Third, the association that integrated care will produce cost savings, is only a "hope" and needs to be carefully calculated. Fourth, there is a need for patient and family involvement in

order to have a successful model of care. Finally, the need for ongoing research and monitoring of an integrated system is essential (62).

A framework has emerged from the Canadian jurisdiction (76). Hollander and Prince's framework for integrated care focused on four vulnerable population groups consisting of the elderly, persons with disabilities, persons with chronic mental health conditions and children with special needs (76). Two-hundred and seventy interviews were conducted with leading experts across the country, and focus groups were held with clients and family members in the vulnerable groups. The framework consisted of three parts: philosophical and policy prerequisites that reflect the values and beliefs that are the foundation of the framework; a set of best practices for organizing a system for administrative and clinical purposes; and a set of methods for linkage and coordination for continuing care across organizations, institutions and healthcare professionals. The framework can be modified to apply to any of the four populations mentioned. Hollander and Prince conclude that developing appropriate, caring, responsive, sustainable and efficient care delivery systems is challenging. So for people with ongoing care needs it is crucial to provide them with a range of health, social and human services (76).

2.11 Alternate Facility Options

Identifying alternatives to institutional care for frail elders is of high importance because of the public and private expenditures for institutional care and the decreased QOL that often occurs in such a setting (77). The following section reviews two alternate levels of care for those entering institutional care. The first is Alternative Housing (AH) for those with no clinical indicators for institutional care and SC designed for those with cognitive impairment.

2.11.1 Alternative Housing Options. The institutional model of NH care remains in many ways the epitome of social isolation for elders, as homes are often geographically segregated from vital community centers, highly regulated, and depersonalized. NHs and their care delivery systems are designed to maximize efficiency and safety, often at the expense of residents' QOL (78). NHs has been the primary source of institutional care for the elderly. However, the combined impact of growing numbers of older adults, a shortage of NH beds, increasing costs of nursing care, the better overall health of new cohorts of older adults, and dissatisfaction with NH care focused awareness on a gap in the ‘‘continuum’’ of care between independent senior's housing that catered to the elderly population without any functional impairments and nursing facilities that catered to the chronically ill (79).

ALFs were modeled after the Dutch residential settings in order to broaden the continuum of care for the elderly. The idea was to provide an "invisible support system" in a residential setting (79). ALF's have been the most rapidly growing segment of senior housing in the United States in the 1990's. As of 1998, there was an estimated 11,459 ALF's nationwide, with 611,300 beds and 521,500 residents (80). According to The Assisted Living Quality Coalition, an ALF is as follows:

> "A congregate residential setting that provides or coordinates personal services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health related services; designed to minimize the need to move; designed to accommodate individual residents' changing needs and preferences; designed to maximize residents' dignity, autonomy, privacy, independence, and safety; and designed to encourage family and community involvement (81)."

Ball et al. set out to understand whether independence was retained in ALFs (82). They conducted interviews with providers and residents in ALF's in the state of Georgia. Their findings showed that ALF clients retained a strong value of independence. Even clients who

needed help with ADLs continued to hold on to independence and find meaning in their remaining abilities (82).

The QOL for residents has been proven to improve in such facilities (83). Mitchell and Kemp examined the impact of four domains: demographics and health; social involvement; facility characteristics; and social climate upon the QOL of senior residents living in assisted living homes (83). Their findings suggested that these facilities can improve the QOL of clients by creating "a cohesive social environment, and encouraging social participation and family involvement" (83).

2.11.2 Dementia. The descriptive term dementia is derived from the Latin root *de mens*, meaning a noticeable decline in mental abilities (84). Dementia "mainly affects seniors and also greatly affects their families and care givers" (85). Although families and patients prefer to stay home as long as possible, most people burdened with the disease are forced to enter institutions for professional care (86).

There are several conditions and diseases with dementia symptoms (87). The types of dementia include Alzheimer's disease, vascular dementia, Lewy body dementia and fronto-temporal dementia (88). Alzheimer's disease is the most common form of dementia seen in the elderly, affecting around 50-80% of those diagnosed with dementia (89-90). It was first identified more than 100 years ago, but only in the last 30 years has science gained momentum on the topic (86). Alzheimer's disease can affect anyone in a variety of ways (86). The most common symptom in Alzheimer's disease is memory loss. Gradually there is difficulty in remembering new information (86,91). This is because damage occurs to the area of the brain responsible for retaining new information. Other symptoms include difficultly in solving

problems and tasks, confusion with time or place, and changes in mood and personality (86). Risk factors for Alzheimer's disease include advanced age, family history, lower education, gender (more females are affected) and a form of the apolipoprotein E (APOE) gene, APO E4 (92-93), however the etiology of Alzheimer's disease is unknown (91). Progression of Alzheimer's disease is associated with declines in higher cognitive abilities (language, thinking, reasoning, memory) and functional abilities (ADLs) and by the development of neuropsychiatric problems and behavioral disturbances (94). It is classified into stages that range from early stage or "mild Alzheimer's disease" which include symptoms of forgetfulness, communication difficulties, and changes in mood and behavior, to late stage or "severe Alzheimer's disease" which include symptoms of severe loss of memory, loss of the ability to speak, agitation, weight loss, and the ability to care for oneself (95).

A recent study commissioned by the Alzheimer Society of Canada reported that the number of Canadians living with cognitive impairment has reached 747, 000 and will double to 1.4 million by 2031 (95). These numbers not only include those diagnosed with dementias, including Alzheimer's, but those with cognitive impairment. In the UK the Department of Health estimates that around 5% of people over the age of 65 years suffer from dementia, and it is estimated that by 2010 around 850,000 people will be affected, rising to 1.5 million by 2050. Prevalence rates for dementia increase with age (95). Thus all indications point to an overall increase in the incidence of dementia and consequently attention needs to be paid to the ways in which formal and informal care can be provided for this particular group (96).

Although families and patients prefer to stay home as long as possible, most people burdened with the disease are forced to enter institutions for professional care (86).

2.11.3 Special Care Units for the Cognitively Impaired. Home may be where most people wish to live out their years, but remaining at home may not be a realistic option for those who have progressed past the early stage of dementia. Historically, people experiencing middle- to late-stage dementia have been admitted to institutional settings where basic and medical needs are met but home-like attributes are lacking (96). Institutional environments can be stark and meaningful activity can be limited. Behavior problems, which occur at some point in the disease progression for up to 90% of persons with dementia, can be minimized through environmental modifications and caregiver skills (96). Design of the physical environment is increasingly recognized as an important aid in the care of people with Alzheimer's disease and other dementias. It is regarded as a therapeutic resource to promote well-being and functionality among people with dementia (97).

Due to this evidence, special care units for those with dementia were developed in hope that a formatted environment, both physically and socially, would reduce excess disability and improve QOL (97). Most studies of special care units have reported no improvements over traditional care in cognition, function, or behavior of residents. However, this may be due to the fact that traditionally special care units are attached to institutional facilities. A study comparing a specialized care facility in terms of QOL for residents with dementia compared to traditional institutional facilities, demonstrated less decline in ADLs, more sustained interest in the environment, and less negative affect (96).

2.12 Discussion

The NL population is ageing, making the provision of LTC in the province a high priority. This chapter provided a literature review on topics that pertain to issues arising from ageing, examining LTC and planning for LTC. The increase in the older populations is an issue

due to the fact that the elderly use the health care system more often whether through medical care, social services, or LTC. This will drive the costs of healthcare up and LTC costs will increase with age.

While one of the benefits of living in Canada is "free" health care through medicare, LTC does not fall under the umbrella of the Canada Health Act, therefore it is not insured by the government. LTC is publicly subsidized by most provinces including the province of NL. In the province LTC options include home support, which has received increased funding in the past few years, PCHs which are privately owned facilities that are subsidized by the government and NHs which are publicly-funded facilities. The St. John's region includes all these options but still lacks alternatives for clients such as SC facilities for the cognitively impaired and housing for those with no overt disability.

Predicting future needs and mortality of LTC clients is necessary for planning. This chapter has shown that other jurisdictions have used methods to predict the future population and costs associated with LTC. With current trends of ageing and disability, the system's needs for predictions will dramatically increase. Although very difficult, predicting mortality for LTC may prove to be a useful tool for health care planning.

NL's LTC system suffers from fragmentation. For example, one must make separate applications if to access either institutional care (PCHs or NHs) or home care so therefore is it not a true single-entry system. Integrated models of care were reviewed as a method to alleviate such a problem. Case Management was the epicenter of integrated care so that a client is smoothly facilitated through the process of entering LTC, which includes being assessed by a multidisciplinary team to appropriate placement into options that include the entire spectrum of

LTC. Models of integrated care for the elderly were examined from other countries including Canada. Although not financially efficient these models reduce the use of health services including emergency and hospital visits, and LTC placement.

NLs LTC system also suffers from limited options for clients applying. AH can be a viable option for clients with no overt disability. These facilities provide independence and improve the QOL for clients. Another feasible option is SC facilities for those with cognitive impairment. The incidence of cognitive impairment is on the rise, and special care units may improve the QOL of clients and slow down the progression of frailty that usually accompanies dementia.

The extent of this chapter has reviewed the LTC system, examined methods for predicting future needs, and discussed possible solutions to alleviate some of the problems. The next chapter will provide the methodology of how institutional LTC in the St. John's region was evaluated.

Chapter 3 Methods

3.1 Introduction

The purpose of this research is to help aid in future planning of LTC in NL by analyzing the St. John's region. Its primary goals were to answer how institutional LTC in the St. John's region has changed in 10 years, and how changes in utilization and mortality influenced prediction of future needs for the system. It was also to gather opinions from stakeholders who worked in LTC in NL and other jurisdictions across Canada on underlying issues in LTC and how to resolve them in the future. Together these results can help provide a platform for future LTC plans. This chapter explains the methods used. It is organized to give insight into how the study was designed and the population studied. It then describes how data from the SES was collected, calculations used to describe the data, and the analysis of that data. A brief description is provided on how the health policy questionnaire was formulated.

3.2 Study Design

Three annual incident cohorts of clients (N=1661) who presented to the SES in the St. John's region were studied (Fig 3.1). This region is now included in Eastern Health. These annual incident cohorts included 1995/6 (N=467), 1999/00 (N=464), and 2005/6 (N=730). The research team extracted necessary data from the adult LTC form collected by the SES on each client (Data Analysis, Appendix A). The research team assessed clients by:

- Annual incidence rates of clients requesting institutional LTC per 1000 people in the population ≥ 65 years
- Characteristics and demographics of clients
- Type of placement recommended by the SES

- RUGs-III classification and ARCS levels of care for each client
- Optimal placement using a decision tree (see Fig. 3.4) with the following placement options: AH; SC for the cognitively impaired; SC; and NH care
- Appropriateness of client placement determined by comparing actual initial placement decision by the panel with optimal placement as determined by the decision tree
- Time to placement
- Median and mean time of survival was calculated by actual placement option (NH or SC) and by optimal placement option (using the decision tree)
- The effect of increased client incidence rates on bed need for the year 2014 by using data from two annual incidence cohorts (1999/00 & 2005/6) and the corresponding census data

In addition the following was undertaken:

- Development and validation of a new mortality risk score for survival in LTC by using demographic and disability variables.
- Interviews with key informants involved with LTC in NL and the Eastern Health region , Nova Scotia, Manitoba and Saskatchewan using an interview guide (Appendix B)
- Integration of the health policy implications of the results from the thesis into the plans envisaged by these decision maker

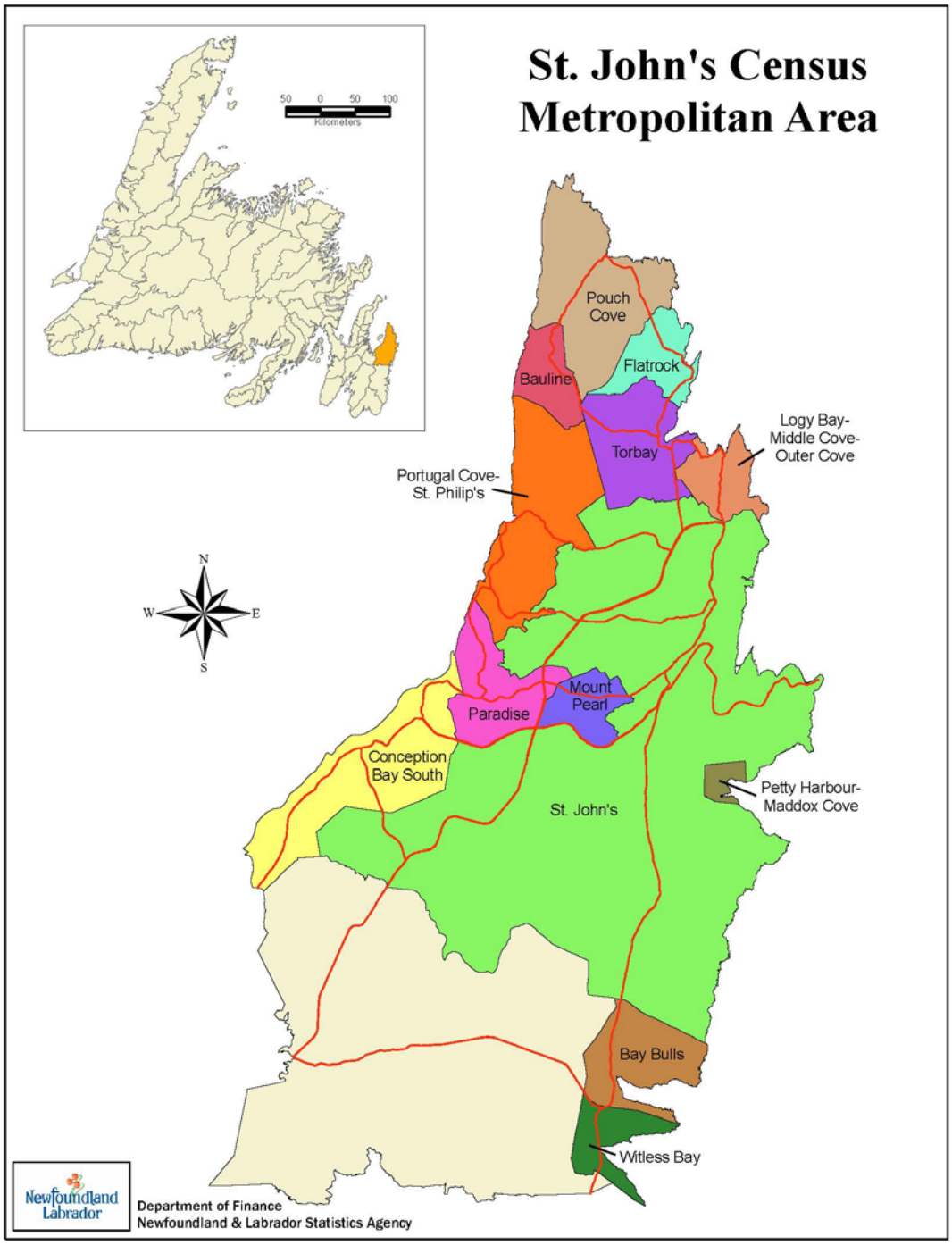

Figure 3.1- Map of the St. John's Region

3.3 Study Population

3.3.1 Inclusion Criteria. Data were collected over a 1-year period (between April 1 and March 30 of each respected incident cohort) on all clients who applied for placement to institutional LTC through the SES in the St. John's region. Over a decade three cohorts were studied: 1995/6; 1999/2000; and 2005/6. Total number of clients was 1661.

3.3.2 Exclusion Criteria. Clients were excluded from the study if they were admitted for short-term respite or they were internal transfers or veterans (N=165) (Fig 3.2). Veterans were excluded because they have their own entry system through veteran's affairs in addition to their own assessment and levels of care. Clients with sufficient data missing from their charts or whose charts were unable to be located were not analyzed (N=117). Survival outcomes were obtained for the 1995/6 and 2005/6 cohorts for those aged ≥ 65 years (Fig 3.3).

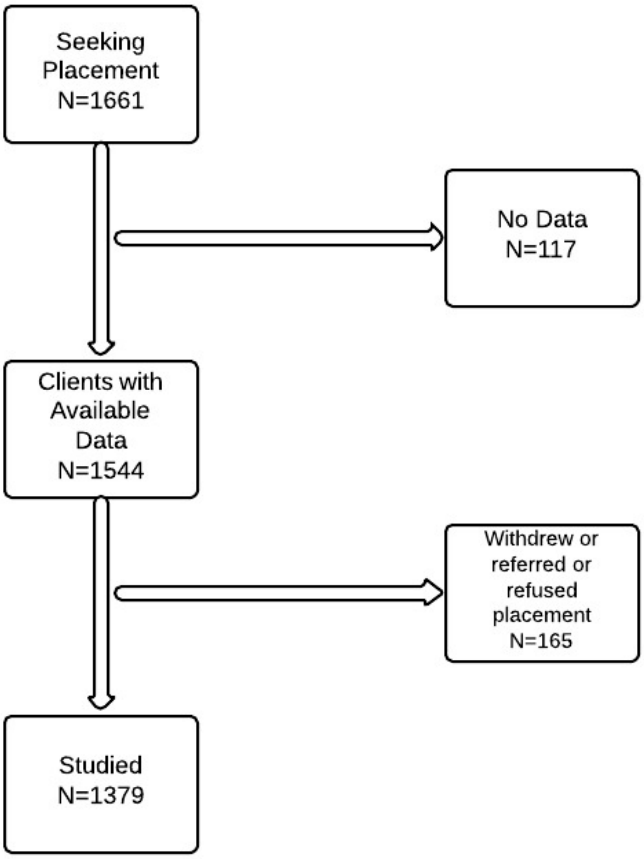

Figure 3.2-Flow diagram of clients assessed in the 3 incident cohorts.

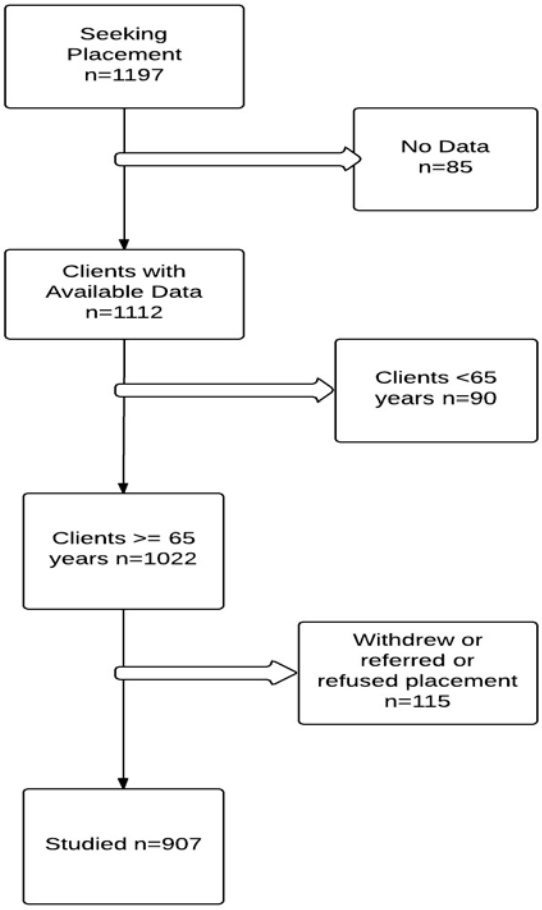

Figure 3.3-Flow diagram of clients in whom survival data were obtained from the 1995/6 and 2005/6 cohorts.

3.4 Data Collection

3.4.1 Client Assessment by the Single Entry System. The SES collected 35 pages of data on each client using the NL Continuing Care Assessment for Adult Long term care form, which includes demographic data, degree of disability, clinical problems, home support, difficulties with ADLs and clinical and social history. Clients are also assessed for cognitive impairment and behavior issues. Clients were then categorized by a multidisciplinary team into levels 1, 2, 3 or 4 according to perceived hours of care necessary. Level I clients are mostly placed in PCHs or level 1 NH beds (SC). Level 2, 3 and 4 clients are recommended for NH care. Clients with mild to moderate cognitive impairment (CI) are normally referred to NH.

3.4.2 Client Assessment by the Research Team. The Research team consisted of Jacqueline McDonald (Research Nurse), Dr. Patrick Parfrey (Clinical Epidemiologist and Nephrologist) and Dr. Brendan Barrett (Clinical Epidemiologist and Nephrologist) who took on the original project in 1995. From the Newfoundland Continuing Care Assessment for Adult Long-Term Care form, data were obtained by the research team to complete the activities of daily living (ADLs), behavior of daily living (BDL) and continence care level (CCL) score, which combined, provide the composite ARCS (Appendix C) (45). This score ranges from A to G based on client's degree of disability, as measured by need for assistance with ADLs (eating, toileting, dressing and transferring), frequency of nursing interactions for coping or behavior problems, urinary and bowel incontinence (45, 99). An "A" score corresponds to a mean of 31 minutes of nursing time, including direct (face-to-face) and indirect care activities, and a "G" score corresponds to a mean of 119 minutes (100).

The RUGs-III classification was also completed (Appendix D). It was determined whether clients fulfilled the criteria for each of the 7 hierarchical groups: rehabilitation, extensive

services, special care, clinically complex, impaired cognition, behavior problems, and reduced physical function. In addition, clients were classified according to the most resource intensive group for which they qualified.

The Alberta Home Care Client Classification - Functional Need Score (FNS) was developed to determine the requirements of clients accessing the LTC sector (Appendix E). It is made up of 13 key indicators that assess the functional needs of the clients. Levels of independence are assessed based on the type and amount of services one would need to maintain independence. A category of functional need is computed from the sum of scores of each of the indicators ranging from low (1) to high (5) (101). This score was used and analyzed as a predictor of survival.

3.4.3 Decision Tree. To determine optimal placement (in the opinion of the investigators), a decision tree that integrated data from the ARCS and RUGs-III classification was created by the research team (Fig. 3.4). It included 4 options: AH; SC for the cognitively impaired; SC; and NHs. Those with a RUGs-III indicator were designated for NH care. Those who were independent for ADLs, continent and not cognitively impaired were designated for AH. People classified in the RUGs-III cognitive impairment groups were designated for SC designed for the cognitively impaired. Those without a RUGs-III indicator but with a score on the ARCS indicating disability were designated to SC. The designations were compared to the actual placement recommendations by the Single Entry Panel, who only had 2 choices; SC or NH.

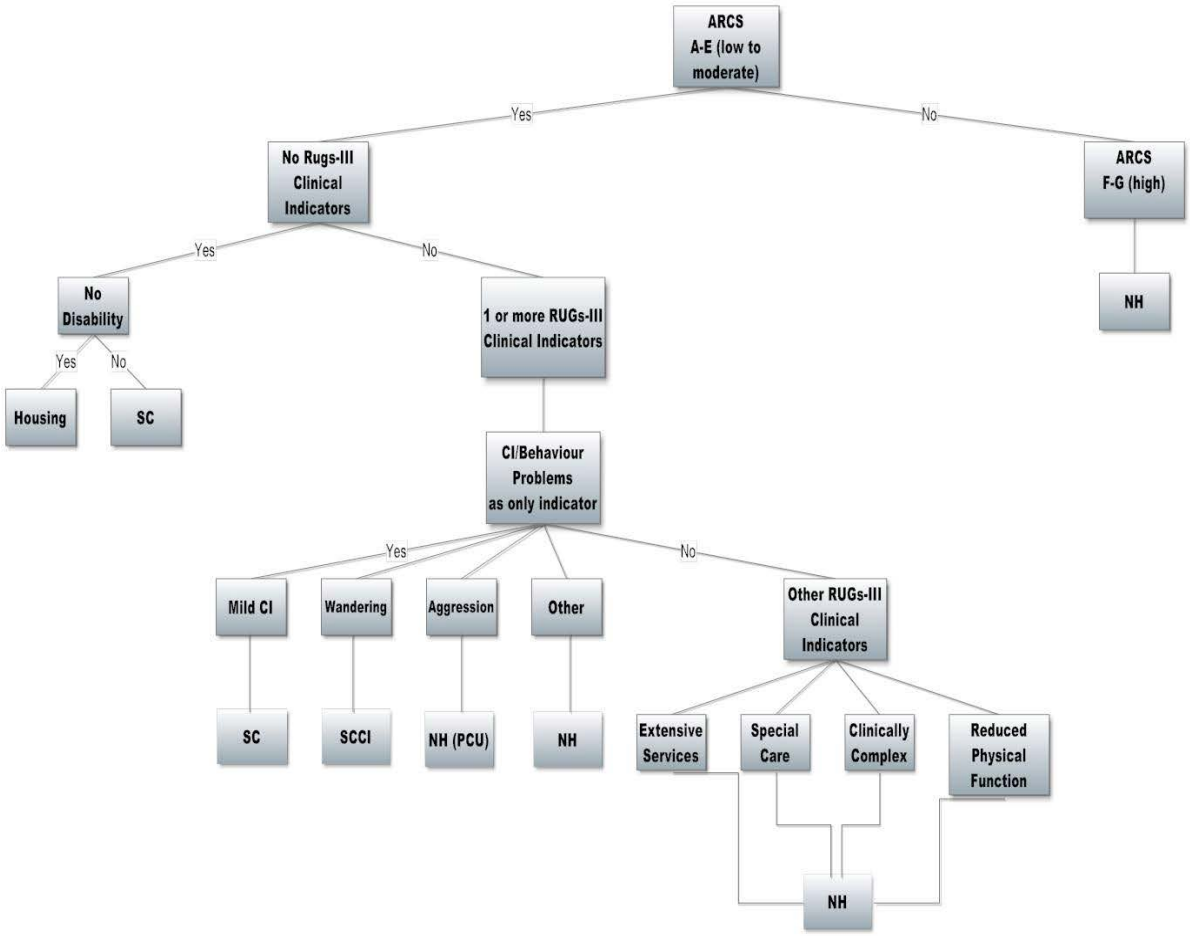

Figure 3.4- The decision tree to determine optimal long-term placement.

3.5 Bed and Incidence Rates.

The number of PCH and NH beds in the region were obtained from the SES. The number of people aged ≥ 65 years by year within the region was identified. The number of beds available was determined per 1000 people ≥ 65. The annual incidence rate of clients by disability and by placement decision was calculated per 1000 people ≥ 65 in the region, with a correction made for the missing clients for whom no data was available.

3.6 Data Analysis

3.6.1 Cohorts. All data analysis was completed with the Statistical Package for Social Sciences (SPSS) version 19. Comparisons of cohorts were made using independent sample, 2-tailed t-tests for continuous variables and chi-squared tests for categorical variables. A p-value less than 0.05 was taken to indicate statistical significance.

3.6.2 Time to Placement and Survival. In each of the 3 cohorts the outcome of each client was obtained from the chart or from the institution to which the client was referred. Kaplan-Meier survival analysis was used and cohorts were compared using the log-rank test for time to placement and survival. Life expectancy following placement was calculated as mean and median time to death following the decision of the single entry panel. Time to placement was calculated as the median time to placement following the decision of the single-entry panel. Independent predictors of survival were identified and their contributions quantitated using Cox Regression analysis. All demographic and disability variables were analyzed by univariate analysis and only variables that were significant at a level less than 0.05 were entered into the multivariate analysis. The assumptions of the Cox proportional hazard model were tested and met.

3.6.3 Prediction of Need. For the 3 time periods studied, predictions of bed need in 2014 were made using incidence rates at the time of study defined by degree of disability, expected survival by optimal placement using the decision tree and predicted number of people aged ≥ 65 years in 2014. Predictions of the number of people aged ≥ 65 years likely to live in the region in 2014 were made from the censuses of 1995, 2000 and 2006 issued by the government of NL.

3.6.4 Prediction of Survival. Survival was estimated by the Kaplan-Meier method and differences in survival between groups were assessed by the log-rank test. Univariate and multivariate Cox proportional-hazards models were used to determine the significance of these variables. To develop a prognostic score, we assigned the risk factors identified by multivariate analysis, weighted points proportional to the β regression coefficient values (rounded to the nearest integer) in a Developmental Cohort (N=405). The Developmental Cohort was randomly selected from the combined cohorts of 1995/6 and 2005/6 (N=907) using IBM SPSS Statistics Software. Approximately fifty percent were chosen. A risk score was then calculated (range: -2-8) for each client, and the population was divided into three categories: low-risk (-2-2), intermediate-risk (3-5), and high-risk (6-8) for death.

The remaining clients were used for the Validation Cohort (N=457). For both the developmental and the validation cohorts, Kaplan Meier survival curves for patients in the three risk groups were generated to illustrate the partitioning of the risk of death. The predictive accuracy of the scoring system was examined by using discrimination and calibration methods. Discrimination of the model was assessed by calculating the AUROC of the developmental and validation cohorts. Calibration of the model was assessed by comparing the probability of survival within 6 months and 1 year periods, calculated as (P_{low}-P_{high}) where P_{low} is the predicted

probability of survival for a client in the low-risk group and P_{high} is the corresponding value for a client in the high-risk group.

3.7 Key Stakeholder Interviews

To determine current LTC issues and future plans in NL and other jurisdictions across Canada, interviews were conducted by the author and Dr. Patrick Parfrey, with key stakeholders working in LTC. The questionnaire was constructed by the author and Dr. Patrick Parfrey, a research professor at Memorial University. It was then edited by Dr. Victor Maddalena, an assistant professor in health policy and health service delivery and Dr. Brendan Barrett, a professor of medicine at Memorial University (Appendix B). The questions were designed to be open-ended so that those answering them could express facts and personal opinions on the matter being addressed. A total of 10 questions were asked that covered topics of the structure and budget allocation, future needs and pressures, whether there were past or ongoing pilot studies or interventions, who are the most vulnerable population, urban-rural divides and finally possible solutions to some LTC issues such as a public LTC insurance plan and integrated care. Stakeholders in NL and across the country were chosen from a contact list provided by the Health Council of Canada. The list contained one key contact in long-term care from each province and territory across the country. Contacts were selected by provinces that had similar geographic area and population to Newfoundland and Labrador (Nova Scotia, Manitoba and Saskatchewan). Each stakeholder was emailed the questionnaire in advance and was given the option to complete a recorded interview via telephone or in person or to simply complete the questionnaire and return it. To analyze the results common themes were compared across jurisdictions from the answered questionnaires by the author. Verbatim quotes were not used because outside provinces emailed responses in short answer.

3.8 Ethics

The Human Investigations Committee of Memorial University of Newfoundland (MUN) approved the study protocol (Reference # 10.67). The client's informed consent was not necessary because data was collected through chart abstractions. Each client was given a study number for database entry and confidentiality was maintained by not using names on any documents or reports. Access to the extraction forms used in this study was confined to individuals involved in the study.

For the interview section of this document, all appropriate measures were taken to ensure confidentiality of participants. The list of stakeholders was provided by the Health Council of Canada and because interviewees responded as requested, no consent was necessary. No names of the interviewee's were revealed in this document. All information, including written and recorded interviews in this study was safely stored on a secure computer at the Patient Research Center in the Health Sciences Center.

Chapter 4 Results: Cohort Studies

4.1 Introduction

The cohort results consist of data from three incident cohorts (1995/6, 1999/00 and 2005/6) of clients presenting to institutional LTC in the St. John's region. A total of 1379 clients met the inclusion criteria and were analyzed. The purpose of this chapter was to report on information collected and changes that have occurred over a 10 year period in: demographics and disability, bed numbers and need, efficiency and appropriateness of placement, and survival time and predictors.

4.2 Characteristics of 3 Incident Cohorts

In the St. John's region, 1379 clients were studied in the three annual incident cohorts (1995/6 N=357, 1999/00 N=403, and 2005/6 N=619). The average age of clients presenting to the SES was 81 ± 9.8 years and 67% were female. 46.7% of clients resided in the community, with 33.9% coming from an acute care setting, 7.7% from chronic care, and 11.7% through transition, rehabilitation or the Dr. Leonard A. Miller Centre. When defined by RUGs-III clinical indicators, 35% had none, 24% had reduced physical function, 23% had indications of cognitive impairment and/or behavior problems, 15% were clinically complex and, 3% needed special care. Forty-eight percent had low level ARC scores (A-B), with 32%, and 23% having moderate level (C-E) and high level (F-G) scores respectively. Seven percent were independent for ADLs, continent and had no cognitive impairment (Table 4.1).

Comparison by annual incident cohort revealed no differences in age, gender or degree of disability classified by RUGs-III or by ARC scores. However, from 1995 to 2006, there was a decrease in the proportion of clients that had cognitive impairment or behavior problems as the

major reason for placement (28% vs. 20%, p=0.005) and an increase in those with reduced physical function as the major reason from placement (19% vs. 30% p=0.000).

Eighty-nine of the clients were under the age of 65 years and not included in predicting mortality. The average age of the clients under 65 was 56.0 ± 7.9 years and 58% were male. Twenty-eight percent of clients resided in the community, with 45% coming from an acute care setting. When defined by RUGs-III clinical indicators, 24.7% had none, 23.6% had reduced physical function, 15.7% had indicators of cognitive impairment and/or behavior problems, 27% were clinically complex and 9% needed special care. Thirty-eight percent had low level ARC scores (A-B) with 27% and 35% having moderate (C-E) and high level (F-G) scores respectively (Table 4.2).

Table 4.1 - Demographic and clinical characteristics of clients seeking long-term care in the St. John's region during 1995/6, 1999/00, and 2005/6.

	St. John's 95/96 N=357		St. John's 00/01 N=403		St. John's 05/06 N=619		Total N=1379	
Mean Age ± SD	81 ± 9.6		81 ± 9.8		80 ± 10.0		**81 ± 9.8**	
	N	%	N	%	N	%	N	%
<65 years	22	6.2	20	5.0	47	7.6	89	6.5
Female	224	62.7	268	66.5	426	68.8	918	66.6
Location at Application: Community	179	50.1	181	44.9	284	45.9	644	46.7
Acute Care	120	33.6	158	39.2	189	30.5	467	33.9
Chronic Care	21	5.9	29	7.2	56	9.0	106	7.7
Transition, Rehab, LAMC	37	10.4	35	8.7	90	14.5	162	11.7
RUGs III Clinical Indicators: Special Care*	10	2.8	16	4.0	21	3.4	47	3.4
Clinically Complex	50	14.0	79	19.6	74	12.0	203	14.7
Cognitive Impairment Behavior Problems	100	28.0	86	21.3	125	20.2	311	22.6
Reduced Physical Function	67	18.8	78	19.4	188	30.4	333	24.1
No Clinical Indicators (RUGs -)	130	36.4	144	35.7	211	34.1	485	35.2
Alberta Resident Classification Score: Low Level (A-B)	153	42.9	181	44.9	283	45.7	617	44.7
Moderate Level (C-E)	127	35.6	128	31.8	192	31.6	447	32.4
High Level (F-G)	77	21.6	94	23.3	144	23.3	315	22.8
Clients with low ARCS (A-B) and no RUGs Clinical Indicators	105	29.4	123	30.5	199	32.1	427	31.0
Independent for ADL's Continent and no CI	17	4.8	28	6.9	49	7.9	94	6.8

This includes special rehabilitation, extensive services and special care.
LAMC: Dr. Leonard A. Miller Centre
ADL: Activities of daily living
CI: Cognitive impairment

Table 4.2-Demogrpahics/Clinical characteristics of clients seeking long-term care in the St. John's region during 1995/6, 1999/00, and 2005/6 aged < 65 years

Variables	**< 65 years N=89**
	Mean ± SD
Age	56.0 ± 7.9
	N (%)
Female	37 (41.6)
Placement:	
Supervised Care	27 (30.3)
Nursing Home	62 (69.7)
Location :	
Community/Chronic	34 (38.2)
Acute Care	40 (44.9)
Transition	15 (16.9)
RUGs-III Primary Indicator:	
Special Care	8 (9.0)
Clinically Complex	24 (27.0)
Reduced Physical Function	21 (23.6)
Impaired Cognition/Behavior Problems	14 (15.7)
No Indicators	22 (24.7)
ARCS:	
Low	34 (38.2)
Moderate	24 (27.0)
High	31 (34.8)
Functional Needs Score	
0	2 (2.2)
1	12 (13.5)
2	9 (10.1)
3	6 (6.7)
4	7 (7.9)
5	53 (59.6)
RUGs ADL Score	
(0-4)	23 (25.8)
(5-6)	8 (9.0)
(7-9)	15 (16.8)
(10-13)	22 (24.7)
(14-20)	2 (23.6)

4.3 Bed and Client Incidence Rates

The results in this section show changes in incidence rates over a 10-year period (1996-2006). It includes rates in bed, client, client by panel placement, and disability rates in institutional LTC in the St. John's region.

4.3.1 Bed and Incidence Rates by Placement. Table 4.3 summarizes the rate of beds per 1000 ≥ 65 years and annual rate of clients per 1000 ≥ 65 years recommended for SC and NH by the assessment panel. From 1995-2006 the number of SC beds increased by 144% from 334 to 815, while the number of NH beds decreased by 6% from 1,048 to 987. The number of SC beds per 1000 ≥ 65 years increased from 19.6 to 41. However, the number of NH beds per 1000 ≥ 65 years decreased by 19% from 61.4 to 49.6.

The number of clients placed in SC per annum increased by 145% (from 84 in 1995/6 to 206 in 2005/6) and by 46% in NH from (251 in 1995/6 to 366 in 2005/6). Factoring out the growth in population, the placement rate per 1000 aged ≥ 65 increased by 106% over 10 years (from 5.4 to 11.1) for SC, and by 22% for NH (from 16.2 to 19.7). The total incidence rate of clients seeking institutional LTC increased by 42% from 21.7 per 1000 population ≥ 65 years per year in 1995/6 to 30.8 in 2005/6.

Table 4.3-Supervised care and nursing home prevalent bed rates and annual incidence rates of clients placed

	1995/1996	2005/2006
Population ≥ 65 years	17,075	19,891
Number of SC Beds **Rate of SC Beds/1000 ≥ 65 years**	334 19.6	815 41.0
Number of SC Clients **Rate of SC Clients/1000 ≥ 65 years ***	84 5.4	206 11.1
Number of NH Beds **Rate of NH Beds/1000 ≥ 65 years**	1,048 61.4	987 49.6
Number of NH Clients **Rate of NH Clients/1000 ≥ 65 years***	251 16.2	366 19.7

*Population rate per 1,000 people ≥ 65 years, adjusted for those for whom no data was available
Note: In 1998 the geographic area of the St. John's region expanded

4.3.2 Incidence Rates by Disability. Table 4.4 summarizes the proportions and annual rates per 1000 ≥ 65 years by demographic factors and by clinical characteristics/disability of clients seeking institutional placement in LTC (in 1995/6 & 2005/6). The mean age was 82 years in both cohorts. A higher proportion was female in more recent years (64.5% in 1995/6 and 70.6% in 2005/6). Comparison of cohorts revealed no difference in proportions by disability except those who had cognitive impairment and reduced physical function. For the primary RUGs-III indicator there was a decrease in proportion of those with cognitive impairment (28.4% vs. 20.6%, $p < 0.05$) and an increase in those with reduced physical function (19.4% vs. 30.2%, $p < 0.05$). However for RUGs-III indicators present, impaired cognition was present in a higher proportion (42.1% vs. 29.9%, $p < 0.001$) as was reduced physical function when comparing 2005/6 to 1995/6 (38.8% vs. 29.3%, $p < 0.01$). Annual incidence rates increased across all levels when defined by demographic factors and disability. There was a 79% increase in incidence for those presenting to the SES aged 65-74 years (from 2.8 to 5.0/1000 ≥ 65 years) and a 105% increase in those coming from transition or rehab (from 2.2 to 4.5/1000 ≥ 65 years). Incidence rates increased across all levels of disability but the biggest increase came from those with cognitive impairment (109%, 6.4 to 13.4/1000 ≥ 65 years), those with reduced physical function (95%, 6.3 to 12.3/1000 ≥ 65 years), and in low levels of disability scores.

Table 4.4-Demographic and Clinical characteristics of clients seeking placement in institutional long-term care and rates /1000 population ≥ 65 years seeking placement in the St. John's region

Variables	1995/6 Total N=335	Disability Rates per 1000 ≥ 65	2005/6 Total N=572	Disability Rates per 1000 ≥ 65	% Change in Rates
Age in years (mean, SD)	82.3 ± 6.9		82.4 ± 7.4		
Age Group:					
65-74 years	43 (12.8)	2.8	92 (16.1)	5.0	79
75-84 years	161 (48.1)	10.4	250 (43.7)	13.8	33
>85 years	131 (39.1)	8.4	230 (40.2)	12.7	51
Female	216 (64.5)	13.9	404 (70.6)	21.9	58
Location :					
Community/Chronic	193 (57.6)	12.4	319 (55.8)	17.7	43
Acute Care	108 (32.2)	7.0	171 (29.9)	9.4	19
Transition	34 (10.1)	2.2	82 (14.3)	4.5	105
RUGs-III Primary Indicator:			*		
Special Care	9 (2.7)	0.6	15 (2.6)	0.9	50
Clinically Complex	43 (12.8)	2.8	64 (11.2)	3.6	29
Impaired Cognition	95 (28.4)	6.1	118 (20.6)	6.6	8
Reduced Physical Function	65 (19.4)	4.2	173 (30.2)	9.6	129
No Indicators	123 (36.7)	7.9	202 (35.3)	11.2	42
RUGs-III Indicators Present:					
Special Care (yes)	9 (2.7)	0.6	15 (2.6)	0.9	50
Clinically Complex	47 (14.0)	3.1	67 (11.7)	3.7	19
Impaired Cognition	100 (29.9)	6.4	241 (42.1)***	13.4	109
Reduced Physical Function	98 (29.3)	6.3	222 (38.8)**	12.3	95
No Indicators	123 (36.7)	7.9	202 (35.3)	11.2	42
ARCS:					
Low	146 (43.6)	9.4	265 (46.3)	14.7	56
Moderate	117 (34.9)	7.6	185 (32.3)	10.2	34
High	72 (21.5)	4.6	122 (21.3)	6.7	46
Functional Needs Score:			*		
0	7 (2.1)	0.5	23 (4.0)	1.3	160
1	23 (6.9)	1.5	59 (10.3)	3.3	120
2	30 (9.0)	1.9	58 (10.1)	3.2	168
3	66 (19.7)	4.3	81 (14.2)	4.4	2
4	32 (9.6)	2.1	31 (5.4)	1.8	-14
5	177 (52.8)	11.3	320 (55.9)	17.7	57
RUGs ADL Score:			***		
(0-4)	112 (33.4)	7.2	189 (33.0)	10.4	44
(5-6)	40 (11.9)	2.6	99 (17.3)	5.4	108
(7-9)	67 (20.0)	4.3	52 (9.1)	2.9	-33
(10-13)	47 (14.0)	3.0	104 (18.2)	5.8	93
(14-20)	69 (20.6)	4.4	128 (22.4)	7.1	61

*p<0.05;**p<0.01;***p<0.001

4.3.3 Incidence Rates and Disability by Placement. Table 4.5 summarizes the incidence rates of clients and proportion with low level disability by placement to indicate appropriateness of placement for each cohort. The incidence rates of clients recommended for SC increased by 106% from 1995-2006, from 5.4 to 11.1/1000 ≥ 65 years. Percentage of SC care clients with low level resource requirement (A-B, ARC scores) increased from 91.7% to 100% (p=0.00) in 2006, and the proportion of clients without RUGs-III indicators decreased from 85.7% to 82.5% (p=0.00).

The incidence rate of clients recommended for NH care increased by 22%, from 16.1 in 95/6 to 19.6/1000 ≥ 65 years in 2005/6. Percentage of these clients with low-level resource utilization (A-B, ARC scores) decreased from 27.5% to 16.1% (p=0.490) in 2006, and those with no RUGs-III clinical indicators decreased from 20.3% to 8.7% (p=0.018).

Table 4.5- Incidence rates, degree of disability in clients recommended for supervised care (SC) and nursing home (NH) by the Single-Entry System

	95/96	**99/00**	**05/06**
Population ≥ 65 years	17,075	18,280	19,891
Placed in Supervised Care			
Number of SC Clients	84	104	206
Rate of SC Clients*	5.4	6.1	11.1
% of Clients with low disability +	91.7	98.1	100
% Without RUG's III Indicators	85.7	84.6	82.5
Placed in Nursing Homes			
Number of NH Clients	251	279	366
Rate of NH Clients*	16.1	16.4	19.6
% of Clients with low disability +	27.5	25.1	16.1
% Without RUG's III Indicators	20.3	17.9	8.7

***Rate per 1000 ≥ 65 years adjusted for missing cases**
+ Alberta resident classification score A or B

4.4 Placement

The results of this section show changes in appropriateness of placement and time to placement in institutional LTC in the St. John's region. In addition, optimal placement determined by the decision tree is provided.

4.4.1 Appropriateness of Placement. Table 4.6 summarizes the demographic factors and clinical characteristics/disability of clients seeking institutional placement in LTC by panel placement decision (SC or NH) in both cohorts (1995/6 & 2005/6). Compared to 1995/6 appropriateness of placement was better in 2005/6 in that only 8.7% of clients recommended for placement in a NH had no clinical indicators for NH compared to 20.3% in 1995/6, and all clients recommended for placement in SC had low ARC scores compared to 91.7% in 1995/6.

Table 4.6 Demographics/Clinical variables of clients placed in supervised care and nursing homes

Variables	1995/6 SC N=84	2005/6 SC N=206	p	1995/6 NH N=251	2005/6 NH N=366	p
Age (years)	81.8 ± 7.0	82.9 ± 6.9	NS	82.5 ± 6.9	82.2 ± 7.6	NS
Age Group:						
65-74 years	14 (16.7)	26 (12.6)	NS	29 (11.6)	66 (18.0)	.030
75-84 years	37 (44.0)	102 (49.5)		124 (49.4)	148 (40.6)	
>85 years	33 (39.3)	78 (37.9)		98 (39.0)	152 (41.5)	
Female	52 (61.9)	145 (70.4)	NS	164 (65.3)	259 (70.8)	NS
Location :						
Community/Chronic	64 (76.2)	153 (74.3)	NS	129 (51.4)	166 (45.4)	.029
Acute Care	17 (20.2)	46 (22.3)		91 (36.3)	125 (34.2)	
Transition	3 (3.6)	7 (3.4)		31 (12.4)	75 (20.5)	
RUGs-III Primary Indicator:			NS			.000
Special Care	- (-)	1 (0.5)		9 (3.6)	14 (3.8)	
Clinically Complex	1 (1.2)	16 (7.8)		42 (16.7)	48 (13.1)	
Impaired Cognition	11 (13.1)	19 (9.2)		84 (33.5)	99 (27.0)	
Reduced Physical Function	- (-)	- (-)		65 (25.9)	173 (47.3)	
No Indicators	72 (85.7)	170 (82.5)		51 (20.3)	32 (8.7)	
RUGs-III Indicators Present:						
Special Care (yes)	- (-)	1 (0.5)	NS	9 (3.6)	14 (3.8)	.000
Clinically Complex	1 (1.2)	16 (7.8)	.029	46 (18.3)	51 (13.9)	NS
Impaired Cognition	11 (13.1)	19 (9.2)	NS	89 (35.5)	222 (60.7)	.000
Reduced Physical Function	- (-)	- (-)	NS	98 (39.0)	222 (60.7)	.000
No Indicators	72 (85.7)	170 (82.5)	NS	51 (20.3)	32 (8.7)	.000
ARC Score:						
Low	77 (91.7)	206 (100.0)	.000	69 (27.5)	59 (16.1)	.003
Moderate	7 (8.3)	- (-)		110 (43.8)	185 (50.5)	
High	- (-)	- (-)		72 (28.7)	122 (33.3)	
Functional Needs Score:						
0	7 (8.3)	23 (11.2)	NS	- (-)	- (-)	.000
1	21 (25.0)	59 (28.6)		2 (0.8)	- (-)	
2	20 (23.8)	55 (26.7)		10 (4.0)	3 (0.8)	
3	31 (36.9)	46 (22.3)		35 (13.9)	35 (9.6)	
4	3 (3.6)	10 (4.9)		29 (11.6)	21 (5.7)	
5	2 (2.4)	13 (6.3)		175 (69.6)	307 (83.9)	
RUGs ADL Score						
(0-4)	72 (85.7)	161 (78.2)	NS	40 (15.9)	28 (7.7)	.000
(5-6)	9 (10.7)	37 (18.0)		31 (12.4)	62 (16.9)	
(7-9)	3 (3.6)	7 (3.4)		64 (25.5)	45 (12.3)	
(10-13)	- (-)	- (-)		47 (18.7)	104 (28.4)	
(14-20)	- (-)	1 (0.5)		69 (27.5)	127 (34.7)	

*p<0.05;**p<0.01;***p<0.001
NS=not significant

4.4.2 Time to Placement. Over a ten year period, time to placement improved for SC with a median time of 3.7 weeks (95% CI 0.0-7.8) in 1995/6 compared to 1.0 week in 2005/6 (95% CI 0.7-1.3) (P=0.000). By week 1, 45.6% of clients recommended for SC were placed in 2005/6 compared to only 29.8% in 1995/6 (Figure 4.1). Time to placement in NH also improved with a median time of 10.9 weeks (95% CI 9.2-12.5) in 1995/6 compared to 6.0 weeks in 2005/6 (95% CI 5.0-7.0) (p=0.021). By week 4, 41% of clients in NH were placed in 2005/6 compared to 21% in 1995/6 (Figure 4.2).

Time to placement for clients coming from community and chronic locations improved with a median time of 11.0 weeks (95% CI 7.3-14.7) in 1995/6 compared to 2.6 weeks in 2005/6 (95% CI 1.6-3.6) (P=0.000) (Figure 4.3). For clients coming from acute care, time to placement improved from 8.9 weeks (95% CI 6.4-11.3) in 1995/6 to 4.0 weeks in 2005/6 (95% CI 2.3-5.7) (P=0.001) (Figure 4.4). Finally those clients coming from either a transitional and/or rehab bed, time to placement improved from 10.0 weeks (95% CI 4.8-15.2) in 1995/6 to 5.9 weeks in 2005/6 (95% CI 4.5-7.3), however it was not statistically significant (P=.363) (Figure 4.5).

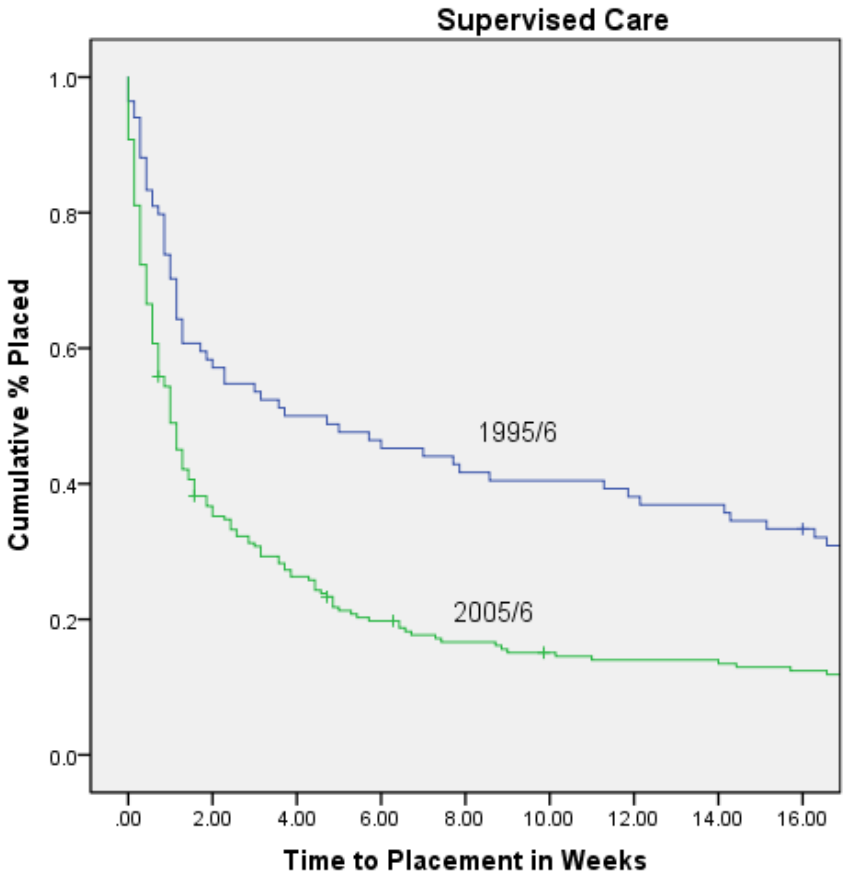

Fig 4.1- Cumulative % placed in supervised care over time in 1995/6 and 2005/6

Legend 4.1- Cumulative % placed in supervised care by week and median time to placement

Cohort	Events	1	2	4	8	12	16	Median Time (95% CI)	P-Value
1995/1996	N=75	29.8	42.9	50.0	58.3	61.9	66.7	3.7 (0.0-7.8)	.000
2005/2006	N=197	45.6	64.8	73.7	83.4	86.0	87.6	1.0 (0.7-1.3)	

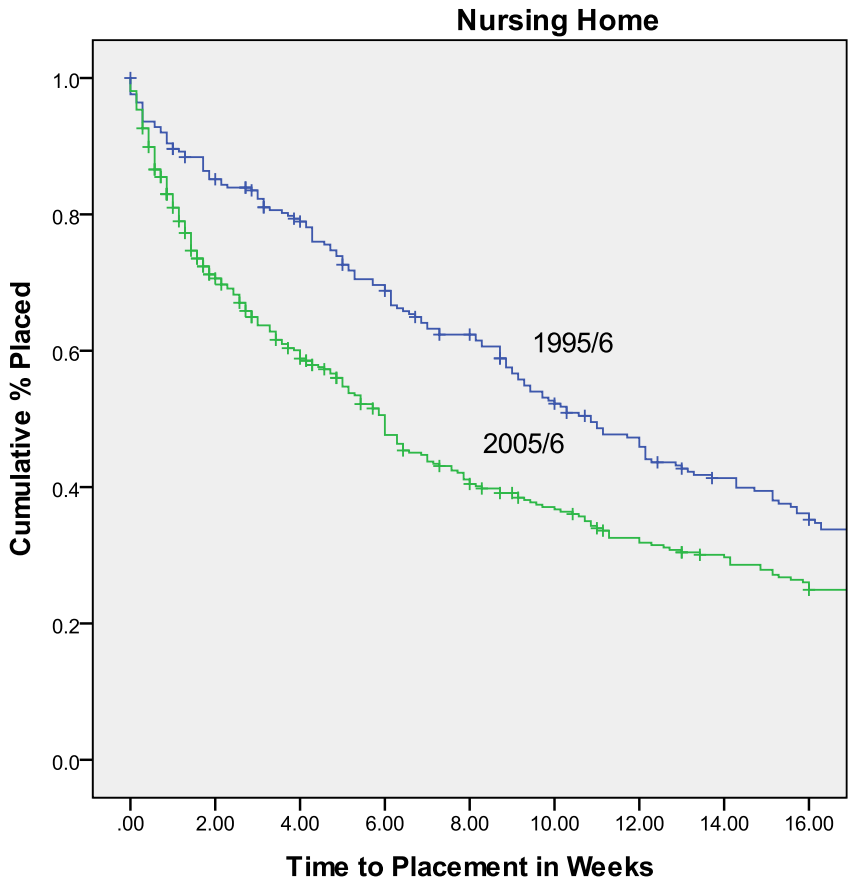

Fig 4.2- Cumulative % placed in nursing homes over time in 1995/6 and 2005/6

Legend 4.2-Cumulative % placed in nursing homes by week and median time to placement

Cohort	Events	1	2	4	8	12	16	Median Time (95% CI)	P-Value
1995/1996	N=213	10.4	14.8	21.1	37.6	54.1	64.8	10.9 (9.2-12.5)	.021
2005/2006	N=297	19.0	29.4	41.2	59.5	68.2	75.1	6.0 (5.0-7.0)	

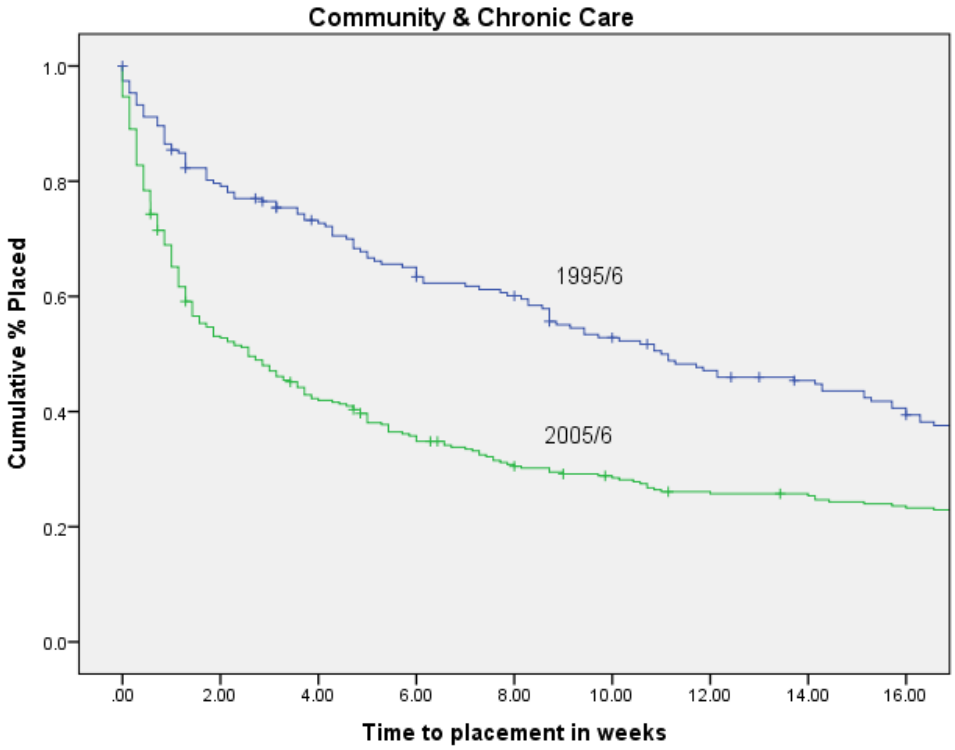

Fig 4.3- Cumulative % placed coming from community/chronic care over time in 1995/6 and 2005/6

Legend 4.3-Cumulative % placed coming from community/chronic in weeks and median time to placement

Cohort	Events	1	2	4	8	12	16	Median Time (95% CI)	P-Value
1995/1996	N=162	14.6	20.9	27.3	39.9	52.9	59.4	11.0 (7.3-14.7)	.000
2005/2006	N=291	31.1	47.2	57.1	69.5	74.3	76.7	2.6 (1.6-3.6)	

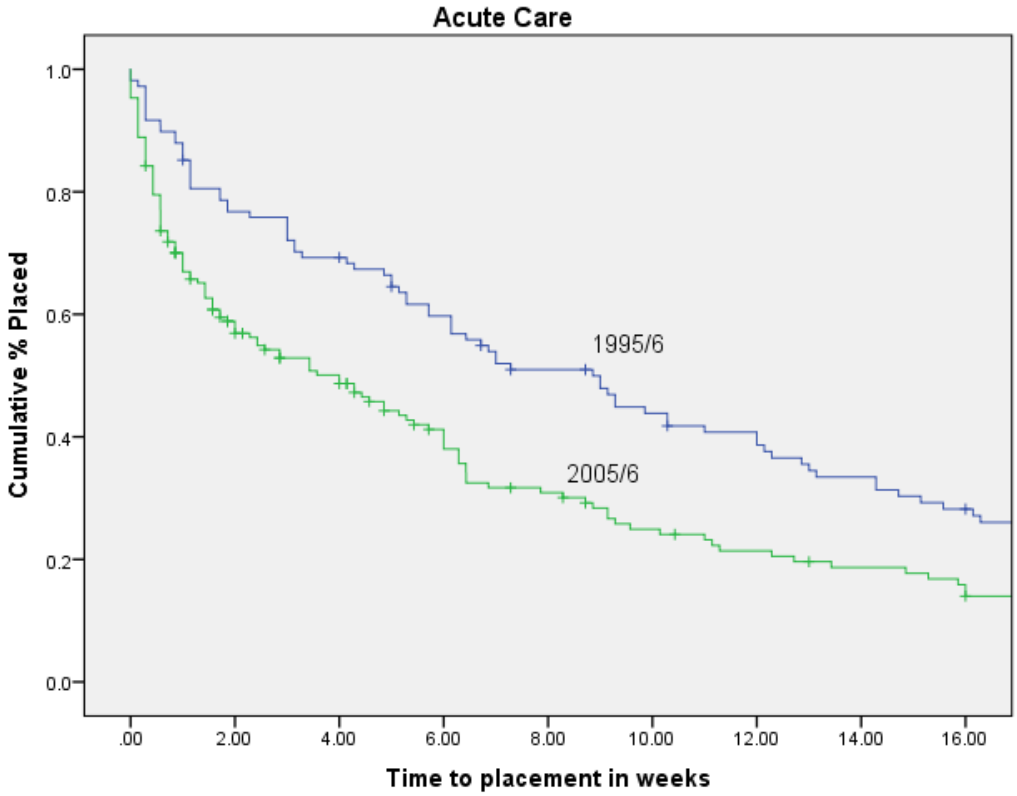

Fig 4.4- Cumulative % placed coming from acute care over time in 1995/6 and 2005/6

Legend 4.4-Cumulative % placed coming from acute care in weeks and median time to placement

Cohort	Events	1	2	4	8	12	16	Median Time (95% CI)	P-Value
1995/1996	N=94	12.0	23.2	30.7	49.0	61.3	71.8	8.9 (6.4-11.3)	.001
2005/2006	N=138	30.0	43.1	51.3	69.1	78.6	86.0	4.0 (2.3-5.7)	

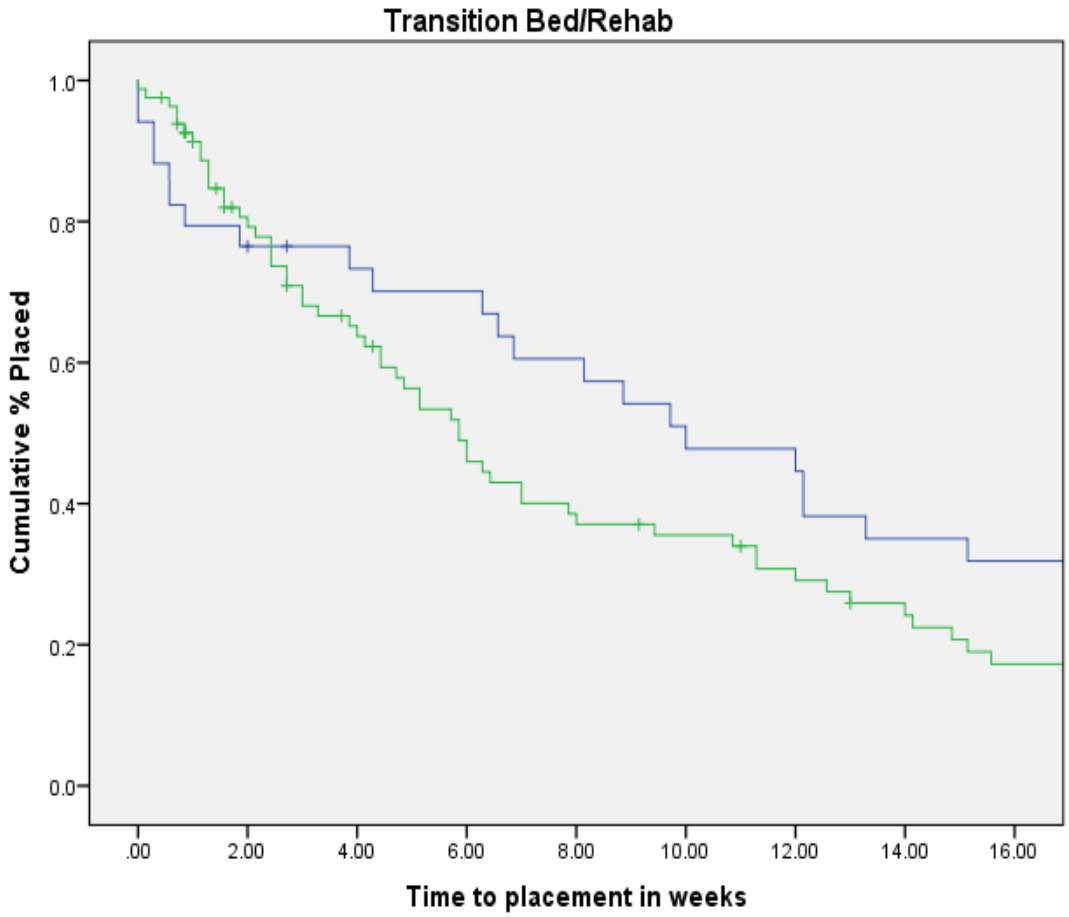

Fig 4.5- Cumulative % placed coming from transition over time in 1995/6 and 2005/6

Legend 4.5-Cumulative % placed coming from transition in weeks and median time to placement

Cohort	Events	1	2	4	8	12	16	Median Time (95% CI)	P-Value
1995/1996	N=32	20.6	23.5	26.7	39.5	55.4	68.1	10.0 (4.8-15.2)	.363
2005/2006	N=65	8.7	20.8	36.3	62.9	70.9	82.7	5.9 (4.5-7.3)	

4.3.3 Optimal Placement. Table 4.7 summarizes the incidence rates and proportions of clients presenting to LTC by optimal placement in the 3 cohorts. Using the decision tree (Fig 3.4), the optimal placement for LTC for each client was determined. In 1995/6 44.8% of clients presenting to the SES needed NH care, 36.1% SC, 14.3% SC for the cognitively impaired, and 4.8% AH for clients with no disability. When comparing the 3 cohorts it was found that: (a) proportion who required AH increased from 4.8% in 1995/6 to 8.2% in 2005/6, (b) proportion who needed SC fell from 36.1% to 34.1%, (c) proportion who needed SC for the cognitively impaired was similar in 1995/6 and 2005/6, (d) proportion who needed NH care was stable at 45% (p=0.259). However, the incidence rates for each option increased substantially: AH increased from 1.1 to 2.5/1000 people $\geq$ 65 years, SC 7.8 to 10.5, SC for the cognitively impaired 3.1 to 4.1 and NH increased from 9.7 to 13.6/1000 population $\geq$ 65 years, respectively.

Table 4.7-Annual incidence rates per 1000 population ≥ 65 years in the St. John's region by optimal placement

LTC Option	95/96			99/00			05/06		
	Rate*	N	%	Rate*	N	%	Rate*	N	%
Appropriate Housing	1.1	16	4.8	1.5	26	6.8	2.5	47	8.2
Supervised Care	7.8	121	36.1	9.0	153	39.9	10.5	195	34.1
Supervised Care for Cognitively Impaired	3.1	48	14.3	2.2	38	9.9	4.1	76	13.3
Nursing Home	9.7	150	44.8	9.7	166	43.3	13.6	254	44.4

*Rate per 1000 population ≥ 65 years adjusted for missing cases

4.5 Survival

Survival outcomes were obtained for clients over the age of 65 in the 1995/6 and 2005/6 cohorts. Figure 4.6, 4.7 and 4.8 summarizes the survival from date assessed in the overall cohorts, SC, and NH. Median survival following assessment was significantly longer in 2005/6 than in 1995/6 (37.7 vs 27.6 months; p=0.003). Within 3 years of panel assessment, 60% of clients in 1995/6 had died compared to 48.5% in 2005/6. The major difference was among those referred to SC. Median survival in 2005/6 in SC was 45.6 months compared to 38.5 months in 1995/6 (p=0.059). By 3 years 46.4% of clients in 1995/6 had died compared to 28.7% in 2005/6. There was no difference in age at placement for those placed in SC between the two cohorts (Table 4.6). Clients recommended for NH showed no difference. Median time to death in 1995/6 was 24.4 months compared to 24.5 months in 2005/6 and by 3 years 64.2% were dead in 1995/6 compared to 59.7% in 2005/6.

Table 4.8 summarizes the hazard ratios associated with different potential risk factors for survival using univariate Cox Regression analysis. Notable significant variables were: RUGs-III primary indicator, Special Care (HR 2.46 95%CI= 1.47-4.14), Clinically Complex (HR 2.51 95%CI=1.90-3.33), and Reduced Physical Function (HR 2.68 95%CI=2.14-3.36) when compared to no indicators; High disability scores such as a high ARCS (HR 2.51 95%CI=2.02-3.12) when compared to a low score and a high RUGs ADL Score (14-20) when compared to a low score (0-4) (HR 2.51 95%CI= 2.02-3.12).

Table 4.9 summarizes the variables that were statistically significant in the multivariable model. Independent of age, sex, RUGs-III as a primary indicator, functional needs score, survival in the 2005/6 cohort was significantly better than the 1995/6 cohort.

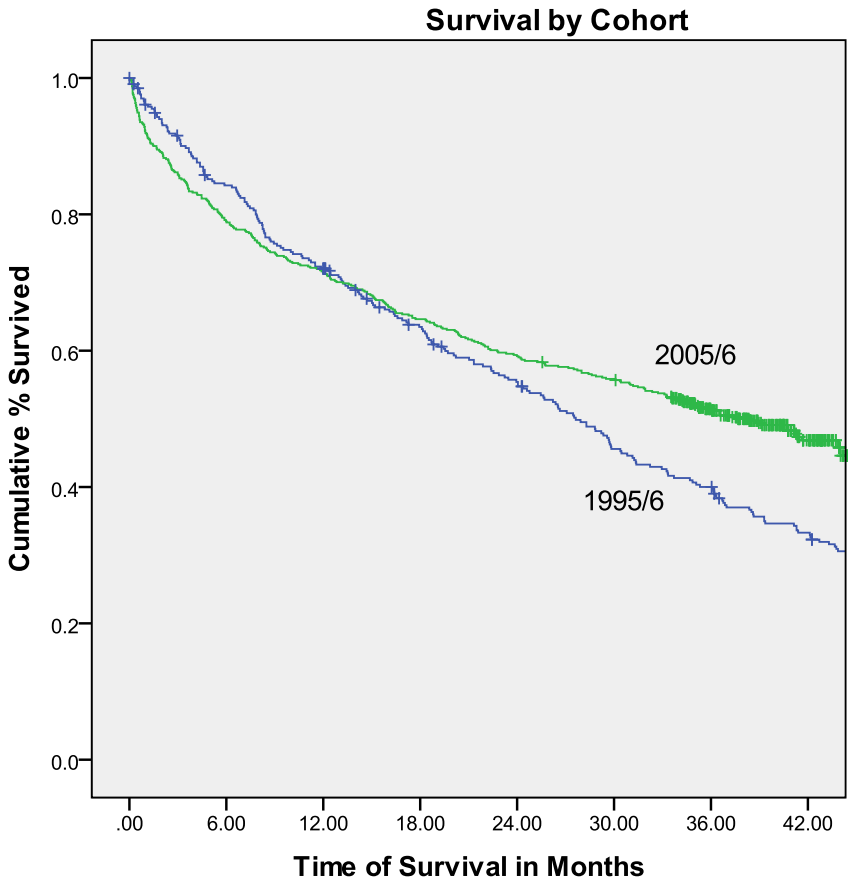

Fig 4.6- Cumulative % of survival in 1995/6 and 2005/6

Legend 4.6-Cumulative % of survival by month and median time to placement in 1995/6 and 2005/6

Cohort	Events	12	24	36	Median Time (95% CI)	P-Value
1995/1996	238	28.0	44.6	60	27.6 (24.2-31.0)	.003
2005/2006	293	28.5	40.8	48.5	37.7 (32.5-42.8)	

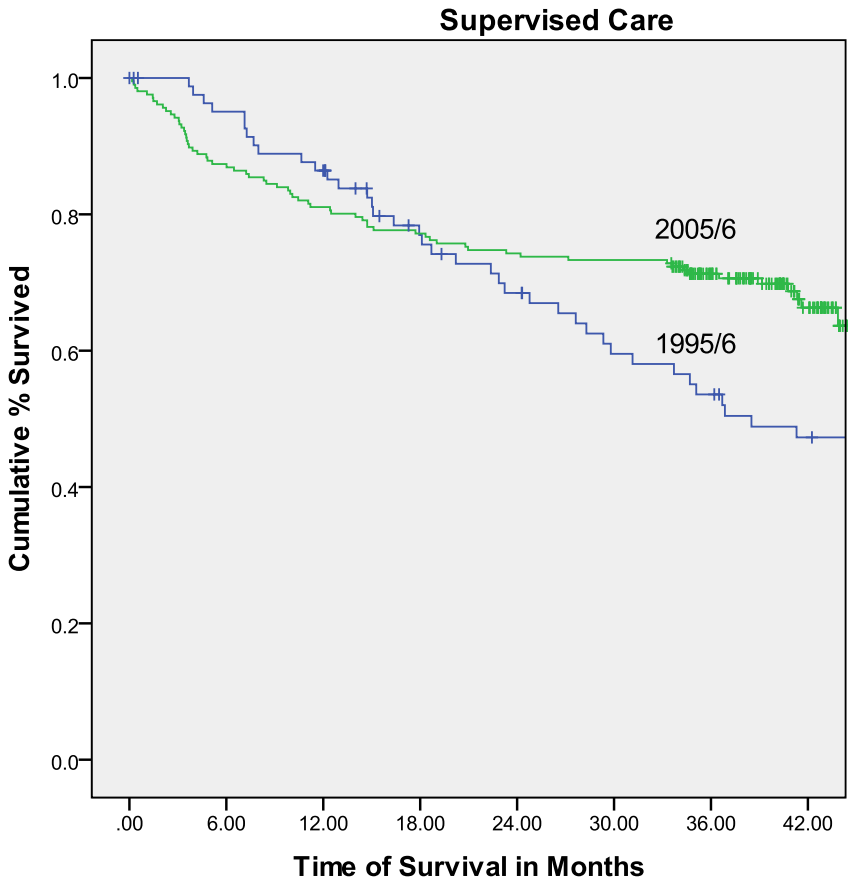

Fig 4.7- Cumulative % of survival in supervised care 1995/6 and 2005/6

Legend 4.7-Cumulative % of survival in supervised care by month and median time to placement in 1995/6 and 2005/6

Cohort	Events	12	24	36	Median Time (95% CI)	P-Value
1995/1996	N=45	13.6	31.5	46.4	38.5 (24.6-52.4)	.059
2005/2006	N=66	18.9	25.7	28.7	45.6 (-)	

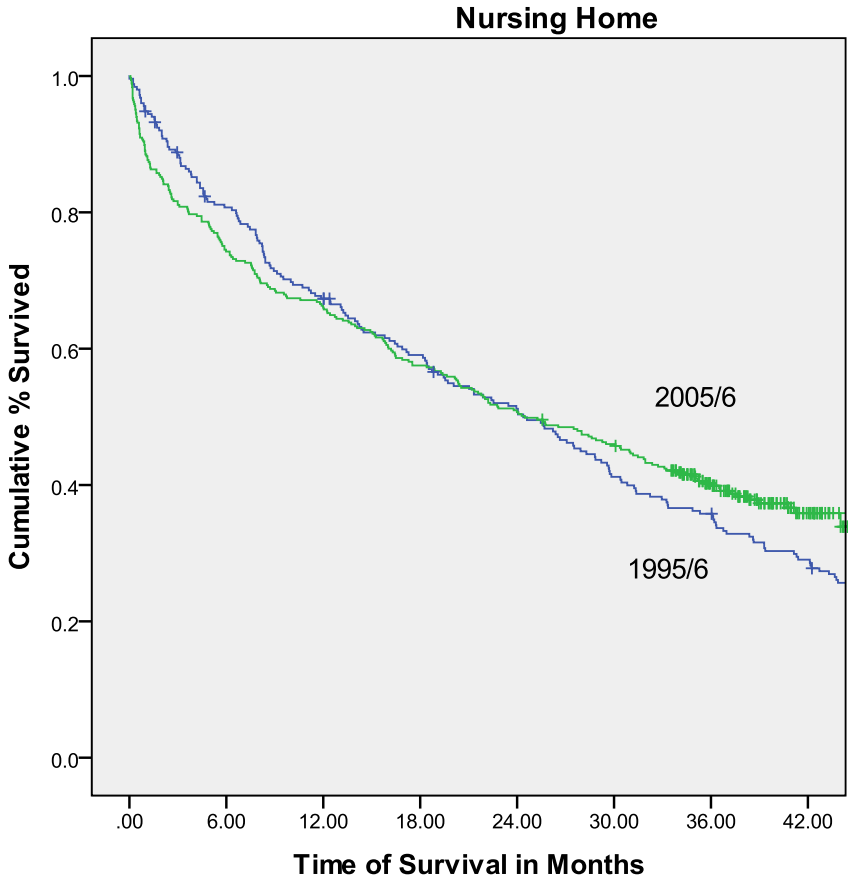

Fig 4.8- Cumulative % of survival in nursing homes in 1995/6 and 2005/6

Legend 4.8-Cumulative % of survival in nursing homes by month and median time to placement in 1995/6 and 2005/6

Cohort	Events	12	24	36	Median Time (95% CI)	P-Value
1995/1996	N=193	32.7	48.8	64.2	24.4 (19.3-29.4)	.306
2005/2006	N=227	34.0	49.3	59.7	24.5 (19.1-29.8)	

Table 4.8-Univariate predictors of survival in the 2 cohorts from 1995/6 and 2005/6 combined

Variables	β	SE	P	Hazard Ratio (95% CI)
Age	.016	.006	.012	1.02 (1.01-1.03)
Male	.234	.092	.011	1.26 (1.06-1.51)
Location:				
Community/Chronic			.000	
Acute Care	.351	.096	.000	1.42 (1.18-1.72)
Transition	.464	.122	.000	1.59 (1.24-2.05)
RUGs-III Primary Indicator				
No Indicators			.000	
Special Care	.901	.265	.001	2.46 (1.47-4.14)
Clinically Complex	.922	.144	.000	2.51 (1.90-3.33)
Impaired Cognition/Behavior Problems	.418	.124	.001	1.52 (1.19-1.94)
Reduced Physical Function	.985	.115	.000	2.68 (2.14-3.36)
RUGs-III Indicators Present:				
Special Care (yes)	.534	.161	.001	1.71 (1.24-2.34)
Clinically Complex	.472	.120	.000	1.60 (1.27-2.03)
Impaired Cognition	.161	.088	.068	1.18 (.99-1.40)
Reduced Physical Function	.720	.088	.000	2.06 (1.73-2.44)
No Indicators	-.753	.100	.000	.47 (.39-.57)
ARC Score:				
Low			.000	
Moderate	.579	.102	.000	1.79 (1.46-2.18)
High	.921	.111	.000	2.51 (2.02-3.12)
Functional Needs Score	.279	.033	.000	1.32 (1.24-1.41)
RUGs ADL Score				
(0-4)			.000	
(5-6)	.341	.148	.021	1.41 (1.05-1.88)
(7-9)	.600	.144	.000	1.82 (1.37-2.42)
(10-13)	.873	.132	.000	2.39 (1.85-3.10)
(14-20)	.996	.122	.000	2.71 (2.13-3.44)
Cohort				
2005/6	-.264	.090	.003	.77 (.64-.92)

Table 4.9-Multivariate model of survival in the 2 cohorts combined

Variables		SE		Hazard Ratio (95% CI)
Age	019	006	003	1.02 (1.01-1.03)
Male	264	094	005	1.30 (1.08-1.57)
RUGs-III Primary Indicator				
No Indicators			000	
Special Care	601	282	033	1.82 (1.05-3.17)
Clinically Complex	640	173	000	1.90 (1.35-2.66)
Impaired Cognition/Behavior Problems	204	146	162	1.23 (.92-1.63)
Reduced Physical Function	620	163	000	1.86 (1.35-2.56)
Functional Needs Score	158	045	000	1.17 (1.07-1.28)
Cohort2005/6	.255	091	005	.78 (.65-.93)

4.6 Match between Beds Needed and Available

Table 4.10 summarizes the rate of long-term beds that are provided compared to those needed when defined by the decision tree (Fig 3.4). Bed need was calculated by multiplying the annual incidence rate of clients for each LTC option by the mean survival of their corresponding group. In the St. John's region during the times of study, AH for those without disability and facilities specialized for the cognitively impaired were not available. Nonetheless in 1995/6 there was a substantial mismatch between supply and need for NH beds. Although there were ample SC beds in the region, there was a deficit of SC beds in the city of St. John's. In 2004 there were 95 SC beds for a population of 19,091 $\geq$ 65 years. By 2005/6 this mismatch between supply and need had improved, with a decrease in NH beds and an increase in SC beds. The number of SC beds in the city of St. John's increased to 204 for a population of 19,891 $\geq$ 65 years. From 1995-2006 the rate of SC beds per 1000 $\geq$ 65 years increased by 27% (32.4 to 41.0) while the rate of NH beds decreased by 15% (58.6 to 49.6). From 1995-2006 the rate of beds needed for SC per 1000 $\geq$ 65 increased by 34% (22.3 to 29.9), 39% for SC for the cognitively impaired (7.6 to 10.6), 39% for NH (19.6 to 27.3) and 123% for AH (3.5 to 7.8).

Table 4.10-Rate of long-term care beds required per 1000 ≥ 65 years, defined by optimal long-term option, compared to rate of beds provided by cohort

LTC Option	95/96	99/00	05/06
Supervised Care:			
Provided	32.4	30.7	41.0
Needed	22.3	24.1	29.9
SC for Cognitively Impaired:			
Provided	-	-	-
Needed	7.6	5.0	10.6
Nursing Home:			
Provided	58.6	53.3	49.6
Needed	19.6	18.8	27.3
Appropriate Housing:			
Provided	-	-	-
Needed	3.5	4.4	7.8

4.7 Prediction of Need for Long-term care in 2014

Table 4.11 summarizes the optimal bed configuration of LTC in the St. John's region in 2014 using data from the 1999/00 cohort and 2000 census compared to the predictions from the 2005/6 cohort and 2006 census including: (1) the rate of demand for LTC beds; (2) the optimal distribution of beds (based on the decision tree) is; (3) the overall survival of clients, defined by disability;(4) the predicted population change for those ≥ 65 years.

From 2000 to 2006, incidence and survival increased in AH from 28 to 50 per 1000 for those ≥ 65 years and 2.96 years to 3.11 years respectively, therefore beds required increased by 72% (from 125 using the 2000 data to 215 using 2006 data). SC incidence increased from 164 to 208 per 1000 ≥ 65 years and survival from 2.73 years to 2.82 years on average, so bed need increased by 19% (from 672 to 801). Currently there are 1009 licensed PCH beds in the St. John's region. Specialized care incidence and survival increased from 41 to 81 per 1000 for those ≥ 65 years and 2.40 years to 2.78 years respectively, therefore bed need increased by 107% (from 149 to 309), and NH incidence increased from 178 to 271 per 1000 for those ≥65 years, survival decreased from 1.91 years to 1.84 years however bed need increased by 34% (from 510 to 681). Currently there are 1069 NH beds in the St. John's region.

Table 4.11- Predicted optimal structure of long-term care in the St. John's region in 2014 using results from the 1999/00 cohort and 2000 census, compared to predictions from the 2005/6 cohort and 2006 census

	2000	2014	2006	2014
Population ≥ 65 years	18,280	27,387	19,891	27,151
Supervised Care (SC)				
SC Beds Available	562	1009	815	1009
Annual Incidence for SC	164	246	208	284
Survival from Assessment (years)	2.73	2.73	2.82	2.82
Number of Beds Required	448	672	587	801
SCCI *				
SC+ Beds Available	-	-	-	-
Annual Incidence for SC+	41	62	81	111
Survival from Assessment (years)	2.40	2.40	2.78	2.78
Number of Beds Required	99	149	226	309
Nursing Home (NH)				
NH Beds Available	974	1069	987	1069
Annual Incidence for NH	178	267	271	370
Survival from Assessment (years)	1.91	1.91	1.84	1.84
Number of Beds Required	340	510	499	681
Appropriate Housing (AH)				
AH Beds Available	-	-	-	-
Annual Incidence for AH	28	42	50	69
Survival from Assessment (years)	2.96	2.96	3.11	3.11
Number of Beds Required	83	125	156	215

*SCCI: specialized care for cognitively impaired

4.8 Prediction of Mortality

The results of this section examine models to predict short-term and long-term mortality in the elderly seeking LTC. A total of 907 clients ≥ 65 years who presented to the SES for institutional LTC in the St. John's region, from 2 annual cohorts identified in 1995/6, and 2005/6, were randomly allocated to a developmental cohort (n=450) or validation cohort (n=457).

4.8.1 Demographic and Clinical Factors. The average age of clients presenting to the SES was 82.4 ± 7.2 years and 31.6% were male. Fifty-six percent of clients resided in the community, with 30.8% coming from an acute care setting. For RUGs-III Indicators Present, 37.6% had impaired cognition or behavior problems, 35.3% had reduced physical function, 12.6% were clinically complex, 6% needed special care, and 35.8% had no indicators at all. 45.3% had low-level ARC scores (A-B), with 33.3%, and 21.4% having moderate level (C-E) and high level (F-G) scores respectively (Table 4.12)

Table 4.12-Demographics and Clinical characteristics of clients analyzed to develop predictive models of mortality

Variables	≥ 65 years N=907
Age	82.4 ± 7.2
Age Group:	
65-74	135 (14.9)
75-84	411 (45.3)
>85	361 (39.8)
Male	287 (31.6)
Location :	
Community/Chronic	512 (56.4)
Acute Care	279 (30.8)
Transition	116 (12.8)
RUGs-III Indicators Present:	
Special Care	54 (6.0)
Clinically Complex	114 (12.6)
Reduced Physical Function	320 (35.3)
Impaired Cognition/Behavior Problems	341 (37.6)
No Indicators	325 (35.8)
ARCS:	
Low	411 (45.3)
Moderate	302 (33.3)
High	194 (21.4)
Functional Needs Score	
0	30 (3.3)
1	82 (9.0)
2	88 (9.7)
3	147 (16.2)
4	63 (6.9)
5	497 (54.8)
RUGs ADL Score	
(0-4)	301 (33.2)
(5-6)	139 (15.3)
(7-9)	119 (13.1)
(10-13)	213 (23.5)
(14-20)	135 (14.9)

4.8.2 Developmental Cohort. Table 4.13 summarizes the demographics and clinically characteristics of clients randomly allocated to either the developmental cohort or the validation cohort. Comparison by cohorts showed no differences in age, sex or degree of disability defined by overall RUGs-III indicators, ARC scores, functional need score, RUGs ADL scores.

Table 4.14 summarizes the univariate Cox regression analysis of the developmental and validation cohorts. In the developmental cohort, significant predictive variables of long-term mortality included: age ≥ 83 years (HR 1.35, 95%CI=1.06-1.72) male sex (HR 1.44, 95%CI=1.11-1.86); location; presence of the RUGs-III indicators reduced physical function (HR 1.94, 95%CI=1.52-2.49), absence of RUGs-III indicators (HR .48, 95%CI=.36-.63); high ARC scores; high functional needs score; RUGs ADL score (Table 4.14).

Table 4.13-Demogrpahics/Clinical characteristics of the development and validation cohorts

Variables	Developmental N=450	Validation N=457	t-test/chi-squared
Age	82.3 ± 7.1	82.5 ± 7.3	.708
Age			
≤ 82	226 (50.2)	213 (46.6)	.276
83+	224 (49.8)	244 (53.4)	
Male	140 (31.1)	147 (32.2)	.733
Location :			
Community/Chronic	255 (56.7)	257 (56.2)	.979
Acute Care	137 (30.4)	142 (31.1)	
Transition	58 (12.9)	58 (12.7)	
RUGs-III Present Indicators:			
Special Care	27 (6.0)	27 (5.9)	.953
Clinically Complex	54 (12.0)	60 (13.1)	.608
Reduced Physical Function	146 (32.4)	174 (38.1)	.076
IC/BP*	167 (37.1)	174 (38.1)	.765
No Indicators	172 (38.2)	153 (33.5)	.136
ARCS:			
Low	210 (46.7)	201 (44.0)	.609
Moderate	143 (31.8)	159 (34.8)	
High	97 (21.6)	97 (21.2)	
Functional Needs Score			
0	12 (2.7)	18 (3.9)	.528
1	40 (8.9)	42 (9.2)	
2	51 (11.3)	37 (8.1)	
3	74 (16.4)	73 (16.0)	
4	33 (7.3)	30 (6.6)	
5	240 (53.3)	257 (56.2)	
RUGs ADL Score			
(0-4)	157 (34.9)	144 (31.5)	.133
(5-6)	65 (14.4)	74 (16.2)	
(7-9)	69 (15.3)	50 (10.9)	
(10-13)	100 (22.2)	113 (24.7)	
(14-20)	59 (13.1)	76 (16.6)	

Table 4.14-Univariate Cox regression analysis of developmental and validation cohorts

Variables	P	HR (95% CI)
Age (per year)	.040	1.02 (1.00-1.04)
Age 83+	.017	1.35 (1.06-1.72)
Male	.005	1.44 (1.11-1.86)
Location		
Community/Chronic	.014	Reference
Acute Care	.025	1.36 (1.04-1.79)
Transition	.014	1.57 (1.10-2.24)
RUGs-III Indicators Present		
Special Care	.107	1.47 (.92-2.35)
Clinically Complex	.279	1.22 (.85-1.74)
Reduced Physical Function	.000	1.94 (1.52-2.49)
IC/BP*	.055	1.27 (1.00-1.63)
No Indicators	.000	.48 (.36-.63)
ARCS		
Low	.000	Reference
Moderate	.000	1.77 (1.33-2.36)
High	.000	2.27 (1.67-3.09)
Functional Needs Score		
0	.000	Reference
1	.555	1.57 (.35-7.10)
2	.238	2.40 (.56-10.26)
3	.113	3.16 (.76-13.12)
4	.040	4.58 (1.08-19.47)
5	.015	5.64 (1.40-22.74)
RUGs ADL Score		
0-4	.000	Reference
5-6	.031	1.57 (1.04-2.37)
7-9	.001	1.96 (1.34-2.87)
10-13	.000	2.45 (1.74-3.44)
14-20	.000	2.86 (1.94-4.23)

*Impaired Cognition and Behavior Problems

4.8.3 Multivariate Model. Table 4.15 summarizes the multivariate Cox regression for survival in the developmental cohort. Using the forward stepwise Cox proportional-hazards model, 4 variables were independent and significant predictors of death including: age 83+, male sex, absence of RUGs-III indicators, and RUGs ADL score.

Table 4.15-Multivariate analysis of the developmental cohort

Variables	β	SE	P	Hazard Ratio (95% CI)
Age >82	.376	.129	.003	1.46 (1.13-1.87)
Male	.368	.134	.006	1.45 (1.11-1.88)
No Indicators	.442	.182	.016	.64 (.45-.92)
RUGs ADL Score				
0-4			.044	
5-6	.395	.221	.074	1.49 (.96-2.29)
7-9	.471	.213	.027	1.60 (1.06-2.43)
10-13	.525	.216	.015	1.69 (1.11-2.58)
14-20	.713	.237	.003	2.04 (1.28-3.25)

4.8.4 Mortality Risk Score. To calculate a risk score, each patient was assigned points for each variable present with the number proportional to its β regression coefficient. Each patient was assigned a score based on the value of the variables in their particular case possessed. Variables associated with longer survival such as having no clinical indicators, received negative 2 points. Variables associated with frailty such as a high RUGs ADL score received positive points (RUGs ADL score: 0-4=0 points; 5-6=2 points; 7-9=3 points; 10-13= 3 points; and 14-20=4 points). The score ranged from -2 to 8 (Table 4.16).

Classification of the developmental cohort according to the risk score resulted in the assignment of 45.3 percent of the clients to the low-risk group (-2 to 2), 40.2 percent to the intermediate-risk group (3-5), and 14.4 to the high risk group (6-8). The 6-month survival rates for the low-, intermediate-, and high-risk groups were 91, 77, and 66 percent respectively (Fig. 4.9). The difference in the probability of survival between the low–risk group and the high-risk group was 25% at 6 months and 26% at 1 year.

The results are similar for the validation cohort. Forty percent of the clients were allocated to the low-risk group, 42.9 percent to the intermediate-risk group, and 16.8 percent in the high-risk group. The 6 month survival rates for the low-, intermediate-, and high-risk groups were 90, 77, and 65 respectively (Fig 4.10). The difference in the probability of survival between the low-risk and the high-risk group was 25% at 6 months and 1 year.

Figure 4.11 summarizes the ROC curve and area under the curve for the mortality risk score. The area under the curve was .70 (95% CI .65-.75) which can be interpreted as fair.

Figure 4.12 summarizes the ROC curve and area under the curve of the mortality risk score applied to the validation cohort. The area under the curve for the validation cohort showed

no improvement from the developmental cohort with a value of .67 (95% CI .62-.72), which is considered poor.

Table 4.16-Multivariate Variables and Scoring System of developmental cohort

Variable	N (%)	B Regression Coefficient	Points
Age >82	224 (49.8)	.376	2
Male	140 (31.1)	.368	2
No Indicators	172 (38.2)	-.442	-2
RUGs ADL Score			
0-4	157 (34.9)		0
5-6	65 (14.4)	.395	2
7-9	69 (15.3)	.471	3
10-13	100 (22.2)	.525	3
14-20	59 (13.1)	.713	4

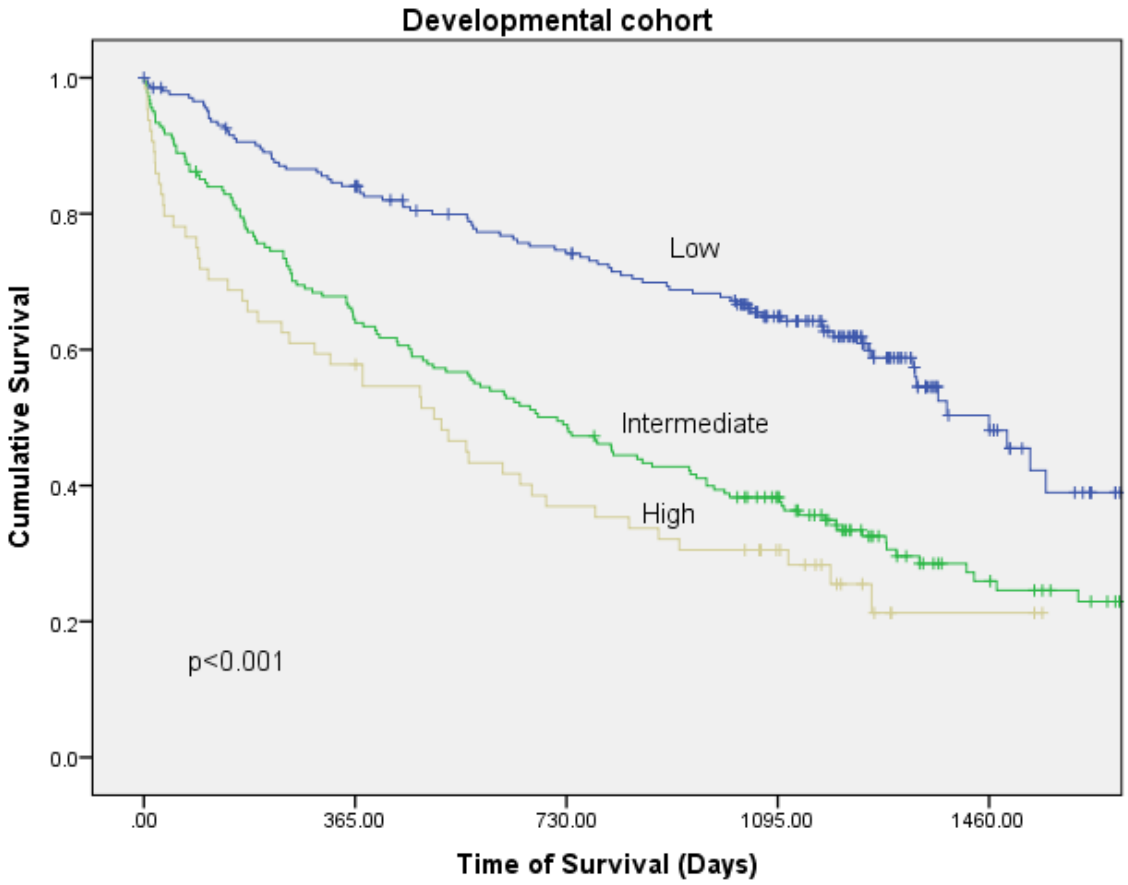

Figure 4.9-Cumulative % survival by risk group in the developmental cohort

Legend 4.9-Prevalence of survival by risk group in months

	Months After Panel Assessment									
Groups	**0**	**6**	**12**	**18**	**24**	**30**	**36**	**Median in Yrs (95%CI)**	**% Survival at 6 Months (95%CI)**	**% Survival at 12 Months (95%CI)**
Low	204	181	167	152	141	129	99	4.0 (3.6-4.4)	91 (87-95)	84 (79-89)
Intermediate	181	139	115	102	88	76	61	2.0 (1.4-2.4)	77 (71-83)	64 (57-71)
High	65	42	37	29	23	20	15	1.4 (0.8-2.0)	66 (54-77)	58 (46-70)

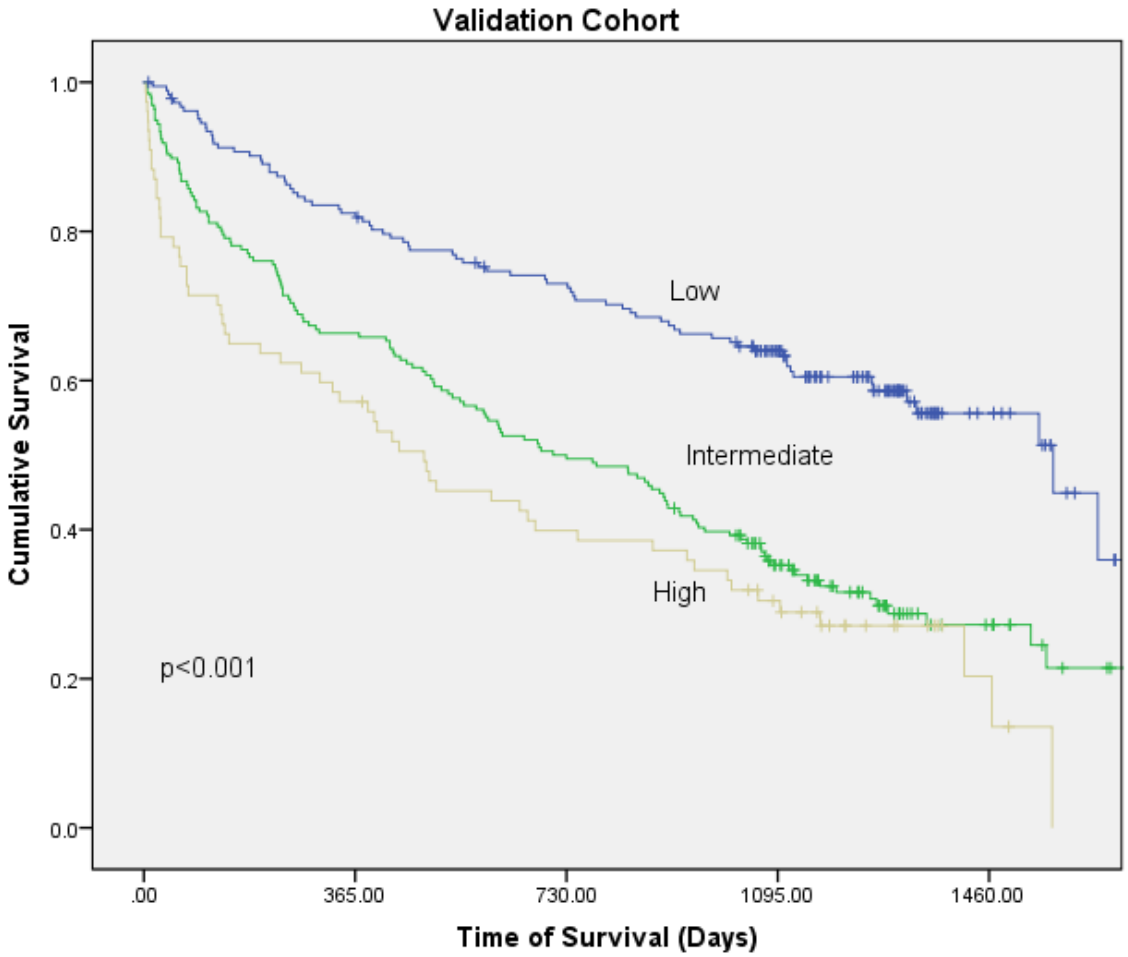

Figure 4.10-Cumulative % survival by risk group in the validation cohort

Legend 4.10-Prevalence of survival by risk group in months

	Months After Panel Assessment									
	0	**6**	**12**	**18**	**24**	**30**	**36**	**Median in Yrs (95%CI)**	**% Survival at 6 Months (95%CI)**	**% Survival at 12 Months (95%CI)**
Low	184	164	150	138	130	120	96	4.3 (3.4-5.2)	90 (77-94)	82 (77-88)
Intermediate	196	150	130	112	97	84	56	1.9 (1.4-2.5)	77 (71-82)	66 (60-73)
High	77	50	44	34	30	28	20	1.3 (0.8-1.9)	65 (54-76)	57 (46-68)

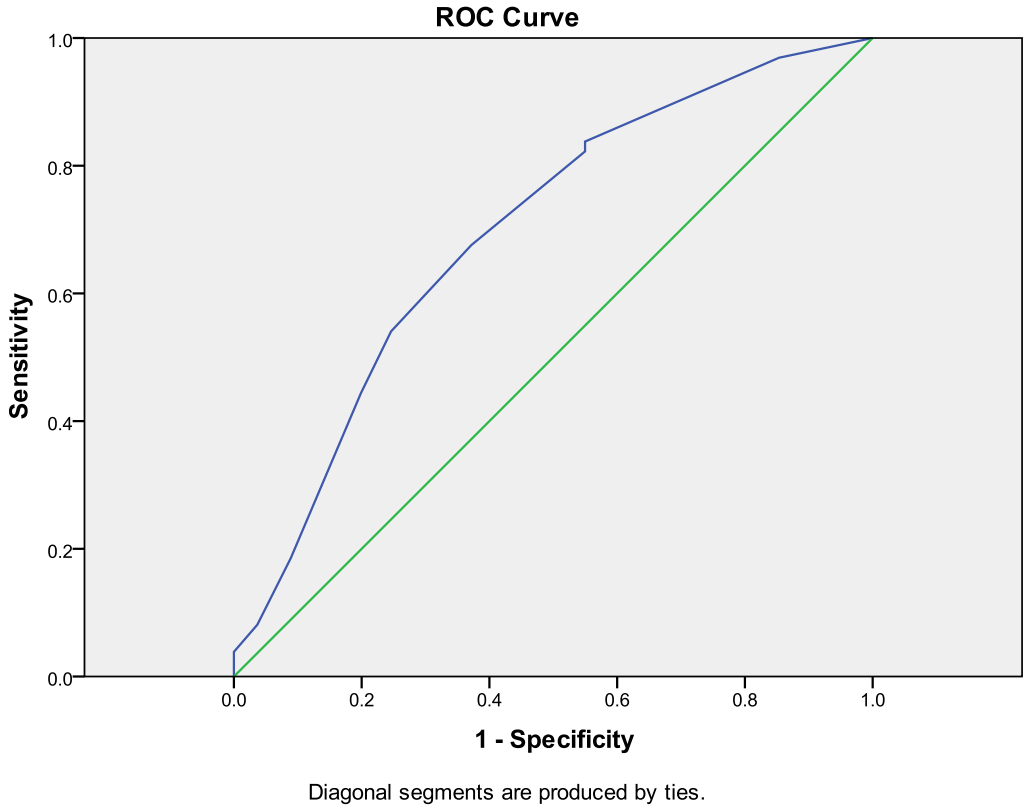

Figure 4.11- Receiver operating characteristic curve of the mortality risk score in the developmental cohort

Legend 4.11-Area under the curve and 95% confidence interval

AUC	95% Confidence Interval
.70	.65-.75

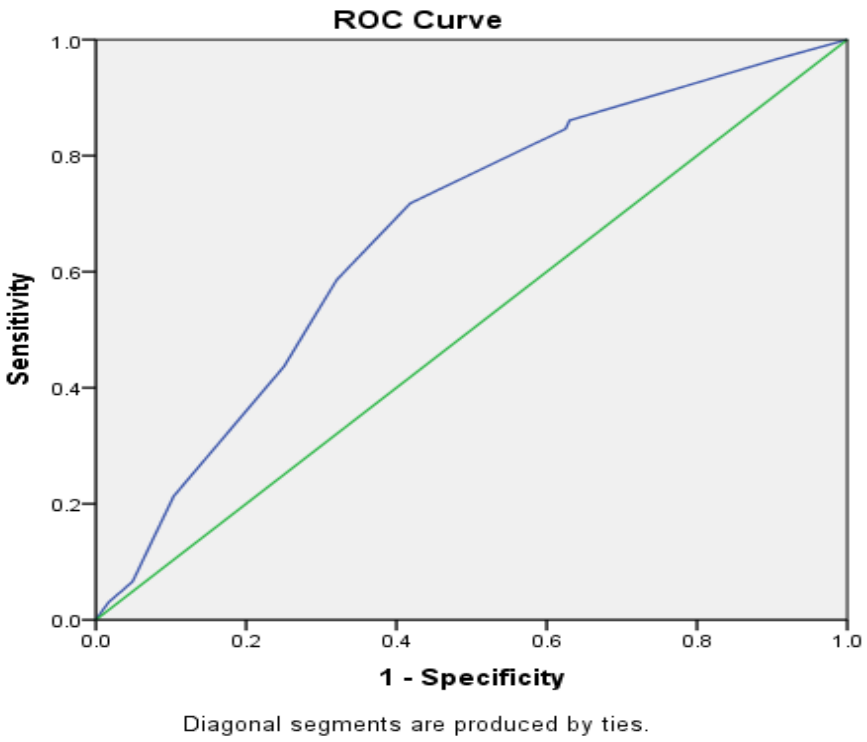

Figure 4.12- Receiver operating characteristic curve of the mortality risk score in the validation cohort

Legend 4.12-Area under the curve and 95% confidence interval

AUC	95% Confidence Interval
.67	.62-.72

4.8.5 Short-term Survival. Significant predictive variables of short-term (6 months) mortality in both cohorts (n=907) included: Location before placement; the need for special care (HR 1.88, 95%CI=1.02-3.46); clinically complex (HR 2.34, 95%CI=1.52-3.61); reduced physical function (HR 4.03, 95%CI=2.85-5.71); absence of RUGs-III indicators (HR .41, 95%CI=.28-.61); high ARC scores; high functional needs scores; and high RUGs ADL scores (Table 4.17).

Table 4.17-Univariate Logistic Regression analysis of 6-month mortality in the developmental cohort

Variables	P	HR (95% CI)
Age 83+	.290	1.20 (.86-1.67)
Male	.082	1.36 (.96-1.93)
Location		
Community/Chronic	.000	
Acute Care	.001	1.87 (1.29-2.71)
Transition	.002	2.16 (1.34-3.49)
RUGs-III Indicators Present:		
SC	.042	1.88 (1.02-3.46)
CC	.000	2.34 (1.52-3.61)
RPF	.000	4.03 (2.85-5.71)
IC/BP	.641	.92 (.65-1.30)
No Indicators	.000	.41 (.28-.61)
ARCS		
Low	.000	
Moderate	.000	2.57 (1.6-3.92)
High	.000	4.44 (2.86-6.90)
Functional Needs Score		
0	.000	
1	.205	.34 (.07-1.80)
2	.972	1.03 (.26-4.07)
3	.973	1.02 (.28-3.78)
4	.872	1.13 (.27-4.69)
5	.050	3.36 (1.00-11.25)
RUGs ADL Score		
0-4	.000	
5-6	.405	1.32 (.69-2.54)
7-9	.112	1.69 (.89-3.23)
10-13	.000	3.98 (2.43-6.53)
14-20	.000	6.36 (3.76-10.76)

*Impaired Cognition and Behavior Problems

4.9 Conclusion

The results from analyzing three incident cohorts in 1995/6, 1999/00 and 2005/6 showed: 1) no differences in age, gender and degree of disability, however there was a decrease in proportion of those with cognitive impairment and an increase in those with reduced physical function; 2) The rate of beds per 1000 ≥ 65 years increased for SC while it decreased for NH, however, the rate of clients placed increased in both; from 95-06 incidence rates increased across all levels when defined by demographic factors and disability; 3) appropriateness of placement improved; 4) time to placement improved for both SC and NH; 5) incidence rates using the decision tree to define optimal placement increased for all options including AH, SC for the cognitively impaired, SC and NH; 6) median survival following assessment was significantly longer in 2005/6 compared to 1995/6 with a major difference in survival for clients placed in SC; 7) Independent factors of survival included age, sex, RUGs-III as a primary indicator and functional needs score; 8) predicted bed need for 2014 increased for all optimal placement options when comparing the 2000 cohort to 2006

The findings of this chapter will be further analyzed in the discussion. They will be combined with the results from the following chapter that consists of interviews with key stakeholders working in LTC to complete the thesis.

Chapter 5 Results: Interviews with Stakeholders

5.1 Introduction

This chapter consists of answers given by key stakeholders who work in LTC in 4 provinces to a questionnaire constructed by the author and supervisors. The purpose of this chapter was to get a better understanding of LTC through an inside perspective in the province of NL and three other jurisdictions which include Nova Scotia, Manitoba, and Saskatchewan.

5.2 Structure of the Long-term Care System

LTC is structured differently in the 4 provinces studied (Table 5.1). Home care supports are similar in providing services such as nursing care and respite care that may include personal care and home management. Fees may be applied to clients based on their income, as in Nova Scotia and Saskatchewan, or as is the case in NL where clients must meet the 'Home Support Emergency Criteria' in order to qualify for such care. SC with 24 hour supervision and accommodations for clients with lower level needs who do not need professional nursing care is provided in NL by PCHs. NL provides means-tested subsidies for PCHs whereas in Saskatchewan the government does not provide any subsidy to clients seeking this form of care. NH care is universal through jurisdictions across Canada in that it provides publicly funded services in facilities for clients who have high medical care needs. The cost of NH care in NL is $9200/month per client, and the client pays a maximum of $2800 depending, on their financial situation.

Table 5.1-How is Long-Term Care Structured in Your Region?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
Home Care-various home supports services based on an 'emergency criteria' basis. **Supervised Care**-provided in PCH's (for-profit), monitored and licensed by the govt. **Nursing Home**-provided in LTC facilities (not-for profit) for clients with high medical needs **Other Programs**-special assistance, alternative family program, special child welfare allowance program	**Home Care**-fees may be applied based on clients income **Supervised Care**-provided in Residential Care Facilities (RCFs) which are govt. funded **Nursing Homes**-for higher-level care clients	**Home Care**-provided through different situations: Elderly Person Housing, Supports to Seniors in Group Living, Assisted Living, Specialized Support **Supervised Care**-provided in Supportive Housing (SH). Govt. subsidized **Nursing Home**-provided in Personal Care Homes (PCHs) which are mostly owned and operated by govt.	**Home Care**-provide acute and palliative care services for low income and/or independent clients **Supervised Care**-offered in PCH's, but privately owned and not funded by govt. **Nursing Homes**-provided in Special Care Homes (SCHs) and publicly funded by govt.

5.3 Budget Allocation to Long-term Care

The proportion of the LTC budget allocated to home care was 32% in NL, whereas in Saskatchewan it was only 16.7% (Table 5.2). NL had the highest proportions of money allocated to SC (4.9%), whereas Saskatchewan does not pay for SC. The money allocated in Saskatchewan is for administrative salaries to assist with clients in accessing this low level care. NH care comprised the majority of the LTC budget in all 4 provinces (Eastern Health had provided their 2012-13 budget). The proportion of LTC budget allocated to home care was 38% with $89.7M, 7% was allocated to SC with $15.4M and 55% went to NH care with $129.2M*)*. The cost per 100,000 of the population for NL was $92.4M, for Nova Scotia it was $77.0M, Manitoba $67.3M, and Sask. $79.1M. NL had the highest budget rate per 1000 ≥ 65 years with $5.6M while Saskatchewan was close with $5.5M. Manitoba and Nova Scotia budget rate per 1000 ≥ 65 was $4.8M and $4.4M respectively.

Table 5.2-What is the Budget Allocated to Long-Term Care Services?

	NL[1] $ In Miilions(%)	NS[2] $ In Miilions(%)	MB[3] $ In Miilions(%)	SK[4] $ In Miilions(%)
HC	155.5(31.9)	196(25.9)	294.6(35.5)	146(16.7)
SC	24(4.9)	32(4.2)*		0.54(0.0)†
NH	308(63.2)	529(69.6)**	535(64.5)	790(83.3)
Budget per 100,000 pop.				
Home Care	$29.4	$20.8	$23.9	$13.2
Institutional Care (NH and SC)	$63.0	$56.2	$43	$65.9
Total	$92.4	$77.0	$67.3	$79.1
Budget per 1000 ≥ 65 years				
Home Care	$1.8	$1.2	$1.7	$0.9
Institutional Care (NH and SC)	$3.8	$3.2	$3.1	$4.6
Total	$5.6	$4.4	$4.8	$5.5

1-NL. provincial budget (2011/12)
2-provincial budget estimate (2013/14)
3-provincial budget (2010/11)
4-provincial budget estimate (2013/14)
*Money allocated to care coordination
**Money allocated to both SC & NH care
† Money allocated to Salaries

5.4 Future Needs

A common theme across all jurisdictions was the need for more resources allocated to home care supports (Table 5.3). This is especially true in the province of Saskatchewan which has the 3rd highest LTC bed rate (113.9/ pop.≥75 years of age) and the 2nd lowest home care funding per population of the same age group. In NL and Nova Scotia further resources required include investments into older facilities, which have increased vacancy rates due to clients choosing more modernized facilities. In NL facilities are needed so that clients can receive the best match of LTC option with degree of disability. This includes AH (ex. seniors cottages) for seniors with no disability, facilities for younger adults with complex issues and dementia specific bungalows for clients with mild-to-moderate cognitive impairment. Protective Community Residences, like those found in western Newfoundland, provide residential care for persons with mild-to-moderate dementia. This enhanced assisted-living facility promotes independence and improves the QOL for these people offering them a home-like setting, featuring a private bedroom with access to walking paths. According to the government of NL, approximately three quarters of the clients presenting themselves to the SES have some form of dementia whether mild to severe, and regular LTC residential services don't meet their needs. Additional needs in NL include a better screening process and ongoing assessments so clients can continue to receive the best match of LTC option with their degree of disability. Screening should ensure the utilization of NH beds by clients who require the professional nursing care provided in a NH. Ongoing client assessment gives facilities a 'revolving door' meaning if clients either improve or deteriorate in health status they may access different facilities. This will enhance appropriate use of facilities post admission.

Table 5.3-Over the Next 5-10 Years What Will the Additional Needs/Resources be?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
• More resources allocated to home care • Resources to upgrade older facilities • Appropriate Housing for seniors • Dementia bungalows in the city • LTC facilities to only focus on complex care • Changes to the provision of lower level care services • Better screening • Meeting the needs of various levels of dementia care • Continued assessment in LTC facilities	• Home Care • Resources for older facilities • Supportive housing	• Continued investment in LTC beds and home care • Ageing in place strategy	• More resources allocated to home care and less to nursing home care

5.5 Future Pressures on Long-term Care

Both NL and Saskatchewan interviewees stated that the greatest pressures were found in the urban areas of the province (Table 5.4). In NL, there is a shift where rural clients are moving to the St. John's region because their children now reside there. A major concern across all provinces is that ageing together with the increase of chronic disease will increase the incidence of clients for the LTC system. Unresolved issues in NL and Nova Scotia include publicly funded assisted living for clients with no or low-level care needs and long-term rehab/convalescent beds. The St. John's region provides ALFs (ex. Elizabeth Towers, Kenny's Pond, Tiffany Village), however these services are private and not licensed or monitored by the government. In addition capital investment in LTC institutions will be necessary. Nova Scotia reported that over 50% of their institutions were over 15 years or older. Newfoundland reports that there are vacant beds in PCHs outside the city due to older facilities, and wait times for new, more modern ones in the city. The western provinces of Manitoba and Saskatchewan state that there is an inconsistent quality and access to health care services which lead to increased wait times.

Table 5.4-Where do you see the greatest pressure coming in the next 10 years?/Unresolved Issues?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
-Home Supports -Rural clients centralizing to St. John's -Young adults with complex needs -Assisted Living	-Current and projected demand not met by existing services -50% of LTC institutions are over 15 yrs old -Affordable/publicly funded AL and long-term rehab/convalescent beds	-Increasing chronic disease -Inconsistent quality and access to health care services	-Baby boomers and chronic disease management -Urban/Northern have greatest pressures -Decreasing wait times

5.6 Pilot Studies

A common project amongst the provinces is providing seniors with the proper resources to stay at home and delay institutional placement while reducing emergency room visits and admissions (Table 5.5). In NL the 'Community Rapid Response Team' allows clients presenting to the emergency department who are medically stable to return home. This will allow a transition to a lower level of care that is within the auspices of home care services. Additional services that would be provided include nursing support, occupational and/or physical therapy, physician home visits and access to special equipment. The 'Hospital Home Teams' innovation is a collaboration between home care and primary care that targets seniors with fragile, unstable health conditions already receiving home care to remain at home. Seniors receive care from a co-ordinated multi-disciplinary team of health professionals whose services are traditionally provided in hospitals. The 'Home First/Quick Response Home Care' project to be initiated in Saskatchewan in 2013/14 assists in early discharge from acute care and provides seniors with adequate resources to ultimately return to home. The overall goal for these projects is to reduce inappropriate ER visits, reduce hospital admissions and allow seniors to keep their independence at home.

Other pilot projects include 'The LTC Needs Assessment Project' in NL that addresses the issue of planning LTC using inadequate data that has been collected retrospectively. Therefore, this project plans to collect current data and develop a model to assist government in projecting and planning. The 'Enhanced PCH Care' project has allocated resources to selected PCHs to allow up to eight Level 3 patients to receive care in these traditionally lower care facilities.

Table 5.5-Do you currently have any pilot projects in LTC?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
-LTC Needs Assessment Program -Community Rapid Response Team -Enhanced PCH Care -InterRAI MDS 2.0	-None. But significant investments made	-Home Care Enhancements -Hospital Home Team -Innovative Rehab -Community Stroke Care Services	-Samaritan Place -Home First/Quick Response -Direct Clients Funding

5.7 Vulnerable Groups

In all jurisdictions a common vulnerable population identified was those with impaired cognition and/or behavior problems (Table 5.6). In NL 75-80% of clients presenting themselves to the SES have some form of dementia. Stakeholders claim that the regular services provided for the population don't meet the needs of this group. Saskatchewan and Manitoba state that the vulnerable population consists of those with disruptive and complex behavior needs who need one-on-one supervision. Other common vulnerable groups include low income seniors in NL and Saskatchewan due to lack of resources for low-level care. Nova Scotia claims that because services are split between two departments (Department of Health and Wellness & Community Services), all clients seeking LTC are vulnerable due to the complexity of the system. NL also states that the morbidly obese group are vulnerable because facilities are not designed to care for them or for young adults with disabilities because the system is modeled to accommodate seniors.

Table 5.6-Who are the most vulnerable in your region?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
-Low income seniors -Adults with disabilities -Low level care clients -Cognitively impaired -Morbidly obese clients	-Clients needing continuing services that are divided by two departments	-Dementia who display disruptive behavior	-Low income seniors needing SC -Impaired Cognition/Behavior problems -Aboriginals

5.8 Urban-Rural Divide

In the rural areas of NL and Nova Scotia the options for LTC are limited (Table 5.7). In some cases clients seeking placement only have one option. Manitoba has trouble in rural areas with staff recruitment and retention, making the implementation of programs otherwise offered in urban settings more challenging. NL and Saskatchewan identified the increased demand for LTC beds in urban areas as a concern. Both jurisdictions have seen an increase in the population due to population transfer from rural areas. For example, in NL rural area clients seek placement in the St. John's region because their children are located in the area.

Table 5.7-Is there an urban-rural divide?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
-Centralizing to St. John's -Rural areas don't have a variety of choices	-Rural areas don't have a variety of choices	-Trouble with staff recruitment and retention in rural areas	- Increased pressure for LTC beds in the large urban areas and the north

5.9 Evaluations of Interventions

P.I.E.C.E.S. stands for “Physical, Intellectual, Emotional, Capabilities, Environment, Social”. PIECES is best practice learning and development for enhancing care to persons with complex/physical and cognitive/mental health and was initiated in Manitoba PCH’s in 2008/9. The intervention included forty hours of frontline staff training that focused on helping people in the care facilities: gain a greater understanding of the causes of changing behaviour; to be more innovative in problem solving; to place greater value on their interaction with family members.

The ‘Assessment of PCH Bed Projections’ by Chateau and Doupe in Manitoba mimics previous evaluations of need for LTC completed in NL (NL Studies). Nova Scotia has analyzed the LTC waitlist and home care data to better understand clients who wish to access LTC services. Analysis of current home care utilization patterns has indicated that a significant percentage of clients on the waitlist for LTC are independent, able to carry out ADL’s and receive relatively low or no home care services. This information suggests that these clients may not yet need LTC and additional home care services could assist them to remain at home longer.

Other ongoing evaluations include ‘The Cost of Publicly Supported Housing for Seniors Implications for Future Funding Approaches’ by Greg Finlayson in Manitoba. The study will compare the costs of supportive housing versus NHs in Winnipeg to ensure that supportive housing is a viable financial alternative to NH care.

A study conducted in NL by Hutchings et al. provided insight into the experiences of family members of residents diagnosed with mild to moderate dementia who were relocated from institutional-based care to a unique assisted-living environment. Semi-structured interviews were conducted with 10 family members, and six themes emerged: (a) ongoing communication

was positive according to all participants, (b) relief and contentment was enhanced knowing that family members were happier in the new environment, (c) meaningful activities provided a sense of contribution and creative means to enhance memory, (d) an enhanced environment was provided through privacy along with security and safety, (e) improved functioning was perceived both physically and cognitively by family members, and (f) engaged staff provided a "very caring", "compassionate" and "patient" environment for residents. They concluded that the study had relevance for future program planning for caring for residents with special needs. Positive outcomes for residents and family members were observed with a client-centered program of care and appropriately designed physical environment.

Table 5.8- Have there been any evaluations of interventions in LTC in the last 10 years?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
-From Institution to 'Home': Family Perspectives on a Unique Relocation Process	-Analyzing LTC waitlist and home care data	-'PIECES' -'The Cost of Publicly Supported Housing for Seniors Implications for Future Funding Approaches' -'Assessment of PCH Bed Projections'	-No evaluations in last 10 years

5.10 Public Long-term Care Insurance Plan

While the provinces of NL, Nova Scotia and Saskatchewan have not examined the concept of a public LTC insurance plan they responded with some individual insight on the matter. Nova Scotia supports the principles that LTC should be of high quality and accessible as well as financially stable over the long-term while not burdening one generation over the next. NL and Saskatchewan suggest that public insurance may not make much difference as LTC is currently heavily subsidized and publicly funded. Manitoba on the other hand, has taken on the concept that all health services should be universal. In the government released document titled "Focused on What Matters Most: Manitoba's Plan to Protect Universal Health Care" released in May 2012 it states: 'While The Canada Health Act requires provinces to provide coverage for hospital services and medically necessary physician services, Manitoba has introduced coverage above and beyond these federal requirements, including universal home care, Pharmacare, chiropractic coverage, supportive housing and other seniors' supports. Many of these services not only offer better care to patients but also help to avoid more costly hospital based care as well'. They believe these efforts will allow Manitoba to meet the increasing demands and build a lasting sustainable health care system.

Table 5.9-Do you think there should be a public LTC insurance plan?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
-Have not examined concept	-Have not examined concept	- "Focused on What Matters Most: Manitoba's Plan to Protect Universal Health Care".	-Have not examined concept

5.11 Integrated Model for Long-term Care

The integrated model of care for the elderly, like SIPA in Quebec, is a community-based model of care that takes full responsibility for delivering integrated care through the provision of community health and social services and the coordination of hospital and institutional care all within the publicly funded healthcare system (SIPA study). The fundamental components of the integrated model include: care coordination through a multi-disciplinary team; a single entry point; a single disability assessment tool; client case management; real time information through regular data collection; and a single envelope of funding (Integrated studies). Nova Scotia agrees with the evaluations of Quebec's integrated model that integrated systems appear to be feasible and have the potential to reduce hospital and NH utilization without increasing costs. Currently Nova Scotia's LTC continuum is divided amongst two government departments however, they are currently working to improve co-ordination and integration of these services. NL has a pilot project in planning with 'The Community Rapid Response Team' that embodies much of the same qualities that an integrated system requires. This project is an action to support the goals included in 'Close to Home: A Strategy for Long Term Care and Community Support Services' that was released by the government in June 2012. This strategy hopes to the guide the province in strengthening and integrating the components of LTC and community support services over the next ten years. NL however lacks a complete SES, where accessing home care is separate from access to institutional care. Manitoba has two projects including the 'Hospital Home Team' and the Program for Integrated Managed care for the Elderly (PRIME). PRIME is for senior's $\geq$ 65 years of age that have multiple health problems that need a moderate degree of monitoring and co-ordination of professional services in order to live independently at home. PRIME is designed to strengthen independent community living while improving the

client's QOL. Services include: regular visits with a physician or nurse practitioner; after-hours support; exercise and therapy; health and wellness education; and counseling and personal care.

Table 5.10-Do you agree with an integrated model for the LTC system?

Newfoundland	Nova Scotia	Manitoba	Saskatchewan
-Similar to Rapid Response Team	-Agree and are in process of increasing collaboration between departments	-Two programs: Hospital Home Teams and PRIME	-Aware of other studies that have used Integrated models

5.12 Conclusion

The results from interviews with stakeholders in the jurisdictions of Newfoundland & Labrador, Nova Scotia, Saskatchewan and Manitoba showed: 1) LTC is structured and budgeted differently throughout Canada; 2) common future needs include more resources allocated to home care, investments in older facilities, alternate facility options and better screening of clients to ensure efficient utilization of beds; 3) pressures exist in urban areas due to a shift of rural clients moving to the city and a lack of options in rural areas; 4) concerns of a need for publicly funded assisted living facilities and concerns around the increase in chronic disease; 5) common pilot projects include adequate resources to stay at home and delay in institutional placement after presenting to acute care facilities; 6) clients with impaired cognition and/or behavior problems were a common group amongst jurisdictions considered to be vulnerable; 7) the concept of public LTC insurance was accepted across Canada including in Manitoba who have introduced coverage above and beyond federal requirements; 8) jurisdictions agree with the concept of integrated care, and some have already implemented programs and services that embody some of the components of such care.

The findings from these interviews will be further discussed in the next chapter and combined with the results from the previous chapter.

Chapter 6 Discussion and Conclusion

6.1 Introduction

Newfoundland & Labrador's population is ageing. The 'Baby Boomer' generation has now reached the age of 65, therefore, the healthcare system along with institutional LTC will need o prepare for the complex health needs of seniors. The current study attempted to construct a vision for restructuring institutional LTC by examining institutional LTC, in the St. John's region, the province and other jurisdictions across Canada. The three cohorts provided answers to two major questions. The first question addressed changes in placement rate of clients, disability rates of clients, the efficiency of placement and the survival of clients over a 10-year period in institutional LTC in the St. John's region. The second question addressed the question whether these changes over time affected predicting optimal beds for the region.

The qualitative piece of this study involved interviewing key stakeholders that work in LTC in NL and three other provinces across Canada that included Nova Scotia, Manitoba, and Saskatchewan. These interviews provided important information such how LTC is structured, the gaps in its current structure and how it would like to be structured in the future. They also provided a template of how to best restructure institutional LTC and gave recommendations based on successful and unsuccessful programs in other jurisdictions.

6.2 Cohort Study

6.2.1 Incidence Rates over the Past Decade. The incidence rate per 1000 people ≥ 65 years of clients seeking placement for LTC through the SES in the St. John's region increased substantially from 1995-2006. The degree of disability of clients seeking placement for LTC through the SES in the St. John's region has not changed much over time but the incidence rate

of clients across the spectrum of disability increased. This occurred even though several studies state that there has been a decline in LTC rates. Alcock et al. (2002) claim that developments in pharmaceuticals and medical technology, higher disposable income levels, increased attention to healthier lifestyles and increased emphasis on early detection and disease prevention has contributed to this trend (104). Martikainen et al. (2009) stated that the pressure on public health and LTC providers may ease in the future as a result of a higher proportion of elderly people living with a partner, more elderly have a higher education, therefore have higher incomes in retirement, and shorter durations of care among these groups once in LTC (103). The baby boom generations in many countries will be better educated and enjoy higher incomes in retirement (103). Cohen (2003) however suggests that in the previous 20 years, institutionalization has declined, but states that the demand for LTC will likely grow quite dramatically in the future as the population ages (104).

From 1995-2006, the rate of SC beds per 1000 ≥ 65 years increased by 110%, while the rate of NH beds decreased by 19%. The rate of clients recommended for SC increased by 106%, and by 22% for NH clients over 10 years. In 1995/6 the St. John's region had several underlying issues in its LTC sector such as over utilization of NHs, a lack of SC beds in the city, and a lack of alternative options for those with no overt disability and those with cognitive impairment. Since then there have been restructuring changes: 253 SC beds were provided after 2000, with the majority provided in the city of St. John's. NH's were downsized and plans were made for the provision of SC facilities for the cognitively impaired. The increased SC bed rate was associated with increased demand for LTC beds across the spectrum of disability, from those with no or modest disability to those with cognitive impairment, and those who required NH care.

The increase in incidence rates across all levels of disability may be related to supply-induced demand arising from the provision of attractive new facilities, enticing clients to make a decision to enter institutional LTC. The elderly want to maintain independence, privacy, social contact and dignity for as long as possible (105). However, at the same time, they do not want to be a burden on their family. Perhaps the new facilities are a secure place where their needs could be met. Furthermore these facilities were built within the city of St. John's, rather than in the rural parts of the health region where the older PCHs were situated, providing a more convenient option closer to family. Other factors causing an increase in incidence rates could include in-migration of seniors into St. John's to enter facilities in the region. This would have a disproportionate effect on rates by increasing the numerator while having no effect on the denominator. It is also possible that outmigration and low fertility rates decreased the amount of formal support and forced clients to present to the SES.

6.2.2 Placement. From 1995-2006, appropriateness of placement by panel decision improved. Compared to 1995/6 appropriateness of placement was better in 2005/6 in that only 8.7% of clients recommended for placement in a NH had no clinical indicators for NH compared to compared to 20.3% in 1995/6, and all clients recommended for placement in SC had low ARC scores compared to 91.7% in 1995/6. Time to placement also improved for both SC and NH.

Prior to 1995, entry to NH and SC was negotiated separately with each institution leading to concern about inappropriate utilization of NH beds for clients with low levels of disability, and about the size of waiting lists for NH. Demands for more NH beds were made despite the fact that empty PCH beds were available. In 1995, a SES was initiated in the region in which each client who requested placement in a LTC home was interviewed, assessed by a multi-disciplinary panel, and recommended for placement to a NH or PCH. The objective was to

improve utilization and efficiency of placement in the region (15). Implementation was associated with a more appropriate case mix of NH residents when residents in 2003 were compared to those in 1997. Compared to 1997, NH residents in 2003 had a decreased length of stay; a smaller proportion had no indications for NH care; a greater proportion were clinically complex and needed special care; and fewer had a low level ARCS.

Appropriate placement also likely improved due to the new beds within the city. Before 1995 clients with modest disability did not have access to a SC bed in the city and therefore were placed in a NH bed for reasons such as convenience and being closer to family. Provision of SC beds after 2000 in the city improved the efficiency of placement. With proper placement occurring, NH's were no longer congested and therefore wait times for clients placed in beds improved in both NH and SC. Other possible explanations could be change of policy for clients entering institutional care.

One major concern is that although time to placement improved with the addition of new SC beds the consequent increase in incidence rates across the spectrum of disability will lead to increase in time to placement as the new beds are occupied and waiting lists have increased again.

6.2.3 Longevity. Median survival following assessment increased from 27.6 months to 37.7 months over a 10 year period. Median survival in SC was 45.6 months in 2005/6 compared to 38.5 months in 1995/6, while there was no change in NH clients over 10 years.

The increased survival in SC observed may have occurred because clients referred to SC in 2005 had fewer risk factors for early death, although proportions of clients defined by degree of disability were similar in the early and later cohorts. It is also possible that the quality of care

has improved in PCHs, advancements in medicine have prolonged mortality or that the observation is an anomaly. However, such trends of increased longevity in the elderly population have been observed and accredited to such theories such as better control of infectious diseases and advancements in medicine (21).

6.2.4 Prediction of Bed Need. Increased longevity in LTC institutions coupled with an increased incidence of clients presenting to LTC can have serious ramifications. As anticipated, the prediction of optimal bed numbers for 2014 was substantially increased by the increased incidence and survival observed in the 2006 cohort. Compared to predictions arising from the earlier cohort, predicted SC bed need increased by 83%, while predicted SC beds for the cognitively impaired increased by 130%. Predicted NH bed needs increased by 30% and housing predicted need for housing for those with no disability increased by 105%.

Theories have been developed to explain the global increases in life expectancy. The first is the "compression of morbidity" theory which was proposed by Fries (1980). It asserts that the onset of chronic, irreversible illness will be delayed toward the end of a fixed life span so that morbidity is compressed into a shorter period before death (106). The second theory is the "expansion of morbidity" which assumes that the increase in life expectancy is caused by a reduction in the fatality rate of chronic diseases rather than by a decline in the incidence of these diseases (107). It holds that gains in longevity are associated with longer periods of morbidity. The theory states that the increase in longevity is a result from medical advances; therefore, those suffering from chronic conditions can live longer (108). The third theory proposed by Manton of "dynamic equilibrium" states that mortality and morbidity are not independent and that the same forces that reduce mortality also reduce the severity and rate of progression of chronic diseases (109). It is not clear which of these theories could apply to NLs LTC sector.

Prediction of future need for LTC makes multiple assumptions about incidence rates, degree of disability, survival, demographic change and care required. In this thesis, I have demonstrated that over time some of these assumptions changed: (1) the incidence of clients requesting LTC has increased substantially from 1995 to 2006; (2) although the degree of disability has not changed much over time, and the incidence rate of clients across the spectrum of disability has increased; (3) survival in those recommended for SC increased; (4) however, the size of the predicted population at risk (≥ 65 years by 2014 was similar whether based on 2000 or 2006 census. Furthermore we assumed that more appropriate types of beds would be provided. AH and SC beds for those with and without cognitive impairment would facilitate less utilization NHs. Even when the horizon for planning was close (2014) the plan based on 2000 data was a substantial underestimate when revised based on 2006 data.

This data has implications for other jurisdictions planning for the future. Wittenberg et al.(47) showed, using various assumptions about the population, that in England from 1996 to 2010 the elderly population (≥ 65 years) would remain fairly constant. However, by year 2031, the population is predicted to increase by 60%, causing a huge demand for institutional services. Thus, the projected number of older people in institutional care by year 2031 is expected to increase by 65% (47). However, current incidence rates (per unit population) of clients seeking LTC may increase, because the addition of new, client friendly, options for LTC to meet demand created by demographic change may also create supply induced demand. Kunkel et al. (48) projected the numbers of older people with need for LTC in the future through different disability/mortality scenarios. Estimates of the over-65 population expected to have a long-term disability in the year 2020 ranged from 9.4 million in the best-case scenario to 13.6 million in the worst case scenario. This compared to approximately 5.1 million older people experiencing a

long-term disability in 1986 (48). However, using disability based scenarios to predict need for LTC beds is problematic given the complex array of personal feelings towards institutional care, family support systems, care options available etc., which may influence the decision of those with disability to apply for LTC.

Clearly, predicting future needs for LTC is difficult. The Congressional Budget Office in the USA concluded that a 1.1 percent annual decline in the prevalence of disability in the elderly may be reasonable, but predicting the future prevalence with any accuracy is impossible (110). In England, an attempt was made to project future LTC demand and costs for cognitively impaired adults. Projections were highly sensitive to the assumptions made and relied heavily on mortality and disability prevalence rates (49). Our study has demonstrated that over a decade from 1995-2005 where disability within the community has likely not changed, short-term projections of LTC beds needed were strongly influenced by increased demand across the spectrum of disability. This may have been created by the provision of desirable SC beds. Although these beds were provided for those with modest disability, the supply may have stimulated people not only with modest disability but also those with more severe disability to enter the institutional LTC system.

One implication arising from the results is that because predictions are unreliable and likely to change over time, re-evaluation of these predictions should be undertaken at regular intervals using more up to date and potentially accurate data. This will require investment in electronic databases, accurate data collection, good methods to aggregate data and provide prediction models for policy makers, as well as to evaluate policy decisions made in response to interpretation of current patterns of supply and demand.

6.2.5 Predicting Mortality. Accurate prediction of death among clients entering LTC would be helpful for planning, for both the individual and the LTC system. Four factors were found to be independently associated with survival in the developmental cohort. Older age, male gender, "no indicators" for NH using RUGs III classifications, and high RUGs ADL score. The AUROC scores were considered fair with a score of .70 (95%CI .65-.75) and poor with a score of .67 (95%CI .62-.72) in the developmental and validation cohorts, respectively. However, with a score of .67 in the validation cohort, the mortality scoring index should be used with caution and no major decisions should be made using predicted instead of actual mortality. The AUROC may improve if more factors predictive of death were included.

Many studies have developed and validated mortality scores in the elderly. Lee et al. (2006) developed and validated a prognostic index for 4-year mortality in older adults using information from patient reports (52). They identified twelve independent predictors of mortality including age, sex, co-morbid conditions such as diabetes, cancer, lung disease, heart failure, tobacco use, and BMI, along with 4 functional variables. Their AUROC showed good discrimination with score of 0.84 in the developmental cohort and 0.82 in the validation. They concluded that the index provided a potentially useful tool to estimate 4-year mortality with readily available patient information (52). The Porock et al. (2005) study aimed to develop and validate a predictive model for 6-month mortality among clients in NHs and to inform research and practice with the goal of facilitating end-of-life planning and medical decision making (53). They used patient information derived from clients who had a full MDS assessment. The validated predictive model had an AUROC of .75 that included age, sex, diseases such as cancer, congestive heart failure, renal failure and dementia, clinical signs and symptoms, and adverse events (53). Flacker et al. (2003) designed a retrospective cohort study with development and

validation cohorts using information from the MDS to predict 1-year mortality in NHs for newly-admitted and long-stay residents (51). Demographic and clinical variables were associated with 1-year mortality in both types of residents. The AUROC showed fair results with scores 0.73 for newly admitted residents and 0.71 for long-stay residents (51). These scores are very similar to the AUROC of 0.70 in this thesis.

Accurately predicting death can be quite difficult as shown by the studies mentioned. Our predictive model showed poor discrimination with a score of 0.67 in the validation cohort. This could be due to the variables measured in this study. The studies referenced used detailed clinical information gathered from the MDS and patient charts, for example whether a client had cancer, lung disease, or diabetes. All of which were not included in the current study.

6.3 Limitations

Limitations of this analysis include:

1) The cohorts studied provided good data on disability and included most of the clients presenting to the SES but data was not collected on co-morbidity. Furthermore the full spectrum of disability in the population was not identified because some wealthy clients were able to enter private NHs without going to the SES and other disabled elderly clients continued to live in their homes with home care or family support.

; 2) The classification systems, while objective, fail to include factors known to the assessment committee that could change the LTC placement recommendation. For example, priority was given by the assessment committee to keeping couples together irrespective of the degree of disability. Furthermore these arbitrary decisions neglect the ability of selected PCHs to care for clients with disability defined by the RUGs III classification as requiring care in a NH.

; 3) The choices made using the decision tree are somewhat arbitrary and some characteristics such as aggressive behavior in those with cognitive impairment may settle over time.

; 4) The data were limited in scope and contained information on areas such as cognitive impairment that was difficult to judge accurately. Clients requesting LTC placement were not always formally evaluated for the presence of cognitive impairment and therefore the number of people with cognitive impairment may be underestimated. Also, the term Impaired Cognition used throughout this thesis is adopted from the RUGs-III disability assessment too and is implied to also mean dementia in clients. ; 5) The predictions made using the 2005/6 cohort may not be representative of future cohorts.

; 6) This thesis only represents the St. John's region and projections and recommendations to other jurisdictions may not be generalizable.

; 7) Future policy may divert more funding to home and community based programs and thus limit use of institutional LTC.

; 8) Although all researchers were trained and supervised by a consistent team, data for this study was collected by different researchers over time therefore data is subject to information bias

; 9) The NLCCA for Adult Long-Term Care form was completed for all clients seeking placement into LTC through the SES, and was the basis for the classification systems used in the current study thesis. Many assessors in Health and Community Services fill out this form and thus the accuracy and quality of this information cannot be controlled. In addition, they obtain information from family members/caregivers that may be biased.

6.4 Policy Implications

Currently LTC in NL is provided at home or in an institution. The latter care is provided in PCHs or LTC facilities. Home care support is provided to clients who fit the "Home Support Emergency Criteria" which are: requiring supportive services for discharge from hospital, caregiver stress which may result in placement breakdown, return to seasonal employment of the caregiver, or unavailability of student assistants during summer resulting in the need for Home Support. With such strict criteria dependence on costly institutional care is likely. Therefore, AH options are attractive. In addition this thesis points out several other areas for consideration in future policy as will discussed below.

6.4.1 Alternative Housing Options. Identifying alternatives to institutional care for the frail elders is of high importance, both because of public and private expenditures for institutional care and because of the decreased QOL that often occurs in such settings (77). NHs has been the primary source of institutional care for the elderly (79). The combined impact of increased seniors, increasing costs of nursing care, the improvement of overall health of older adults and dissatisfaction with NH care focused awareness on a gap in the "continuum" of care between housing for those with no disability and nursing facilities for the chronically ill (79).

ALF's were modeled after the Dutch residential settings in order to broaden the continuum of care for the elderly. The idea was to provide an "invisible support system" in a residential setting (79). ALF's have been the most rapidly growing segment of senior housing in the United States in the 1990's. As of 1998, there was an estimated 11,459 ALF's nationwide, with 611, 300 beds and 521,500 residents.

A number of factors are responsible for the rise of assisted living as the current LTC alternative of choice, one of them being that the elderly today are in better physical condition than their predecessors (111). The number of elderly with low to moderate care needs will increase as the population continues to age as well. The demands for alternatives that promote QOL and independence should increase accordingly. An ALF type residence may be a realistic option for Canada, adapting to senior's needs by providing optimal care.

The St. John's area provides housing options to seniors in facilities such as Kenny's Pond and Tiffany Village, however they are managed by the private sector and are expensive. Currently there are no subsidized housing options for clients without overt disability who request but do not need institutional care. In the current study 8% of incident clients seeking institutional LTC in 2005/6 were independent for ADL's, were continent and had no cognitive impairment. These clients appear that they would be better well suited in AH rather than institutional care.

6.4.2 Housing for the Cognitively Impaired. Dementia involves "a chronic deterioration of intellectual function and other cognitive skills severe enough to interfere with the ability to perform activities of daily living" (85). Its characteristic insidious onset combined with slow deterioration makes diagnosis of this disorder difficult. A person is often diagnosed as having Alzheimer's Disease once cognitive impairment is sufficient to interfere with normal social functioning and other causes of dementia have been excluded (92).

Remaining at home may not be a realistic option for those who have progressed past the early stage of dementia. Historically, people experiencing middle-to late-stage dementia have been admitted to institutional settings where basic and medical needs are met but home-like

conditions are lacking (96). Institutional environments can be stark and meaningful activity can be limited. Behavior problems, which occur at some point in the disease progression for up to 90% of persons with dementia, can be minimized through environmental modifications and caregiver skills (96). Design of the physical environment is increasingly recognized as an important aid in the care of people with Alzheimer's Disease and dementias. It is regarded as a therapeutic resource to promote well-being and functionality among people with dementia (97).

Special care units for older adults with dementia have been developed on the conviction that a non-traditional institutional environment that mirrored "home" like settings and a supportive social environment would reduce excess disability and improve QOL (98) Most studies of special care units have reported no improvements over traditional care in cognition, function, or behavior of residents. However, this may be due to the fact that traditionally special care units are attached to institutional facilities. A study comparing a specialized care facility to traditional institutional facilities with regard to QOL for residents with dementia, demonstrated less decline in ADLs, more sustained interest in the environment, and less negative affect (96).

Historically the care options available in NL, in particular the St. John's region, for clients with mild to moderate stages of dementia have been limited to LTC facilities. In the absence of aggressive behavior/wandering, care maybe provided in PCHs (112). In many instances institutional care is oriented towards a medical model of care, whereas a social model of care-one that is resident oriented and directed-may be more appropriate to support individuals with mild to moderate dementia. Often individuals with early to moderate stages of dementia can function well with supervision and limited professional and medical support; therefore, medically based institutional care options may not be appropriate for those individuals (112). In the western region of the province, Parfrey and McDonald, found that 15% of clients in one LTC

center had mild-to-moderate cognitive impairment as the only indicator present for permanent placement and were deemed more suitable for an alternate care environment. In addition, 23% of those waiting for NH placement in one location in the region were also deemed more suitable for enhanced assisted-living options (112). In 2004, the Provincial Government dedicated funding for the redevelopment of LTC services within the Western RHA. Within that budget the construction for new bungalows, referred to as the Protective Community Residences (PCRs), included and was based on a model of assisted living developed for the dementia population in Alberta and British Columbia. These PCRs were constructed to provide a home like environment, with common areas and private space to meet the needs of persons with dementia. Their physical design, including safety features, is based on best practices for dementia care. The approach and skills of staff was deemed essential to promoting QOL for residents.

As previously described, Hutchings et al. (2011) provided insight into the experiences of family members of residents diagnosed with mild to moderate dementia who were relocated from institutional-based care to a unique assisted-living environment and concluded that these residences were beneficial in the LTC of residents with special needs (112).

In the St. John's region in 2005, 12% of clients presenting to the SES had cognitive impairment and no disability indicators for institutional care. These clients would be deemed more suitable to enhanced assisted-living facilities such as those that are provided within the Western RHA. Over the past decade in the St. John's region restructuring of institutional LTC has occurred: Bed rates per 1000 people $\geq$ 65 years have substantially increased for SC and moderately decreased for NH. However, the Incidence rates of clients seeking institutional placement have increased by 42% and across all levels of disability. However there appears to be a need for more AH options and for protective community residences.

6.4.3 Government 10-year Plan. Consultations that occurred across the province indicate people wanted programs and services with a greater emphasis on removing barriers to social inclusion and building community capacity to support healthy ageing (113). In addition, a need for age-friendly policies, improvements in service coordination, and the availability of housing options to maximize independence was identified. A plan was developed by the Dept. Of Health and Community Services to promote the creation of a system that no longer relies heavily on institutions but provide a more fully integrated, client-centered model that is fiscally feasible and sustainable. Components of the client-centered model would include: case management, client-centered assessment, home support services, human resources, primary care providers, caregiver support, and medical supplies/equipment (113). It emphasized that a strategy that included: Healthy Living and Wellness; Person-Centered Service; Family and Informal Care-giving Support; Quality Services and Service Delivery; and System Sustainability. Each priority had multiple goals, and with them actions to achieve those goals. The data in this thesis cannot make comments from this information but can plan along with the government's visions and intentions.

6.4.4 A Plan with Government. Developing and organizing plans and health-care delivery systems for a population that need LTC services can be very complex (76). The need to improve the quality of care for those with chronic conditions and the continued sustainability of Canada's publicly funded health care system are critical and ongoing challenges for health policy makers and service providers (64). All services, including health, social care, housing, transport, social security, education, leisure and other community facilities, should provide the best possible opportunity for people to continue to lead the lives they want, whatever their age (75). However, poor co-ordination between and within different services, both at times of episodic

events and in the long-term, may contribute to failure in meeting the needs of many older people. Since 2006 the Government has made many strides in accordance with their strategy by investing almost $480 million across the continuum of care such as PCH programs, home support programs, LTC and community support services system, building and renovations. However, an integrated care approach that links the investments already made to new initiatives may be a viable option for the province. The projections made in the current research will be influenced by more investment in home care, more AH strategies to prevent institutionalization, and by increased demand stimulated by the provision of alternative new facilities. Consequently planning for the future requires an integrated approach.

The goals of integrated care efforts have been to improve accessibility, quality of care and financial sustainability (75). The SIPA (French acronym for System of Integrated Care for Older Persons) is a program of integrated care for vulnerable community-dwelling elderly persons in Quebec. SIPA offered community-based care with local agencies responsible for the full range and coordination of community and institutional health and social services. The program was compared to normal care in a randomized controlled trial for outcomes in utilization and public costs of institutional and community care. Results indicated, although cost neutral, SIPA succeeded in changing the configuration of care with a reduction in the overall acute hospital and NH utilization associated with a concomitant increase in community care (70). The Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) in Quebec considers itself a different model of coordination-based integrated care (74). As opposed to fully integrated systems, this model uses all the public, private, or voluntary health and social service organizations involved in caring for older people in a given area. Every organization keeps its own structure but agrees to participate under an umbrella system and to adapt its

operations and resources to the agreed requirements and processes. Hébert et al. (2009) used a population-based quasi-experimental design with pretest, multiple posttests and a comparison group (74). The three experimental areas in Eastern Quebec were matched with three comparison areas in the same region. A total of 1501 persons identified at risk of functional decline were randomly selected (experimental n=728, comparison n=773). Participants were assessed over a 4-year period for disabilities, unmet needs, satisfaction with services, and empowerment. In the fourth year of the study, the annual incidence of functional decline was lower by 137 cases per 1000 in the experimental group, whereas the prevalence of unmet needs in the comparison region was nearly double the prevalence observed in the experimental region. Health services utilization, a lower number of visits of emergency rooms and hospitalizations than expected was observed in the experimental group. Based on the positive PRISMA experiment, the Quebec Ministry of Health and Social Services decided to generalize the model to the entire province (74). The On Lok model experimented in San Francisco's Chinatown on a small number of people (n=140) with cultural homogeneity (67). Results showed significant differences in favor of the intervention group compared to the control group for functional independence measures and less use for nursing homes. This model of care for the frail elderly could be generalizable to NL, which had a low population and is culturally homogenous much like Chinatown in San Francisco.

In the current research, when asked about an integrated care approach, Nova Scotia policy makers agree with the approach, more so because their services which include institutional care and home care are divided amongst two departments, however are working towards integrating. Manitoba has developed the Program of Integrated Managed Care for the Elderly (PRIME). PRIME is for seniors ≥ 65 years of age who have multiple health problems

that need a moderate degree of monitoring and co-ordination of professional services. NL has a pilot project in planning called 'The Community Rapid Response Team' which embodies much of the same qualities that an integrated system requires, however there are no results from this study as of yet and the fact remains that the spectrum of LTC in NL is disjointed.

6.4.5 A Framework for Newfoundland and Labrador. The following is an integrated framework for care that involves new and old government programs, along with new options that could be valuable to the province. The framework is a combination of the three frameworks for integrated care found in the literature.

Care needs may require services from all levels of the health, community, and social services systems. Services must be coordinated and provided over long periods of time, often measured in years and even decades (75). The approach must be client-centered and geared to improving the efficiency, cost-effectiveness and organizational aspects of the health system in which curing, caring and patient management takes place (62). This philosophy is 'easier said than done', and must be formatted into a flexible framework that can be applied to the population. Frameworks of integrated care are tools that can be used to guide the implementation of reforms. Frameworks do not dictate how a health reform must be structured; local or regional integration models should include framework features combined in ways that are appropriate to the goal(s) of reform and local contextual features of care (64).

6.4.5.1 Vision/Principles. Experience and theory in the field of complex adaptive systems highlights the importance of a clear vision and direction of travel set by national policy (116). This is important in integrated systems where they rely on a range of organizations and sectors. Whether they are voluntary or non-governmental, private-for-profit, professional or

community, they all need to work together (75). In the document 'Close to Home: A Strategy for Long-Term Care and Community Support Services' the Government of Newfoundland and Labrador states their Vision, Mission, and Guiding Principles that provides its commitment to sustainable LTC (8). The Vision states: *Individuals and families requiring long-term care and community support services will achieve optimal independence and quality of life in their homes and communities.* From the stakeholder interviews a common theme across all jurisdictions was a need for more resources allocated to home care supports. Despite NL having the highest rate of expenditure per 100,000 people and per 1000 ≥ 65 years old, there was still a demand for more funding. A study by Fischer et al (2003) found that termination of community-based LTC programs was associated with a significant increase in the probability of long-term NH placement (73). Hollander et al. (2007) claim that home care can be a cost-effective substitute for residential care if incorporated under an integrated umbrella (115). The governments ambitions aims to be guided by a 'Person-Centered Model of Care' which focuses on working with the individual to establish a plan to match services with identified needs utilizing a varied range of services and to ensure individuals receive supports early enough to prevent crisis or deterioration (8). Banks, Kodner and Hollander believe that a successful integrated system for vulnerable populations places the patient at the center of the system (75, 62, 76). The government's principles also state that care should: involve family involvement and support; be accessible; be flexible and responsive to changing needs; be accountable; and be fair and just. The current system does encourage family involvement and support through the entire process starting at one's application. Its accessibility to institutional care has improved from 1995-2006, however there is still an average delay of 6 weeks to access NHs. Its flexibility could be improved if there were more appropriate options for clients such as SC for the cognitively

impaired, AH for clients with no overt disability, and a 'revolving door' for clients that change in disability status. The government is accountable, fair and just for its clients.

6.4.5.2 Funding. More often than not, form follows financing (8). This means that the division, structure and flow of funds for health and social care and related services can affect virtually all aspects of integrated care. A single funding envelope is critical to maximizing the efficiency, effectiveness and quality of care provided (76). Control over funding allows for resource transfers between system components and allows administrators to resolve many practical problems across the system components such as different limits on caps on funding, varying user fees, different eligibility requirements, and policies about inconsistent remuneration for similar services or providers. Because of the changing demographics, governments are concerned about the future costs of sustainable health and social care. These concerns are driven by increased incidence rates of clients requesting LTC, increased longevity, decreases in informal care provided at home, and the increase in chronic disease. Therefore a plan is necessary to maintain optimal funding for long-term and continuing care in the future. Some examples of possible approaches to financing care are private savings such as medical savings accounts, private insurance which would be purchased by the user, private insurance with public sector support such as subsidy, tax concession or partnership arrangements and finally public sector tax based support that is funded from general tax revenue. The final option has been a topic of interest in Canada. The Institute for Research on Public Policy (IRPP) conducted a study entitled "Financing Long-Term Care in Canada" and claimed that LTC warrants some form of insurance, preferably public (116). Private long-term insurance is subject to significant market failures resulting in heavy government regulation and large subsidies. On the other hand a universal public insurance plan that provides full coverage based on care needs would be an

equitable solution for Canadians (116). This innovation has been implemented in countries such as Germany and Japan in recent decades to address the demographic change (117).

In the current research, when asked about a public LTC insurance plan, NL and Saskatchewan policy makers suggest that it may not make a difference as LTC is currently heavily subsidized and publicly funded. The province of Manitoba has expanded its universal care to home care, pharmacare, chiropractic coverage, supportive housing and other seniors' supports to help build a lasting sustainable health care system.

6.4.5.3 System Best Practices. Administrative best practices would involve a single or highly coordinated entry structure for clients requesting LTC, a central electronic database to monitor incidence rates in home care and institutional care, and application of evidence based interventions. The manner in which government regulatory and administrative functions are structured and devolved can help eliminate program complexities, streamline eligibility and access, and better manage system resources (62). A major problem with current systems is the negative impact of silos for different components of care. All services for a given population group should be under the administrative and financial control of one administrative entity, or, if there must be two or more entities, a highly coordinated structure must be in place (115).

This thesis indicates that Nova Scotia clients needing LTC and continuing services are vulnerable because their LTC continuum is divided amongst two government departments. In NL the SES to institutional LTC is separate from the SES to home care.

The increasingly complex challenges facing the Canadian and other health care systems require sophistication in the arrangement of these systems (118). Linking information from different sources at an individual level has been accepted as a way to conduct population-based

health research. The long-time existence and use of cancer registries, perinatal databases and a lengthy list of single-use study databases demonstrate the effectiveness of informatics, both for epidemiological study and for health care management (118). An integrated electronic information system eliminates the need for multiple assessments with clients and families having to tell their stories repeatedly. Regularly collected information on clients, service utilization and costs, with population data, can be used as the basis for sophisticated research and analysis on a range of clinical and administrative issues (117). Currently, much of the information used for LTC planning is provided on a retrospective basis as standardized provincial collection databases are not available (DHCS). Phase 1 of 'The LTC Needs Assessment Project' is already underway. It includes scanning of client records to develop a model to assist the department in projecting and planning for LTC needs. However, submission of MDS 2.0 data to CIHI is not mandated in the province.

In the current research I have demonstrated increasing incidence rates of clients seeking institutional LTC across all levels of disability and increased longevity within PCHs, outcomes that impact on the predictions of need in the future. Furthermore, NL stakeholders believe there should be ongoing assessments to give facilities a 'revolving door'. This would allow clients who have either improved or declined in health status to transfer to a more appropriate setting post admission. The Quality Care Program is one of three goals in the 'Translational and Personalized Medicine Proposal' proposed by Dr. Patrick Parfrey and Memorial University. It aims to decrease health care costs while improving the appropriateness of health care service utilization (119). One of the initiatives is to develop the electronic infrastructure and the predictive analytics platform to improve the planning and provision of LTC in NL. It proposes a province-wide database that will be linked to a health analytics program, with relevant decision

tools and prediction models capable of providing incidence rates, predicted future needs, wait-times for transfer, policy recommendations on provision versus actual need, and predicted mortality. It can be linked to monitoring of primary and acute care visits following transfer to an institution (119). The Quality of Care Program would thus provide a basis for monitoring changes in incidence rates and the impact of new interventions of these incidence rates.

6.4.5.4 Clinical Systems. Clinical best practices suggest a SES across the entire continuum of LTC, multidisciplinary teams, and a single standardized assessment tool. A single-entry provides for a consistent screening mechanism that ensures an appropriate match between needs and demand (115). NL does not have a single point of entry and is divided into separate entities of home care and institutional care. A single or coordinated-entry system increases overall systems efficiencies because it minimizes the possibility that unnecessary care may be provided. It can provide a focal point in local communities for care services, which means clients don't have to speak to multiple sources to find out what is available to them and how they can obtain it (115). In this thesis Eastern Health decision makers were not convinced that separate entry systems for home care and institutional were a concern and believed that coordination between these systems was adequate.

A multidisciplinary team including individual case managers/coordinators would provide ongoing assessment and guidance through the continuum of care. The multidisciplinary team approach widely recognized as a central element of geriatric care. In an evaluation of international experiments in integrated care for the elderly, common features of an effective integrated care involved case management, geriatric assessment and a multidisciplinary team (67). The role of case management was shown to be an important channel of clinical responsibility, an essential means of linking medical and social services, and a link to financial

responsibility for future and current clients. Integrating case managers into a multidisciplinary team ensures that geriatric evaluation is coupled with long-term management.

My current research reveals that new pilot projects across jurisdictions include co-ordinated multidisciplinary teams. Saskatchewan, Manitoba, and NL have initiated enhanced home care projects to avoid hospital admissions and frequent ER visits. The home care team usually includes a care coordinator, family physician, nurse practitioner, registered nurses and other allied health professionals that are found in acute care facilities.

A consistent client classification system across all levels of care allows for the analysis of clients across service delivery components and facilitates an "apples to apples" comparison (76). The Inter-RAI is a series of standardized assessment tools developed to improve health care for persons who are elderly, frail, or disabled and collects high quality data about the characteristics and outcomes of persons served across a variety of health and social services settings (119). Additionally, the inter-RAI instruments utilize a common language, clinical concepts and measures that provide data from an individual, community, regional, provincial, and national perspective essential for the provision of efficient, effective service options. Approximately six years ago RHAs in NL began to implement the assessment instrument and as of 2006 a total $3.9 million had been invested (27). In 2012/3 the inter-RAI will be introduced for home care in each region. The Quality of Care Program proposes this tool along with provincial LTC planning electronic infrastructure to improve planning and evaluation. The information will permit comparison of home care defined by disability to institutional LTC (119).

This thesis reveals the utility of a consistent classification system as an accurate comparison of incidence rates by level of disability applied across one decade. However, the data were collected manually and this was an expensive time consuming undertaking. Fig 6.1 provides a framework for integrated care and Fig 6.2 shows how LTC care for individual clients could flow.

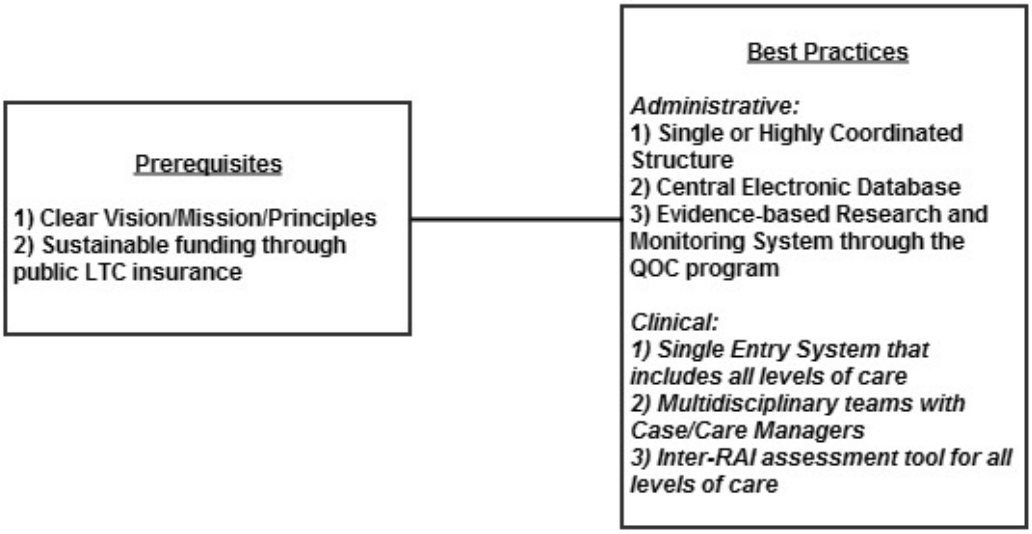

Figure 6.1 A Framework for Integrated/Coordinated Care.

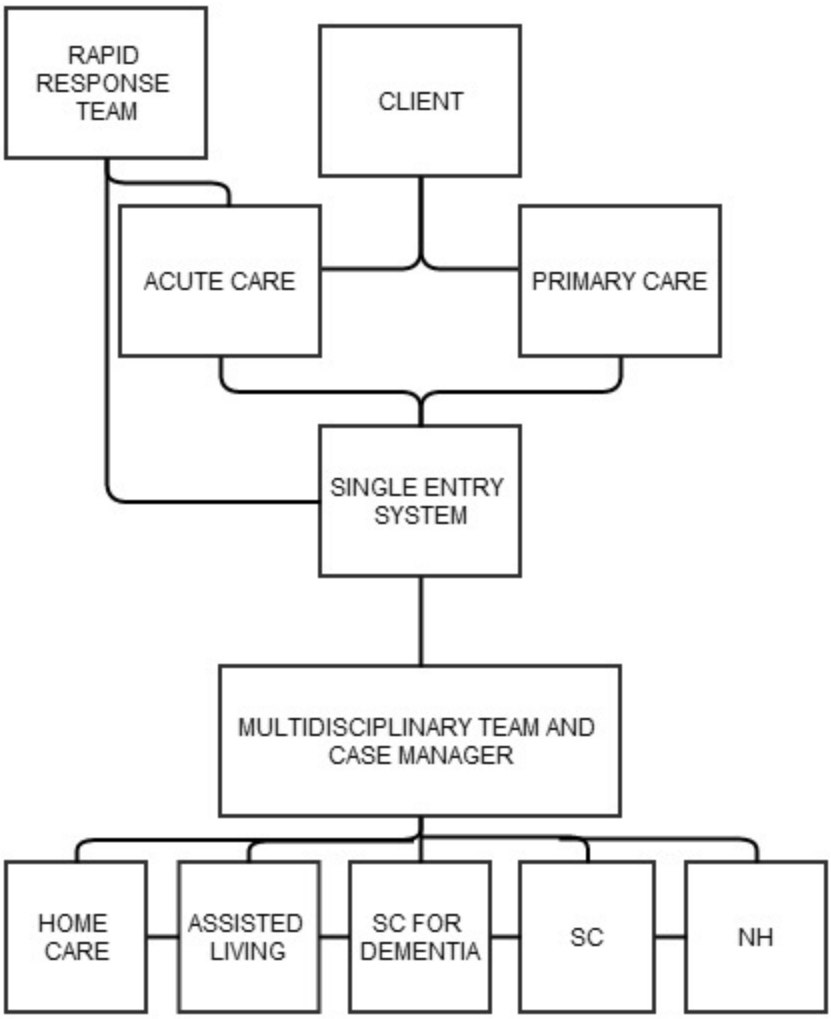

Figure 6.2 Care Flow for Long-term Care Clients

6.5 Conclusions and Recommendations

Across one decade in the St. John's region incidence rates of clients applying to institutional LTC increased substantially and longevity increased in PCHs. As a result predictions of need were changed substantially. Predictions of bed need for AH, facilities for those with cognitive impairment, PCHs and NHs suggested capital investment was necessary to provide more beds for those with moderate disability. It appears that the supply of new PCHs in the region was associated with increased demand across all levels of disability. However, as current predictions of bed need will be influenced by future interventions, particularly in home care, and by increased demand arising from the population it is proposed that LTC be structured to improve co-ordination, to prevent institutionalization, and to develop informatics and analytics that facilitate planning and evaluation.

The main results of my research have found that: 1) from 1995-2006 the rates of clients applying to institutional LTC in the St. John's region have substantially increased; 2) appropriateness and efficiency of placement had improved however increasing rates may cause waitlists to once more increase; 3) when comparing predictions of future need using the data from the 2000 cohort to that from the 2006 cohort, bed need was drastically different between the two; 4) while a useful tool, predicting mortality showed poor discrimination in this thesis and; 5) LTC across the country is diverse in structure and budget allocation, however it has similar pressures in home care, chronic disease and the ageing population.

From these results, I recommend the LTC sector in the St. John's region: 1) provide options such as AH for those with no overt disability, SC for the cognitively impaired, and housing for younger adults with complex needs; 2) operate under an integrated care system that is centered by the client and includes the entire spectrum of care from home care to NH care and

facilitated by a case manager and a multidisciplinary team and; 3) Finally, develop methods to monitor the system annually and provide informatics and analytics tools that facilitate planning and evaluation.

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Appendix A LONG-TERM CARE CLASSIFICATION WORKSHEET

LONG TERM CARE CLASSIFICATION WORKSHEET **Single Entry**

Clients **COHORT** _____

Computer (CC #)_____

Initials:_____ Age:_____/Birth Date_____ ID Number:_____
(MCP)

Sex:_____ Assessment date :_____ Residence (to determine Health Region) _____
(by community health assessors') Currently waiting from at time of Assessment (home, hospital etc.) _____

Panel Date_____ **Panel Level of Care** (1-4)_____ Was Protective Care Reco_____
Panel Placement Decision : _____ Nursing Home _____Personal Care Home
Comment on Clients Choice ? – Note 1st & 2nd choices_____
_____
If recommended for Personal Care Home: note if Private Pay _____ or Subsidized_____
Comments if portable subsidy or other and if waitlisted for portable subsidy
_____

Current Status: **on the day the researcher extracted data from LTC application) Date:**_____
.. **Placed in LTC:** ***NH or PCH(circle);*** **Date Placed**_____ **Name of Facility**
_____
.. Still actively on waiting list for Institutional Placement _____
.. Receiving Home Support Services, not currently on waitlist _____
.. Receiving Home Support Services/ also on waiting list for placement
_____
.. **Deceased** while waiting _____ (Note date of death if available)
.. Other _____ (eg. Note if precautionary, referred out of region, withdrew & note approximate date this occurred**)**

Home Care Functional Needs Indicators - **put in appropriate scores below**
'9' is used if it doesn't apply i.e. toileting – incontinent-does not toilet'

**Eating* ☐ *Bathing* ☐
note if g-tube feeds

**Toileting* ☐ *Grooming* ☐
note if incontinent/attends, does not toilet

**Transferring* ☐ *Indoor Mobility* ☐
note if cane, wheelchair

**Dressing* ☐ **Outdooor Mobility* ☐

Potential for Injury ☐ *Memory* ☐
Note specifics: wandering, aggressive etc *Note specifics if available*

Sum of 13 Functional Need Indicators ____
___*****

Coping ☐ *(1-5)*
note specific: depression, chronic anxiety etc.

Urinary Management ☐ *(11-20)*
Note if indwelling catheter in place

Bowel Management ☐ *(26-62)*
Note if ileostomy, colostomy in place

*categories with n/a, totals will be adjusted by computer

Functional Need Score (1-5)

1-
2 – (6-10)
3-
4-(21-25)
5-(26-

Comments: in this section (Reason for seeking placement, social supports network etc. and relevant diagnosis

_____
_____
_____
_____
_____
_____
_____
_____

Informal Supports: (Y/N) _____

(*unpaid & unsupervised persons eg. family, friends)* _____

_____

_____

Support services currently _____

_____

in place *(type & quantity* _____

_____
if available)

Resident Classification System 'RCS' (using translation Paradigm from APPI; computer generated from score on first page)

Eating ☐ Potential for Injury ☐ Urinary Continence ☐

Toileting ☐ Ineffective Coping ☐ Bowel Continence ☐

Transferring ☐ **BDL Score** ☐ **CCL Score** ☐

Dressing ☐

ADL Score ☐

RESIDENT CLASSIFICATION SCORE ☐ **(A-Low to G-Very High)**

RUGs III Professional Care Requirements ✓ **all that apply and** comment below if necessary- could be more than one;
*(based on **RUGs III** seven Hierarchical Categories with each category having a number of conditions; see RUG's descriptors)*

Special Rehabilitation ☐
Extensive Clinical Services ☐

Special Care ☐

Clinically Complex ☐

Impaired Cognition ☐

Behaviour Problems ☐

Reduced Physical Function ☐

Comments: _____

_____

***RUGs ADL:** (used to assess ADL's/reduced physical function, score below- refer to RUGs index ordinal scale)

Bed Mobility ☐

Toilet Use ☐

Transfer ☐

Eating ☐

RUGs-III ADL Index Ordinal Scale

ADL Variables	Score
Bed Mobility	Independent or supervision 1
Transfer	Limited assistance 2
Toilet use	Extensive assistance or total dependence:
	Other than 2-person physical assist 4
	2 or more persons physical assist 5
Eating	Independent or supervision 1
	Limited assistance 2
	Extensive assistance or total dependence 3

RUGs III ADL SCORE ☐ sum of ADL's (ranges from 4 "completely independent" to 18 "high")

Appendix B QUESTIONNAIRE

1. How is long-term care structured in your region? (You can provide a link or possible document to answer this question). Is LTC and home care connected? And Acute Care? What are the different levels of LTC available (and who funds these services).
2. What is the budget allocated to home care, nursing homes, and personal care homes? (If you don't know the answer, can you provide a person to contact or resource to answer the question)
3. Over the next 10 years, what do you think the additional needs of long-term care will be in your region? (e.g. More beds, more resources allocated to home care)
4. What are the unresolved issues in your region at present time? (E.g. St. John's: more supportive housing, more subsidies for personal care homes, more specialized facilities for cognitive impairment, more funding for home care, integration across the continuum of care.)
5. Who are the most vulnerable in your region and are their needs being met?
6. Is there an urban-rural divide in long-term care in your region?
7. Should there be a single entry point for all LTC?
8. Have there been evaluations of interventions of long-term care in your region in the last 10 years? (E.g. Have you examined cohorts of clients entering the long-term care system?) Are there at the present time evaluations of interventions? Can you provide titles and resources for these interventions?
9. Do you think there should be a public long-term care insurance plan?
10. Quebec has evaluated an Integrated Model for long-term care (SIPA). Do you think this is a reliable system? (See attached article).

Any additional comments:

Appendix C ALBERTA RESIDENT CLASSIFICATION SYSTEM (ARCS)

The Alberta Resident Classification System for Long Term Care Facilities used eight indicators to predict variation in nursing resource use derived from three domains: Activities of Daily Living (ADL), Behaviours of Daily Living (BDL), and Continuing Care (CCL).

Predictors within each of the domains:

Activities of Daily Living (ADL) Indicators:

1. Eating
2. Dressing
3. Toileting
4. Transferring

Behaviours of Daily Living (BDL) Indicators:

5. Ineffective Coping
6. Potential for Injury to Self and Others

Continence (CCL) Indicators:

7. Urinary Continence
8. Bowel Continence

Nursing Resource Use for the ARCS Categories

Measure of resource use was computed from actual time spent by providers caring for patients. Both direct (face to face) and indirect care activities were included in measuring the time spent. Indirect care activities were defined as those tasks specific to an individual patient but not performed in his or her presence. These included such items as charting, family consultation and coordination with other providers. To allow comparison across providers and summation of individual provider measures into a composite index, staff time was measured in a common unit, relative labor cost weights. (A minute of RN time was counted as a minute of RN equivalent time (relative weight= 1.00. Since RNA and NA salaries were lower than RN salaries, their weights were less than one: thus a minute of RNA time was less than a minute of RN time.

A resident's score on each of the eight indicators is combined using a series of decision rules which place the individual in one of seven classification categories. These categories labeled A through G are ranked from low to high in terms of care requirements and resource use. Weights were assigned to each category based on the differences between the nursing resources used by residents in the seven categories.

Categories	Weighted Nursing time (RN, RNA, NA)		
	Mean	**S.D.**	**Relative Weight****
A	30.92	18.36	1.00
B	43.21	23.63	1.40
C	59.68	24.47	1.93
D	69.88	31.78	2.26
E	89.57	34.88	2.90
F	105.12	37.90	3.40
G	119.20	44.32	3.86

Table taken from the "Alberta Patient Classification System for Long Term care Facilities: Final Report" Semradek J et al.

***Relative weight= Mean Resource Use Category I ÷ Mean Resource Use for Category A (i= A, B, C….G) When these weights are standardized, with category A having a weight of 1.0, then resource use measures for the seven categories are noted above (Category B resident requires, an average, 1.4 times as much nursing care time as a category A resident, and a category G resident requires 3.86 times as much)*

Category 'A'- patients with low ADL's, low BDL's and non-med incontinence problems. They have little or no functional impairment who require minimal supervision, although they may require a supportive environment to function at their potential levels (e.g. patients prepared for independent living or who require supervision to prevent deterioration in their condition).

Category 'B'- patients with a low ADL and a med to high BDL, or those with a med·low ADL and a low to medium BDL. These combinations require about the same levels of care (e.g. patients with minor physical handicaps that require restorative rehab, or in patients with mild cognitive impairment- early Alzheimer's). Higher BDL's arc offset by lower ADL's in this category. Patients with highest level of incontinence are excluded.

Category 'C'- comprise three clusters of patients. As in 'B', the clusters represent different combinations of ADL and BDL levels: lowest ADL with highest BDL, med-low ADL with high BDL and med ADL with low-med BDL levels. However, in 'C', the BDL's are higher for any given ADL level than they arc for 'B'. Patients with highest level of incontinence are also excluded (patients with early stage multiple sclerosis requiring little physical care, but are emotionally liable, or stroke patients with moderate physical deficits who need emotional support).

Category 'D'- comprise the largest number of combinations: patients whose combined ADL and BDL would have put them in A, B, or C but who have incontinence of both bowel and bladder: patients with no or occasional incontinence if they have med-low ADL's and very high BDL's, med ADL's and high BDL's, or med-high ADL's and BDL's from low-high (paraplegics having bowel/bladder retraining, younger CVA, MS, organic brain syndrome etc.).

Category 'E'- four different combinations: patients with lower ADL's must have either med-high CCL's or very high BDL's. Patients with med-low ADL's *only* if very high BDL's **and** need management or retraining for urinary incontinence. Those with medium ADL's and high BDL's and bladder management problems are also in this category. Patients with no or low incontinence

are in this category only if they have very high BDL needs. Patients with med-high or high ADL requirements, whether they require management of urinary incontinence or have no incontinence, if they do not have very high BDL requirements (very frail, confused elderly, old stroke patent, severely arthritic patient, alcoholic with Korsakoffs syndrome, brain injured patient).

Category 'F'- primarily patients with heavy care requirements: highest ADL's who also have some incontinence problems. Without the highest ADL's a patient could fit in category F, if the physical care requirements (ADL and incontinence) are complicated by behavior problems. Patients with very high BDL's are not included unless they have lower ADL's (advanced dementia, bedridden, non-mobile with incontinence, MS, or palliative care).

Category 'G'- Highest BDL's and med-high ADL's. Those with med-high ADL requirements must also have some incontinence (advanced neurological diseases such as MS, ALS. Huntington 's disease, Palliative Care, severe dementia requiring high physical care, severe rheumatoid arthritis).

Appendix D RESOURCE UTILIZATION GROUPS (RUGs III)

The RUGs-III classification system consists of seven main clinical groups devised as hierarchy, ranked by cost. The seven groups are:

1) **Special Rehabilitation**- four subcategories - based on amount of therapy resources (any combination of physical, occupational, or speech therapy) provided to the resident, with further splits based on ADL scores.

4 subcategories:

1. Very high intensity multidisciplinary rehabilitation-450 minutes or more of rehabilitation therapy, at least 5 days per week of one type of therapy, and at least two of the three therapies provided.
2. High intensity rehabilitation-300 minutes or more of rehabilitation therapy per week, and at least 5 days per week of one type of therapy.
3. Medium intensity rehabilitation ·150 minutes or more of rehabilitation therapy per week, and at least 5 days per week of rehabilitation therapy.
4. Low intensity rehabilitation· 45 minutes or more of rehabilitation therapy per week, and at least 3 days per week of rehabilitation therapy, and at least two types of nursing rehabilitation occurring at least 5 days per week.

2) **Extensive Services-** residents who have a RUG-III ADL index score of at least 7 and who meet at least one of the following criteria: parenteral feeding, suctioning. tracheostomy, ventilator/respirator.
3) **Special Care-** residents who have a RUG-III ADL index score of at least 7 and who meet at least one of the following criteria:, burns, coma, fever, with vomiting, weight loss, pneumonia, or dehydration, multiple sclerosis, pressure ulcers or stage 3 or 4, quadriplegia, septicemia, intravenous medications, radiation treatment, tube feeding.
4) **Clinically Complex-** residents who meet at least one of the following criteria: aphasia, aspirations, cerebral palsy, dehydration, hemiplegia, internal bleeding, pneumonia, stasis ulcer, terminal illness, urinary tract infection, chemotherapy, dialysis. four or more physician visits per month, respiratory or oxygen therapy, transfusions, wound care other than pressure ulcer care, including active foot care dressings
   OR;
   Residents who meet the criteria for the extensive services or special care categories but who have a RUG-III ADL index score of 4 - 6.

5) **Impaired Cognition-** residents with a RUG-Ill ADL index score of 4-10 who have cognitive impairment in all of the following dimensions; decision making (not independent; orientation (any problem recalling current season, location of own room, staff names or faces, or that he/she is in a nursing home).; short-term memory loss.
6) **Behaviour Problems-** only residents with a RUG-III ADL index score of 4-10 are classified in this category. Residents who display daily problems with; inappropriate behavior, physical abuse, verbal abuse, wandering or with hallucinations.

7) **Reduced Physical Function-** Residents who do not meet the conditions or any or the earlier categories, including those who would meet the criteria for the impaired cognition or behavior problems categories but have a RUG-III ADL index of more than 10.

The ADL index is a summary measurement of functional capacity, produced by combining four ADL measures (toileting, eating, bed-to-chair transfer and bed mobility)

Appendix E THE ALBERTA HOME CARE CLIENT CLASSIFICATION – FUNCTIONAL NEED SCORE (FNS)

To determine the care requirements of the clients accessing the Long Term Care sector and those currently in the system, a classification worksheet was developed to include keys indicators that would assess the functional needs of the clients and group them according to their level of independence.

13 key indicators were selected for review. These indicators were studied in detail in the province of Alberta* and found to be both reliable and valid. They include:

1. Eating
2. Toileting
3. Transferring
4. Dressing
5. Grooming
6. Bathing
7. Indoor Mobility
8. Outdoor Mobility
9. Memory
10. Potential for Injury to Self and Others
11. Ineffective Coping
12. Urinary Continence
13. Bowel Continence