Tipping Points to Institutional Care for Persons Living with Dementia: Analyzing the Policy Trajectory in Ontario

by

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Institute of Health Policy Management and Evaluation
University of Toronto

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Abstract

Most people, if given a choice, would remain in their own home and community as they age. This desire does not diminish for persons living with dementia (PLWD), yet many end up prematurely or inappropriately in residential long-term care (LTC), or waiting in a hospital bed for placement. While institutional care is valuable for those in need of high intensity care, it is ill-suited for those with lower intensity care needs. Premature or inappropriate placement of PLWD is not good for individuals (PLWD and their caregivers), or for the system (inappropriate use of resources), yet occurs in part because PLWD often have multiple complex, ongoing health and social needs; however, this thesis argues that it also is a result of care systems focused on episodic, curative care, and by fragmented services that are ill-equipped to support PLWD safely and cost-effectively in the community.

While much policy analysis has focused on demand side issues (e.g., an aging population, dementia projections and needs), this research addresses supply side factors – particularly local system capacity to provide needed community-based care options for PLWD to live safely and cost-effectively in the community for as long as possible. It uses Neo-institutionalism, a high-
level theory drawn from political science, to explore the historical and policy legacies for community based care of PLWD and predict what one would expect to see in the future if Ontario remains on the same familiar path. It also uses a *Balance of Care (BoC) simulation methodology* to explore what the system will actually provide PLWD to age safely at home. The conceptual and applied approaches combined are expected to provide a greater understanding of the policy trajectory for home and community care, its impact on current resource allocation decisions at the local level in Ontario and the potential for H&CC and concerted health and social care interventions to help offset the growing healthcare costs for high intensity users of the system like PLWD.
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Chapter 1
Introduction

1.1 Purpose for Inquiry

Most people, if given a choice, would remain in their own home and community as they age (Sinha, 2012; Van Hoof et al., 2013). This desire does not diminish for persons living with dementia (PLWD). While a majority of PLWD do reside in the community (Alzheimer Society of Ontario (ASO), 2007; Alzheimer Society of the United Kingdom, (ASUK), 2011), many end up in long-term care (LTC) homes or on a LTC placement “wait-list” while remaining in a hospital alternative level of care (ALC) bed\(^1\) or in the community. While LTC homes are valuable resources for those with high level care needs, there remains a number of PLWD who encounter premature or inappropriate institutionalization even at relatively low levels of need. A 2010 report by the Canadian Institute for Health Information (CIHI) entitled *Caring for Seniors with Alzheimer’s Disease and Other Forms of Dementia* cites one in six (17%) seniors with dementia and low impairment (little difficulty with cognition and self-care) as living in residential care (not including PLWD in ALC beds or in the community on a LTC wait-list for placement) (CIHI, 2010a). Dementia is the primary cause/risk factor for LTC placement among older Canadians and a key diagnosis related to hospital emergency department (ED) visits and ALC beds (Gill et al., 2011; CIHI, 2011c,d; Andel et al., 2007); this has PLWD occupying some of the most expensive places in the health care system.

The use of high cost institutional care by PLWD in part results from the complex, chronic and progressive nature of dementia (neurocognitive and eventually physical deterioration); however, this thesis argues that it may also be the consequence of a failure of health care systems to adapt to changing demand side factors (i.e., an aging population with increasing

\(^1\) Alternative Level of Care is a term used in acute care hospitals where patients who no longer need acute care hospital services remain in hospital beds until they can be discharged to a more appropriate care setting.
numbers of PLWD and their growing health and social care needs), which limits their capacity (supply side factors) to support PLWD safely and cost-effectively in the community for as long as possible. Where demand side factors play an important role in service utilization and policy planning; supply side factors, particularly system capacity to support PLWD in the community, are crucial in determining where people end up.

In making this argument, this thesis aims to go beyond a conventional focus on naturally occurring demand side issues to investigate linkages between the current capacity for PLWD (particularly those in the early to moderate stages of dementia) to age at home and the policy legacy that has influenced this capacity (i.e., how historical policy decisions impact on individuals and the system), and document a history of attempts for policy change at different points in time between 1995 and 2012. Specifically I will examine home and community care (H&CC) needs and interventions for PLWD (demand side factors); structural dynamics of the health care system (supply side factors) and the extent to which it is able to meet demand; identify any detectable gaps between demand and supply; if/where gaps exist, explain them at a conceptual and an applied level; and reflect on what one can expect to see in the future if nothing changes.

At a conceptual level I will draw on neo-institutionalism, a macro level theory derived from political science, to investigate how relevant institutions and structural relationships provide the context for historical and current policy decisions related to the way in which health care is organized and delivered; how these decisions have shaped supply side factors at a local level in Ontario; and consider the impact of this historical trajectory for care of PLWD in the community.

At an applied level, a Balance of Care (BoC) simulation methodology, derived from BoC research conducted in the United Kingdom (Challis & Hughes, 2002) and adapted for use in Ontario will be used to explore what the system might actually provide PLWD to age safely at home. The conceptual and applied approaches combined are expected to provide a greater understanding of the policy trajectory for H&CC, its impact on current resource allocation decisions at the local level in Ontario, and the potential for H&CC and concerted health and
social care interventions to help offset the growing health care costs for high intensity users of the system like PLWD.

The remainder of this chapter will build the context for this thesis highlighting the growing impact of dementia (demand) on the health care system (supply), the policy relevance for addressing the needs of PLWD, and previous attempts at policy change. It will also provide a framework for the research approach (research questions and methods of analysis) and a summary outline of the organization of the thesis.

1.2 The Growing Impact of Dementia on Ontario’s Health System

1.2.1 Rising Numbers of PLWD

Seniors are the fastest growing sector of the population in Canada and the most likely to suffer from chronic health conditions (Division of Aging & Seniors, 2002). According to the 2010 Rising Tide report commissioned by the Alzheimer Society of Canada (ASC), the greatest risk factor for developing a dementia is age, with approximately 90% of people with dementia being 65 years of age and over (ASC, 2010). The general term dementia refers to a chronic progressive disorder of the brain that can slowly destroy neurocognitive function (e.g., memory judgment, and reasoning, erode functional independence) and, eventually, take life. While PLWD are not a homogeneous group and their needs cannot be easily categorized or standardized, the progression of a dementia is generally described in three general groupings based on stages of the progression – early, moderate, and late stage dementia. As a dementia progresses it can become challenging for the individuals themselves, their families, and the current health care system to manage and accommodate the condition. Depending on the type of dementia and point of diagnosis, its progression can involve a gradual or rapid decline of memory and overall brain function. Although dementia is not a normal part of aging, age is the greatest risk factor

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for dementia with nearly 200,000 Ontarians over the age of 65—or one out of ten—now living with the disease, and close to one quarter of a million seniors projected to be living with dementia by 2020 (Alzheimer Society of Ontario, 2012). These numbers do not reflect a growing number of people experiencing early onset dementia (prior to age 65) or Mild Cognitive Impairment (MCI), thought to be a potential precursor to dementia of the Alzheimer’s type. The 2010 Rising Tide report warns of an impending dementia epidemic. It predicts that if measures are not taken to mitigate the growing demand, the rising number of people living long enough to experience some form of dementia will place great burden and strain not only on the individual and their immediate caregivers, but also on an already strained health care system and the economy in general (ASC, 2010). In 2012 the World Health Organization (WHO), jointly with Alzheimer Disease International (ADI), released Dementia: A Public Health Priority which shows that around the world a new case of dementia occurs every four seconds. That is the equivalent of 7.7 million new cases each year (WHO & ADI, 2012). Both reports call for national strategies to deal with dementia and provide suggestions for meeting this growing population.

A report by the Health Council of Canada (HCC) entitled Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada (HCC, 2012), provides home care data from five provinces and territories, including Ontario. It cites that 75% of home-care clients are seniors with 40% of clients being over the age of 85. Given the greatest risk factor for dementia is age, it is not surprising that 20% of clients were identified as having a dementia (excluding results from the Yukon). The report further cites that between 95 to 98.5% have some difficulty with instrumental activities of daily living (IADLs) such as taking important medications, getting to and from appointments, buying groceries, using the phone correctly, where only 23 to 41% need help with basic activities of daily living (ADLs) such as feeding oneself or getting dressed (HCC, 2012).

1.2.2 Increasing Needs of PLWD

According to a 2011 report by David Walker entitled Caring for Our Aging Population and Addressing Alternate Level of Care, Canadians are experiencing a burgeoning aging population
of individuals living with frailty and/or multiple co-morbidities, all of which may be confounded by the challenges of dementia (Walker, 2011). In Canada approximately 80% of individuals living at home over the age of 65 experience at least one chronic health condition (Gilmour & Park, 2006), which can include mental as well as physical conditions. The average number of conditions accrues with advanced age with 33% of seniors experiencing more than one chronic condition (Gilmour & Park, 2006; Jeste et al., 1999). PLWD have been shown to have a significantly higher burden of chronic diseases (e.g., diabetes, angina, cancer) that can exacerbate the challenge of dementia even further (ASO, 2007). Dementia has also been associated with two to five times higher rates of health service utilization across the spectrum (including the use of home care, EDs, acute care and ALC hospital services, and LTC institutions); and more negative clinical outcomes occur among PLWD compared to older adults without dementia (Aminzadeh et al., 2012; Weber et al., 2011). The complexity of caring for those affected by dementia at various stages of its progression is also increasing as PLWD are living longer than in previous decades in each of the stages. A diagnosis of dementia can affect a person’s cognitive and functional capacity and inhibit their ability to remember, manage or accomplish various tasks; however, the degree and rate of impairment will vary by person, by day, and by circumstance.

1.2.3 System Response

Health care systems in Ontario have been described as largely focused on episodic acute care and characterized by fragmented services by a number of recent reports including Public Services for Ontarians: A Path to Sustainability and Excellence by the Commission on the Reform of Ontario’s Public Services by Don Drummond (2012), Living Longer Living Well by Dr. Samir Sinha’s (2012) and Caring for Our Aging Population and Addressing Alternate Level of Care by David Walker (2011), (Drummond, 2012; Sinha, 2012; Walker, 2011). These reports also point

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3 When considering all of the 28 disease diagnoses that the Resident Assessment Instrument for Homecare (RAI-HC) records, Community Care Access Centres long stay homecare clients with dementia had on average 3.9 conditions, compared to other long stay homecare clients who had 3.3 (ASO, 2007).
to the fact that they were originally built to address acute care needs of the population; however, health care needs have now shifted to be more chronic and complex in nature with people of all ages, including those with formerly life limiting conditions, living longer (Sinha, 2012; Drummond, 2012; Walker, 2011). Sinha’s (2012) report notes that most seniors report they are coping well despite many having one or more chronic conditions, yet there exists a minority of seniors in Ontario who struggle with multiple complex and often inter-related health and social care issues. According to the Ontario Ministry of Health and Long-Term Care (MoHLTC), sub-populations with multiple chronic and complex conditions account for a disproportionate amount of health care spending: while they only represent about five per cent of Ontario’s population, they account for approximately two-thirds of Ontario’s health care budget (MoHLTC Health Links, 2014) with the oldest seniors (those 80 years and older), and those close to death (palliative) being the most intensive users over the age of 65 (Medical Advisory Secretariat (MAS), 2008). In David Walker’s report on the use of ALC beds in Ontario, he warns:

“as [the aging population] becomes the reality, and the health care system’s ability to manage the diseases of aging improves, there is a pressing and urgent necessity to address the needs of this population in new ways...Current models of health care rely too heavily on acute care hospitals and ‘permanent’ placement for seniors.” (Walker, 2011, p. 6)

The reports by Walker (2011), Drummond (2012) and Sinha (2012) highlight additional concerns with Ontario health care indicating that the “system” itself is not a coherent and integrated one but rather a series of fragmented/fractured services that do not work very well together. The “system” appears to be entrenched in a pathway of care which focuses on clinical approaches to care (biomedical model) which is resistant to a move toward broader more holistic or preventative approaches to health and social care policy (determinants of health model).

As a result, many people are placed in hospital and LTC home beds that may not be appropriate for their level of care need. With costs to individuals and the larger system in mind, these reports highlight the importance of considering new ways to address the needs of frail and vulnerable groups, in order to avoid the premature or inappropriate use of high cost institutional care settings when needs could potentially be addressed with lower cost
community care services. To this point, there is a growing body of evidence that identifies the potential for H&CC to help many frail or compromised individuals to live at home (Kuluski et al., 2012(a), Williams et al., 2009a,b,c; Billings & Leichsenring 2005; Chappell et al. 2004; Hollander and Prince 2008; Leichsenring & Alaszewski 2004; MacAdam 2008; Onder et al. 2007; Hughes & Challis, 2004; Challis & Hughes, 2002).

1.3 Policy Relevance

Policy trajectories for health care have largely focused on hospital and physician care – the Medicare Mainstream – with less attention paid to health policy sub-fields at the margins of the care system (e.g., long-term home care) (Baranek et al., 2004). Furthermore, while much dementia related policy analysis has looked at issues from a demand-side perspective (e.g., characteristics and needs of PLWD, incidence rates and projections related to the increasing number of persons experiencing or expected to develop dementia) (ASC, 2010; WHO & ADI, 2012; CIHI, 2010a), there has been little systematic policy analysis of community-based care needs and options for those affected by dementia. Indeed, there is little evidence to show how well PLWD are living in the community, or if that situation is sustainable over a period of time, and little work to assess the system’s capacity to provide for their needs (including such “low level,” but often critical IADL supports as transportation, medication management, meal preparation, personal care, and housekeeping). Further, there is even less analysis of how these needs are currently being met, or could potentially be met, from a policy planning perspective, and the historical factors shaping system capacity at the local level to address these needs. This thesis will attempt to expand on this area.

1.3.1 Reliance on or Default to High Intensity Resources

The impact of an aging population on the health care system and possible ways to address their needs is gaining more attention provincially, nationally and internationally as policy makers, health care managers and researchers look towards system sustainability. Senior-focused health policy initiatives are complicated to create and implement for many reasons, not the least of which is that seniors are not a homogenous group – their needs and ability to access care will differ depending on a host of individual and system related variables. Health policy
developed to address the health and welfare of all seniors as a collective tends to overlook the more specific needs and concerns of complex and chronic sub-populations, which is particularly germane in Ontario where these groups account for the majority of healthcare spending. Generalized policies are not likely to capture important nuances of the needs of vulnerable and potentially expensive populations like PLWD whom are high users of expensive places in the system (ED, ALC and LTC beds). In addition, policies that are geared towards senior populations may also fail to address the needs of those who age prematurely (e.g., the disability community) or PLWD that experience early onset dementia (prior to the age of 65). To this point, Preyra (2010) as cited in the Drummond Report (2012) states that “any [health care] system designed to address the needs of the majority of the population will be overwhelmed and diverted by the special needs of the truly complex and expensive cases” (Preyra, 2010 in Drummond, 2012, p. 161). A consequence of a reliance on high intensity resources to address health care needs, many hospital beds being occupied by [ALC] patients who could get better quality care at a lower overall cost elsewhere in the system” (Drummond, 2012, p. 159). The high use of ALC beds by individuals with complex and chronic needs like PLWD has been a matter of considerable focus by government and hospitals since 2007. The Ontario Ministry of Health and Long-Term Care (MoHLTC) definition of ALC bed is:

“When a patient is occupying a bed in a hospital and does not require the intensity of resources/services provided in this care setting (acute, complex continuing care, mental health or rehabilitation), the patient must be designated ALC at that time by the physician or his/her delegate. The ALC wait period starts at the time of designation and ends at the time of discharge/transfer to a discharge destination (or when the patient’s needs or condition changes and the designation of ALC no longer applies).” (MoHLTC, 2012)

The use of ALC beds can be costly to hospitals financially and logistically (affects patient flow and the ability of those in need of acute care/surgery to access it), and it is not good for the health and well-being of those occupying ALC beds (e.g., risk for further functional and/or cognitive decline or hospital born infections). Furthermore, ALC patients “reflect a failure of the health care system to meet the needs of older adults with complex and declining health” (ALC Expert Panel 2006 in Costa & Hirdes, 2010, p. 34). This poor use of resources results in poor outcomes for both individuals and the system (e.g., crowding of emergency facilities,
cancellations of surgeries because beds are not available and a clogging of ambulance services bringing people to and from hospitals) (Drummond, 2012, p. 160).

At this point dementia, a chronic and often complex condition affecting older adults who often experience multiple comorbidities, is one of the most common causes of ALC, ED, and LTC home usage (Walker, 2011; CIHI, 2011c,d; Gill et al., 2011). PLWD are more likely than those without dementia to be hospitalized and when in hospital pose unique challenges requiring special attention during their stay (e.g., confusion, anxiety, agitation, delirium, poor outcomes and extended stays than those without dementia) (Phelan et al., 2012, Weber et al., 2011).

While population aging and the growing sub-population of PLWD may occur primarily as the result of demographic trends outside the reach of policy-makers, a considerable degree of freedom exists for policy-makers in Ontario in deciding how to use scarce resources in response to this growing population. The Walker report states:

“Current models of care still rely too heavily on acute care hospital resources and a culture that emphasizes “permanent” placement of seniors in LTC Homes, without appropriate consideration of the patient’s potential to improve or recover and be cared for at home with support. An outcome of this delivery system is that far too often the hospital Emergency Department becomes the default, which leads to acute care hospital admission.

From there, in the absence of alternatives, too many seniors remain in the hospital while waiting to be transferred to an alternate level of care (ALC). Some wait excessively long periods of time, which is detrimental to their overall health and well-being. The acute care hospital is not designed to meet a patient’s restorative, supportive or rehabilitative needs, but has conversely been shown to advance functional deterioration and place patients at significant risk of hospital related infections, falls and other adverse events. The end result of this patient journey is often permanent placement in a LTC Home – an outcome that could often have been avoided.” (Walker, p. 6, 2011)

While the reports by Drummond, Sinha and Walker do not specifically address the system’s response to PLWD or the additional complications it’s fragmented and siloed nature might cause for them, it is likely that the challenges they describe are magnified for PLWD. They experience the same risk for age related and chronic conditions as the general senior population (e.g., changes in vision, hearing, heart conditions, diabetes, arthritis) yet with a
reduced capacity to adapt to them (e.g., progressive declines in memory, judgment and reasoning, ability to communicate). Added to this is the burden, the symptoms of dementia erode functional independence and inhibit both the ability to access appropriate services when available, and the insight to recognize that such services are needed. Research has also shown that quality of care for PLWD in the primary care setting is also relatively low (e.g., missed or delayed diagnosis of dementia, poor care management post diagnosis) (Aminzadeh et al., 2012; Weber et al., 2011; Lee et al., 2014; Lee et al., 2010; McAiney et al., 2008). As such, the increasing volume and complexity of dementia is expected to place additional strain on health care systems already feeling challenges from this population (ASC, 2010).

While health care in Ontario remains siloed and largely focused on hospital and physician based care with relatively modest development of H&CC capacity (Walker, 2011; Drummond, 2012), there is a growing body of research that points to the value and necessity of a wide range of proactive and preventative community based health and social care options to help maintain at-risk seniors (e.g., frail, cognitively impaired) in the community safely and for as long as possible (Peckham et al., 2014; Kuluski et al., 2012a,b; Williams et al., 2009a,b,c; Williams et al., 2010; ASC, 2010; Duru et al., 2009; MacAdam, 2008; Boekhorst et al., 2008; D’Amour & Oandasan, 2005; Lum et al., 2005). The literature also emphasizes the benefits of collaboration and care coordination between various health and social care sectors, community organizations and consumers with a focus on enhancing prevention and greater access to care (i.e., supportive housing/assisted living, inter-professional models for care) as part of a well-integrated health service plan (Ibid).

1.4 Attempts at Change: Ontario’s Policy Trajectory

In response to some of the trends discussed above, attempts have been made at different points in time between 1995 and 2012 to effect policy change. One key attempt was Ontario’s Alzheimer Strategy and Related Dementias (1999 – 2004) and resulting Transition Project (2004 – 2007). Where Ontario used to be the only province with a provincial strategy targeting the needs of PLWD, and whose ten initiatives received very positive and supportive evaluations, there has not been a formal coordinated Alzheimer’s Strategy since. This is an interesting
development given calls from the National Advisory Council on Aging (NACA) in 2004 for Canada to build on the success of Ontario’s Strategy, and more recent calls from the national Alzheimer Society, WHO, ADI, and other countries that Canada recognize dementia as an urgent matter in need of a national dementia strategy. At this time Canada remains a country without such a strategy and where Ontario was actually the first and only province to have one, it no longer does.

Tuohy’s (1999) research on health policy in Canada helps to explain this change in direction noting that health care is largely path dependent and “locked in”, so that big system or transformative change is difficult to accomplish and unlikely to occur without the right conditions or windows of opportunity (e.g., the political will to make change, timing of a policy episode/critical juncture when a decision is being made, and/or massive public support for an issue) (Tuohy, 1999). Neo-institutional theory also suggests that, while there may be attempts at health policy change from time to time, history really is determinant. Some change may happen in health care, but it will generally not veer too far off the established biomedical pathway even when faced with evidence of a need for change. Consequences of these and other relevant attempts at reform will be explored, as will the notion of “path dependence” that has established a policy trajectory focused on institutional care as the dominant destination for PLWD.

1.5 Research Questions

To investigate factors that influence the current capacity for PLWD to age at home in the community and the policy legacy that has influenced this capacity, analysis will be conducted at both a conceptual and an applied level guided by the following research questions.

1) Conceptual Level – What is the historical legacy of policy decisions around H&CC for PLWD in Ontario? What political and institutional factors have shaped this legacy? How does this legacy continue to shape care options for PLWD?

2) Applied Level – What proportion of individuals waiting for placement in LTC in one region of Ontario, could potentially be safely and cost-effectively supported at home if
given access to needed H&CC resources? How does this change for persons with cognitive impairment/dementia?

1.6 Analysis

1.6.1 Literature Review

To better understand the pace and direction of change at a policy level and explore the evolution of a seeming gap between the needs of community dwelling PLWD (demand) and supply (capacity of the system to meet these needs), this thesis will turn to theoretical, evidence-based, and grey literature to document the historical policy legacy of H&CC in Ontario and how history impacts on the current situation for PLWD and their caregivers. Factors to be explored in this historical trajectory include:

- Characteristics, incidence rates for, and projected needs of community dwelling PLWD
- Dementia friendly interventions/care practices/services that might meet those needs and capacity of the formal system to provide them
- Historical service utilization patterns for PLWD and their caregivers
- Key historical junctures and policies that have had a significant impact on the pace of change in Ontario’s long-term home care sector and the ability of PLWD to receive care at home in the community

To help guide and place this knowledge, neo-institutionalism – a theory that emphasizes the role that institutions, historical events, and legacies play in shaping current policies, patterns, and policy outcomes (e.g., ways they facilitate or constrain opportunities for PLWD to age at home) – will be used as my conceptual framework. It will also be used to predict opportunities for future change. Neo-institutional theory directs one to look at the specific ideas, patterns of thinking, timing and sequence which create a policy legacy and explains why systems are the way they are. In Canada, this theory has been applied most notably by Carolyn Tuohy (1999) to explain why there has been relatively little significant change or reform within the hospital and physician mainstream of universal Medicare since the 1960’s, compared to jurisdictions like the United States and the United Kingdom, where change and reform have been much more
prevalent, albeit in different directions (Tuohy, 1999). While this may true for Canadian Medicare – ‘medically necessary’ hospital and physician services protected under the *Canada Health Act (1984)* – Baranek, Deber and Williams (2004) have described massive policy shifts in Ontario in the area of H&CC. Unlike hospital and physician services under Canadian Medicare, H&CC services are unconstrained by institutions such as the Canada Health Act and major interests including hospital and physician associations (Baranek et al., 2004).

### 1.6.2 Methodology

#### 1.6.2.1 Conceptual-Level

Using Carolyn Tuohy and Baranek and associates’ version of historical neo-institutionalism (Tuohy, 1999; Baranek et al., 2004), this thesis will examine how and why change occurs at the policy level. Specifically it will explore the institutional mix and structural balance of Canadian Medicare juxtaposed with the proximate policy sub-field of long-term home care. In doing so it will highlight key historical junctures and policy episodes between 1995 to 2012 resulting in major policy shifts and reversals that have impacted upon the ability of PLWD to receive care in the community, and using the predictive power of neo-institutional theory, make predictions on prospects for future change.

#### 1.6.2.2 Applied-Level

At an applied level this thesis will explore services available in one large region of Ontario (South West Ontario) to address the needs of PLWD using a mix of qualitative and quantitative methods in the *Balance of Care* (BoC) Simulation Methodology. The BoC is a policy planning framework originally developed in the United Kingdom (UK). It emphasizes the role that supply-side system factors play in determining whether or not individuals with multiple, chronic needs can be safely and cost-effectively cared for in home and community. This framework has been applied in the UK and Ontario to estimate the most appropriate mix of institutional and community-based resources at the local level needed to support an aging population outside of institutional settings (Kuluski et al., 2012a,b; Williams et al., 2009a,c; Hughes and Challis, 2004; Challis & Hughes, 2002). The BoC is particularly strong in that it combines the best available data with the knowledge and insight of experienced decision-makers and front-line case
managers. These individuals understand population needs at a local level, and are knowledgeable about the local capacity to meet those needs. The BoC will help to assess how the historical trajectory affects the extent of any detectable gaps between what PLWD need (demand) and what they receive (supply) by looking at:

- present day policy and supports at a local level for PLWD in the community (e.g., access to appropriate, cost effective H&CC)
- supply factors (e.g., what is available), particularly system capacity at a local level to support PLWD.

In doing so, the BoC will provide insight regarding the system’s ability at the local level to support PLWD to age in place and possible options for re-balancing health system resources to better meet this need.

1.7 Summary

Dementia is not a marginal issue for PLWD, their families or the health system. Dementia is impacting on the system with PLWD being some of the most common users of ALC, ED, and LTC beds. A preliminary review of the literature points to a health care system in crisis because the needs and populations it was originally designed to serve are changing and becoming more complex and chronic in nature. Furthermore, there appear to be institutional and structural impediments that make it difficult to shift from a health care system focused on episodic acute care needs to one that can address needs that are more chronic in nature.

This seeming disparity between demand and supply side factors for populations with complex and multiple chronic needs is likely worse for PLWD given their additional neurocognitive related disabilities, needs and considerations. This disparity is likely to worsen in the absence of a sustainable policy reform to address their needs as the demands of PLWD continue to grow (i.e., increasing numbers of PLWD, and living longer with greater periods of time spent in each of the various stage).
This thesis is timely and particularly relevant to policy makers concerned about issues of health system sustainability and the growing demands of an aging population, particularly those with dementia.

1.8 Organization of the Thesis

Following this introductory chapter the thesis is laid out in the following manner:

Chapter 2: Methods

This chapter describes the study design and methods used to conduct this research including the literature review process, ethics approval, data sources and a detailed description of the BoC Simulation Methodology as a framework for understanding supply and demand issues at a local level.

Chapter 3: Conceptual Framework

This chapter uses neo-institutional theory to look for the influence of dominant institutions as a means to understand the pace and direction of change in a policy area. This theory provides the foundation from which to understand path dependency, why and how history matters, and guidance for the historical review of provincial policies impacting on PLWD and their caregivers, especially access to long-term H&CC services.

Chapter 4: Demand and Dementia (Understanding Need)

This chapter explores demand side factors related to caring for PLWD in the community particularly those in the early to moderate stages of their dementia. Specific attention is paid to the nature of the condition, its impact on the individuals themselves and their caregivers, and possible interventions to assist them to remain as independent and safe in the community for as long as possible.

Chapter 5: Supply and Dementia (Meeting Need)
This chapter explores supply side factors related to caring for PLWD in the community, with a specific focus on the types of H&CC services and support mechanisms available to PLWD and possible enablers and barriers impacting upon their ability to remain as independently and safely at home for as long as possible.

Chapter 6: Ontario Home Care Policy Trajectory and its Impact on PLWD

This chapter documents a history of policy development around H&CC in Ontario between 1995 and 2012, and the political and institutional factors that have shaped the legacy of H&CC options for PLWD and their caregivers.

Chapter 7: Balance of Care Findings for the South West LHIN Region

This chapter presents results and key findings of the BoC Simulation including characteristics of LTC wait-listed individuals in Southwestern Ontario, the development of care packages, care package cost estimates, and diversion rates of individuals who could potentially be safely and cost-effectively supported at home if given access to needed H&CC resources. This chapter specifically focuses on care package development for persons with cognitive impairment/dementia, for both in-home settings and Supportive Housing settings to provide insight into the supply-side factors affecting where PLWD end up in the system, and potential options for re-balancing health system resources at the local level to allow greater numbers of individuals to age at home.

Chapter 8: Discussion and Conclusions

This chapter discusses insights and implications related to the current and future ability of health systems to provide for the needs of community dwelling PLWD and their caregivers and reflect on prospects for change off of the current “pathway” of defaulting to prematurely or inappropriately to institutional care. Strengths and limitations of this research, and recommendations for future research are also considered.
Chapter 2
Research Methods

2.1 Literature Review

While demand issues are often the starting place for health policy initiatives, less is known about the political and institutional factors, or the system-level configurations, that contribute to the way in which dementia care has been, or can be addressed in the community. In this connection, this thesis sought to investigate both conceptually and at an applied level the policy legacy in Ontario for dementia care in the community and key factors which determine the “tipping point” between the opportunities of PLWD to age at home or move to a residential LTC home.

At the conceptual level this thesis examined theoretical, evidence-based and grey literature published between 1980 and 2012 in English on:

- Potential services, options and interventions required by community dwelling PLWD
- Provincial, national and international approaches to care of PLWD and their caregivers with the prospects for maintaining these individuals at home or in home-like environments (e.g. supportive housing) to avoid premature or inappropriate use of institutional settings (hospital or LTC home)
- The historical trajectory for H&CC services in Ontario
- How historical policy decisions of governments provide the context for and shape current policy decisions around addressing the needs of an aging population – particularly those with dementia,
- The lasting effects of policy legacies, and
- Neo-institutionalism as a theory to place the need for such knowledge

The literature review also provided important information on Balance of Care (BoC) research as an applied methodology for this research (to be described in detail later in this chapter). The review of previous BoC research enabled the researcher to conduct a more thorough analysis of the BoC simulation results in South Western Ontario, including the characteristics of individuals...
waiting for LTC facility placement; possible answers to the question “why does LTC placement appear to be the default option for persons with dementia” and; determine the extent to which a community-based care package can safely and cost effectively substitute for care in a LTC facility for individuals with dementia.

2.1.1 Literature Search

The researcher searched for scholarly articles, books, reports and relevant grey literature/position papers using the following data bases and websites: PubMED; AgeLine; PsychINFO; Health Sciences: A SAGE full-text collection; MEDLINE; Goggle Scholar; the Canadian Institute for Health Information (CIHI) Research (under their Aging Stream); Health Canada/Santé Canada ; the National Advisory Council on Aging; the Ontario Ministry of Health and Long-term Care; the Ontario Senior’s Secretariat; and Alzheimer Knowledge Exchange, and the Alzheimer Societies of Ontario and Canada. The review searched for articles and publicly available resources representing dementia-specific key words such as “dementia”, “Alzheimer”, “cognitive” plus the following key words:

- “Balance of Care”, “neo-institutionalism”, “historical institutionalism”, and “path-dependency.”
- “provincial (national and international) dementia strategy”, “Alzheimer’s Strategy”, “provincial (national and international) dementia policy”
- “Neo-institutionalism”, “Balance of Care”

The literature review revealed that information on demand side factors, including studies that examine setting-specific health care (e.g., utilization in dementia clinics, dementia centers, and skilled nursing facilities), projected costs PLWD impose on mainstream health care, and more
recently, the needs and service use of dementia caregivers were more readily available (Weber et al., 2011) than information on the utilization of H&CC support services by PLWD and their caregivers, or the influence of broad system-level factors (institutional and structural) in determining individual-level outcomes (in this case, outcomes for PLWD in the community).

As such, this thesis turned to neo-institutionalism, a high level theory drawn from the political science literature that emphasizes the role that historical events and legacies play in shaping current policies and policy outcomes as a conceptual framework for this investigation. In particular this thesis focused on Carolyn Tuohy and Baranek and associates’ version of historical neo-institutionalism (Tuohy, 1999; Baranek et al., 2004). In Canada, this theory has been applied most notably by Tuohy to explain why there has been relatively little significant change or reform within the hospital and doctor mainstream of universal Medicare, compared to jurisdictions like the United States and the United Kingdom, where change and reform have been much more prevalent, albeit in different directions (Tuohy, 1999). Baranek and associates focus has been on the institutional mix and structural balance of Canadian Medicare juxtaposed against the proximate policy sub-field of long-term home care (Baranek et al., 2004). For the purposes of this research, neo-institutional literature has been used to:

- identify institutional factors and structural relationships between key stakeholders that have had the most significant impact on the pace of change in Ontario’s long-term H&CC sector
- examine the influence these factors have played in the dementia policy response for PLWD in the community
- consider critical junctures or policy episodes that have influenced the ability of community-dwelling PLWD to age in place or be referred to residential LTC homes between mid-1990’s to 2012
- guide analysis of what would be needed to support persons with dementia safely and cost-effectively in the community.
2.2 Applied Research Design

The applied level of this thesis uses a sequential mixed methods explanatory design (see Table 3.1 below) approach using the Balance of Care simulation methodology, to investigate the nexus between the historical policy legacy for dementia care in Ontario and the likelihood that community-dwelling older persons with dementia will be referred to LTC homes even at relatively low levels of assessed need. The rationale for using this form of mixed methods design was that qualitative data (often inductive in nature) helps explain or build upon initial quantitative results [generally deductive in nature], and that there is a need for qualitative data to explain significant [or non-significant], outlier or surprising results (Morse, 1991 in Creswell & Plano, 2007). While the purpose of the sequential explanatory design typically is to use qualitative results to assess in explaining and interpreting the findings of a primarily quantitative study, this study uses the quantitative portion to provide data for the qualitative portion of the study (in this case providing information by sub-groups on people on a long-term care placement wait-list in order to consider care packages that would assist them in safely getting off that list and remaining in the community).

The Balance of Care (BoC) simulation methodology is particularly well suited for this type of investigation as it investigates “supply side” issues entrenched in Ontario’s policy legacy for PLWD and their ability to remain in the community (e.g., life like simulation of what was there and how it got there). The BoC is a proven methodology has been utilized in previous research in the United Kingdom (Clarkson et al., 2005; Tucker et al., 2008; Challis & Hughes, 2002; Hughes & Challis, 2004) and more recently in Ontario (Williams et al., 2009a,c; Kuluski et al., 2012a,b; Peckham et al., 2014).

Key characteristics of this mixed methods approach involved: the collection and analysis of quantitative data and then connecting it to a second phase of qualitative data to explore the research questions; persuasive and rigorous procedures for both the quantitative and qualitative methods; and finally, the integration of these two data sources in the interpretation phase of the research (Creswell & Plano, 2007).
### Figure 2.1  SW BoC Sequential Explanatory Design

<table>
<thead>
<tr>
<th>Quantitative Portion</th>
<th>Qualitative Portion</th>
<th>Integration</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quantitative Data Collection</strong></td>
<td><strong>Quantitative Data Analysis</strong></td>
<td><strong>Qualitative Data Collection</strong></td>
</tr>
<tr>
<td>Access anonymized secondary dataset of individuals on SW BoC LTC home wait-list at one point in time</td>
<td>Stratification by four key variables and vignette development</td>
<td>SW BoC Expert Panel Simulation and Supportive Housing review</td>
</tr>
</tbody>
</table>

Adapted from: Creswell, 2003, Figure 11.2a, p. 213

The quantitative phase of this research was based on secondary assessment data derived from an internationally validated and reliable tool, the *Resident Assessment Instrument – Home Care (RAI-HC)*, and described further in section 2.3.6.1. The study variables were clearly defined based on BoC the simulation methodology and used to example a large sample (N = 2876) of individuals waiting for placement in residential LTC in South West (SW) Ontario using the software package SPSS 11.5. Findings from this phase were used to construct “vignettes” described further in section 2.3.7.3, and used in the qualitative phase of research. This quantitative phase of research demonstrated replicability, generalizability and a lack of bias (Creswell, 2003).

The qualitative phase of this research immediately followed and built on the quantitative data analysis. Vignettes created using the assessment data and filtered by sub-groups were then used to enhance and inform discussions with an expert panel. The South West (SW) BoC panel
was selected by the SW Local Health Integration Network (SW LHIN) “Best Level of Care and Quality” Steering Committee which itself was comprised of senior leaders of organizations providing a range of health and social services to older persons in the (please refer to Appendix A for a list of Steering Committee members and their affiliations). This Steering Committee assumed the role of the South West Balance of Care Steering Committee (SW BoC Steering Committee) and in that role selected and invited expert panelists to participate in this research. The expert panel was comprised of 15 local experts drawn from knowledgeable frontline care organizations across the care continuum including the South West Local Health Integration Network (SW LHIN), South West Community Care Access Centre (SW CCAC), hospital, and community representation (please refer to Appendix B for a list of expert panelists). The SW BoC Steering Committee sent out letters of invitation through the SW LHIN to a purposive sample of frontline health and social care providers and decision makers (e.g., community care service supervisors, Alzheimer Society coordinators, CCAC case managers, hospital discharge planner, SW LHIN consultant). This sample included panelists from both urban and rural communities. The city of Stratford was used as a centralized location to host the expert panel.

Expert panelists reviewed the vignettes (assessed needs of individuals in their region on a wait-list for residential long-term care) and were then asked to construct care packages that would allow sub-groups described in the vignettes to live as independently as possible in the community. These expert panel discussions occurred over the course of three days and followed a similar format to that of a focus group. While focus groups sessions typically last between one and two hours, the expert panel worked full-day sessions with refreshment and lunch breaks in-between paid for by the SW LHIN. The format ran much like a focus group in that panelists were nominated from a study population of interest across the SW LHIN region (both homogeneity and heterogeneity respectively). The panel was small in number (15 panelists) to ensure that everyone was able to contribute, but large enough to share diverse opinions across the whole group representing the health care spectrum, rather than fragmenting into smaller parallel discussions (Krueger, 1994 in Freeman, 2006).

A particular strength of an expert panel is the “advantage of making use of group dynamics to stimulate discussion, gain insights and generate ideas in order to pursue a topic in greater
depth” (Bowling, 2002, p. 394 in Freeman 2006). The views and opinions of expert panelists were noted in detail over the course of the simulation by the LHIN representative acting as both participant and note taker. Key suggestions were shared on a large screen in real time to aid panelists in making decisions about care packages. The detailed notes were used in the analysis of possible diversion rates of the LTC home wait-listed clients back to home and community care. During care package construction the researcher asked the panelists a mix of structured and probing questions for each vignette to better understand the issues and complexity involved in the development of community care packages. All care packages were crafted collectively and only accepted after reaching consensus. The analyses of the two phases are linked through the key variables (predictors of LTC home placement) from the quantitative phase and represented in the vignettes and in the questions discussed during the expert panel sessions (Teddlie & Tashakkori, 2009).

2.3 Balance of Care

2.3.1 Balance of Care Methodology

The “Balance of Care” (BoC) methodology was originally developed and applied by the Personal Social Services Research Unit in the United Kingdom (PSSRU), University of Manchester headed by Dr. David Challis (Challis and Hughes 2002; Clarkson et al. 2005; Hughes and Challis 2004; Tucker et al. 2008). It assumes that the need for LTC facility placement is determined by two major factors:

1) care needs of the individuals and,

2) the availability of community based health and social care to meet those needs.

It has been adapted for use in Ontario by the University of Toronto Balance of Care Team lead by Dr. A. Paul Williams (Williams et al., 2009a,c; Kulski et al., 2012a,b). This framework emphasizes the role supply-side system factors play in determining whether or not individuals with multiple, chronic needs can be safely and cost-effectively cared for in home and community. Many health service utilization and policy decisions have been based on demand side factors (e.g., projections of care needs for an aging population leading to the assumption that a greater number of older persons will require a proportionately greater number of
residential LTC beds); however, the BoC theory leads us to look beyond demand to supply side and underscores that “the need for such beds will be determined as well by supply-side factors such as access and availability to appropriate, cost-effective community-based care. Other things being equal, where H&CC is more accessible, the tipping point\(^4\) for residential LTC will be higher and older persons will be more likely to age successfully at home” (Williams et al., 2009a; Kulski, 2012a,b). BoC simulations help to demonstrate the current policy mismatch in addressing demand within the current acute-centred medical focused health care system, leaving PLWD and other vulnerable groups susceptible to premature or inappropriate institutionalization.

BoC is used to determine the appropriate balance of institutional and community-based care for frail seniors, who might otherwise be at risk of losing independence and being admitted to a LTC facility by targeting and assessing the needs of seniors at-risk for LTC home placement and matches them to available or potential community care packages. The BoC approach aims to estimate the proportion of at-risk seniors that could be safely maintained in the community with better outcomes for individuals, caregivers and funders, and the mix and cost of the services which would be required to allow this to happen. Findings from BoC studies in the United Kingdom concluded that up to a third of individuals already in LTC home beds could be cared for in the community with better outcomes for individuals and carers, at the same or lower costs to the system as a whole (Challis & Hughes, 2002; Hughes & Challis, 2004).

The BoC methodology has been adapted and applied to BoC projects in Ontario. To ensure comparability with the results of previous studies, this research replicated the BoC

\(^4\) Note: Tipping points are described as happening at the margins; they are incremental until they happen and then they can rise or fall in one dramatic moment. Three key characteristics of tipping points are:

\begin{enumerate}
  \item contagiousness;
  \item the fact that little causes can have big effects; and
  \item change happens not gradually but at one dramatic moment.
\end{enumerate}

(Gladwell, 2002, p. 9)
methodology used in previous Ontario BoC research. Ontario findings from previous BoC projects include:

- Between 25 and 50% of individuals currently placed on LTC wait-lists could be safely and cost-effectively cared for in the community if given access to appropriate integrated H&CC packages

- Ability to perform instrumental activities of daily living (e.g., meal preparation, laundry) is a key factor driving wait-lists

- The presence of H&CC services at the local level in itself does not guarantee access; a variety of factors (e.g., cognition, language, ability to navigate system, geography) also impact on the ability to access needed services (Williams et al., 2009a,c).

2.3.2 Balance of Care Study Context

For the purposes of this research the BoC methodology was applied in South Western Ontario. The region of study falls within the boundaries of the South West Local Health Integration Network (SW LHIN) stretching from Tobermory in the north to Long Point in the south. Within the SW LHIN region, the South West Community Care Access Centre (SW CCAC) serves nearly one million people living in a very large geographic area (nearly 22,000 sq. km) and has a significant urban population in the City of London, and many rural communities in its surrounding counties of Grey, Bruce, Perth, Huron, Middlesex, Elgin, Oxford and part of Norfolk County (please refer to map below). At the time of data collection the proportion of seniors in the SW LHIN was 14.7%, greater than the provincial average of 12.9% and expected to increase by almost 43,000 by 2016. In addition, the SW LHIN had 6,739 beds in 72 homes and the occupancy rate for LTC beds in the SW was, and remains at almost 100%. The SW LHIN region is home to over 100 community services agencies (including Community Health Centres, Community Mental Health agencies, Community Support Services, and Addictions Services and wait-lists exist primarily for friendly visiting, home making and transportation services (SW LHIN website, 2009).
This region, with its large geography and rural/urban mix, combined with its higher percentage of seniors, higher rates of hospitalization, and higher proportion of people living with chronic health conditions than province-wide averages, thus presents unique challenges to “aging at home.”

Figure 2.2  South West LHIN Region
2.3.3 Balance of Care Simulation Planning

Project planning for this research occurred in the following five stages:

2.3.3.1 Stage 1

Initial planning for the study took place in the late summer of 2008 when a “connected” attendant-care provider, Judi Fisher, working in the SW LHIN region approached myself (the researcher) and my thesis advisor, Dr. Paul Williams, to consider their region for a BoC simulation. A follow-up teleconference between the researcher, thesis advisor, attendant care provider, and senior members from the SW LHIN and from the SW CCAC occurred on September 2008 where it was decided conducting a BoC simulation in SW Ontario was a good fit between researcher and researched. An in-person meeting was held in October 2008 in London Ontario to finalize details. The researcher undertook an ethics submission to the University of Toronto Research Ethics Board, which was submitted in November 2008 and approved in January 2009. This ethics proposal was shared and reviewed with leads from the SW LHIN and SW CCAC and used as a “Memorandum of Understanding” between all parties. The SW CCAC provided the researcher with secondary assessment data (described later in 2.3.6.1) stripped of all identifiers of all individuals waiting for LTC residential placement in the SW LHIN as of February 24, 2009, for stratification and vignette development.

2.3.3.2 Stage 2

In the project’s early stages, the researcher was able to leverage the SW LHIN’s “Best Level of Care and Quality” Steering Committee (please see Appendix A) comprised of senior leaders of organizations providing a range of health and social services to older persons in the SW LHIN region. This Steering Committee performed a dual role in that it also assumed the role of the South West Balance of Care Steering Committee. The leaders on this Steering Committee represented a care continuum that includes hospitals, social services, long-term residential care, community supports, the SW CCAC, supportive housing, mental health and addictions, primary care, and the SW LHIN. A presentation on the BoC Methodology was given to the committee in January 2009 after which the committee provided guidance and insight in the
planning and development aspects of the research. In particular they nominated individuals for the expert panel (please see Appendix B), and later reviewed and validated preliminary findings, and assisted with knowledge transfer of these early findings.

2.3.3.3 Stage 3
An expert panel which included experienced front-line case managers and decision-makers comprised from a range of providers across the health and social care continuum (i.e., hospitals, community support services, supportive housing, the SW CCAC, community mental health, and attendant care) was nominated by the steering committee in February and later convened in Stratford from March 3 – 5, 2009.

2.3.3.4 Stage 4
Using the daily cost of a LTC bed as a comparator, costing and diversion rates from the LTC wait-list were later estimated by the researcher based on each of the H&CC and SH care packages and using cost data provided by the SW LHIN, the SW CCAC, and two of the four SH providers interviewed (note: only two of the providers were able to provide hourly unit costs which were then averaged for SH cost estimates). Due to procurement competition across CCAC, none of the SH providers wanted to be identified to ensure their specific costs were not identifiable to other SH providers.

2.3.3.5 Stage 5
Detailed analysis of the data as it relates specifically to dementia/cognitive impairment followed the August presentation of SW BoC preliminary findings to the expert panel. Results from this analysis were then integrated with contextual information on the historical trajectory of H&CC policy as it relates to PLWD and their caregivers.

2.3.4 Balance of Care Ethics Approval
Ethics clearance to conduct a BoC simulation in South West Ontario was received from the University of Toronto Ethics review Board in January 2009. As mentioned above, this document
also served as a memorandum of understanding between all parties in the research as to roles and responsibilities for this research.

2.3.5 Balance of Care Simulation Sample

The BoC simulation sample is comprised of sub-groups stratified from individuals (N = 2876) on the SW CCAC LTC residential placement wait-list as of February 24, 2009. All individuals on this list were assessed by the SW CCAC using the Resident Assessment Instrument – Home Care (RAI-HC), and deemed eligible for LTC placement.\(^5\) Consistent with a research focus on sub-groups with similar needs rather than on the characteristics of any individual, the data set provided to the researcher by the SW CCAC was stripped of all information which could identify individuals (see table below), and no further information about individuals was gathered. It is important to note there was no direct contact between the researcher and the researched. Additionally, analysis was only conducted on sub-groups containing more than 2.5% of the population to further ensure that individuals could not be identified.

\(^5\) All those currently on LTC wait lists have had a full RAI-HC assessment, now the standard in Ontario and in other jurisdictions, and been judged by a professional case manager to be eligible for a residential LTC placement.
Table 2.1  SW BoC Wait-list Exclusions

To ensure removal of all individual identifiers, the following variables from the RAI- HC were excluded from the data set generated by the SW CCAC prior to sending to the researcher:

**SECTION AA: Name & Identification Information**

<table>
<thead>
<tr>
<th>1. Name of Client</th>
<th>2. Case Record No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Last/Family Name</td>
<td>3a. Health Card No.</td>
</tr>
<tr>
<td>b. First Name</td>
<td>3b. Province/Territory Issuing Health Card No.</td>
</tr>
<tr>
<td>c. Middle Name/Initial</td>
<td></td>
</tr>
</tbody>
</table>

| 2.3.6 Balance of Care Data Sources |

The BoC simulation methodology, as applied in this and previous Ontario studies, involves analysis of two main data sources: **Assessment Data** and **Cost Data**.

### 2.3.6.1 Assessment Data

The researcher undertook a secondary analysis of existing administrative assessment data using the *Resident Assessment Instrument-Home Care* (RAI-HC) – an internationally validated and reliable tool used by all CCAC’s across the province of Ontario. The RAI-HC is a comprehensive standardized instrument for assessing and recording person-specific needs, strengths, and preferences of older adults living in the community on a Minimum Data Set form. In addition to assessment of multiple key domains of function, the measures incorporate guidelines to assist with problem-oriented interpretation of this assessment data. (Morris et al., 2002; Heaney et al., 2003) The RAI-HC is clinically useful for a wide variety of client populations,
ranging from medically complex clients needing close attention to relatively well older adults who receive and require less formal support (Morris et al., 2000 in Heaney et al. 2003).

The RAI-HC is considered reliable because:

- it provides good inter-rater reliability (consistent assessment of a client regardless of whom the [RAI-trained] assessor is) (Morris et al., 1997; Morris, Fries & Morris, 1999 and Sgadari et al., 1997 in Heaney et al., 2003)
- inter-rater reliability of the RAI has also been found to be similar across cultures (Sgadari et al., 1997 in Heaney et al., 2003)
- domains measured by the RAI displayed adequate internal consistency (Morris et al., 2000 and Hirdes, Morris et al., 1999 in Heaney et al., 2003)
- outcome measures were found to be equally reliable in terms of internal consistency cross-nationally (Morris et al., 2000 in Heaney et al., 2003)
- the RAI displayed acceptable test-retest reliability (Hirdes et al., 1999 in Heaney et al., 2003)

The RAI-HC is considered valid because:

- the RAI displays good face validity, content validity, high levels of convergent validity, and good predictive validity (Hirdes et al., 1999 in Heaney et al., 2003).

Postal code information was also used to indicate where the sample was clustered geographically, keeping in mind that there is considerable variation within the SW LHIN in terms of service availability.

### 2.3.6.2 Cost Data

Publicly available Ministry of Health and Long Term Care funding data was provided to the researcher by the SW CCAC, and average hourly cost estimates from two SW supportive housing providers were used to estimate the costs of community-based care packages, and supportive housing options, in comparison to the costs of residential LTC. At the time of data collection the average ministry cost for an average patient in a LTC home bed was $77.00/day.
This cost is a conservative approach and only reflects costs to governments and not resident co-payments. Potential “divert” rates were calculated based on the above mentioned funding data and RAI-HC data to determine the proportion of individuals overall that could potentially be both safely, and cost-effectively supported in home and community sector.

2.3.7 Balance of Care Simulation Steps

Utilizing the sample and data sets described above, the researcher undertook the following steps in conducting the full BoC Simulation for the SW LHIN region.

2.3.7.1 Step 1: Established a Steering Committee

As mentioned above, the researcher was able to leverage the SW LHIN “Best Level of Care and Quality” Steering Committee, comprising senior leaders of organizations that provide a range of health and social services to older persons in the region, to oversee and guide BoC research activities, help with the recruitment of expert panelists, and help disseminate findings of the research (please refer to Appendix A for further information on this committee).

2.3.7.2 Step 2: Stratification and Analysis

The researcher used the statistical package SPSS 11.5 to determine what proportion of those on the LTC wait-list fell into each of 36 relatively homogeneous sub-groups defined by the four key multi-measure indicators of need listed below. These measures included: cognitive performance including short term memory, cognitive skills for decision-making, expressive communication and eating self-performance; level of difficulty with activities of daily living (ADLs) including eating, personal hygiene, locomotion, and toilet use; level of difficulty with instrumental activities of daily living (IADLs) including meal preparation, housekeeping, phone use, and medication management; and presence of an primary (informal/family) caregiver in the home. These key variables were chosen as they are considered prominent triggers for placement in residential LTC.

In order to determine level of need this research used three standardized scales comprised of RAI-HC variables: The Cognitive Performance Scale, ADL Hierarchy Scale and IADL Difficulty.
**Scale.** The answer categories for the variables listed below correspond to how individuals score on these scales:

1) Level of Cognition was determined using the *Cognitive Performance Scale*  
   • deemed as intact (score of 0 or 1) or not intact (score of 2 – 6)

2) Level of difficulty with activities of daily living was determined using the *Activity of Daily Living Hierarchy Scale*  
   • deemed as low, medium, or high

3) Level of difficulty with activities of daily living determined using the *Instrumental Activity of Daily Living Difficulty Scale*  
   • deemed as low, medium, or high

4) Presence of a primary caregiver in the home of the client  
   • deemed as Yes or No

A chart outlining the distribution of all individuals on the SW CCAC wait-list can be found in Appendix C.

### 2.3.7.3 Step 3: “Vignette” Development

The researcher, after establishing the proportion of individuals falling into each sub-group, developed detailed profiles – “Vignettes” – based on the SW CCAC RAI-HC data and written for typical individuals within sub-groups with more than 2.5% of population. The 2.5% threshold was used to ensure that there were sufficient numbers of cases to ensure that individuals could not be identified, and that they warranted analysis.

In the SW LHIN, 14 of 36 possible sub-groups had over 2.5% of their populations wait-listed; these 14 sub-groups accounted for 88% (2,541) of the 2,876 individuals on the LTC wait-list. Vignettes were then enriched with additional data from the RAI-HC (e.g., which ADLs are particularly problematic for individuals in each sub-group). Vignettes were based on characteristics of individuals at the 75th percentile within each sub-group (e.g., a higher than average level of need). Vignettes simulated what one might find in a case manager’s notes.
when making actual care decisions. A sample vignette for the first sub-group – Copper – is listed below and a full set of vignettes can be found in Appendix D.

**SAMPLE VIGNETTE**

*Copper is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Copper has no difficulty using the phone, some difficulty with transportation, managing medications and meal preparation, and great difficulty with housekeeping. Copper has a live-in caregiver (adult-child or spouse). This live-in caregiver provides advice/emotional support and assistance with IADLs.*

1) Cognition- Intact (short-term memory recall is good, makes consistent/reasonable/safe decisions and can express ideas without difficulty)

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- No difficulty using the phone, some difficulty with transportation and managing medications (needs some help, is very slow/fatigues), great difficulty with meal preparation and housekeeping (little or no involvement in the activity is possible).

4) Caregiver (in home?) - Yes, adult-child provides advice/emotional support and assistance with IADLs. Yes. (49% = adult-child, 44% = spouse)

Vignettes were presented to expert panel members who were asked to construct appropriate H&CC care packages considering only safety and appropriateness, not costs. Care packages were designed as generic and not individualized packages and looked at the potential for what could be done for persons in that current situation not wanting to over-serve or under-serve clients within the context of what types of services would be necessary to help vulnerable seniors at risk of LTC placement safely in the community. Additional details from the RAI-HC were provided to expert panel members on request. Typical requests concerned health issues, possible behaviours such as wandering or verbal and physical aggression, and the ability of caregivers to cope and maintain support to the individuals in the vignettes.

Wait-listed individuals were also stratified into five SW CCAC sub-regions. Of the 2,876 wait-listed individuals, approximately 44% of the cases were generated by the London site, 30% by
the Stratford Site and 16% by the Woodstock Site. These numbers reflect the urban and rural nature of the sites (London is urban, Stratford is very close to London, and Woodstock is a major center for many rural communities).

2.3.7.4 Step 4: Care Package Development

Care packages were constructed for the 14 sub-groups in two phases:

2.3.7.4.1 Phase 1

An expert panel nominated by members of the steering committee, which included experienced front-line case managers from across the health and social care continuum (i.e., hospitals, community support services, supportive housing, the SW CCAC, community mental health, and attendant care) was convened in Stratford from March third to fifth, 2009. The panel reviewed each of the 14 SW vignettes and constructed H&CC care packages to support typical individuals in each vignette safely and appropriately in the community given their current condition. Panelists were asked to consider only the needs of individuals (and caregivers as they felt appropriate), not costs (which would be estimated later). Care packages were designed as generic and not individualized packages and looked at the potential for what could be done for persons in that current situation not wanting to over-serve or under-serve clients. Packages also took into account services available at the local level. Care packages were not developed if safety and appropriateness was not possible. Additional details from the RAI-HC were provided to Expert panel members on request. Typical requests concerned health problems, behaviour, wandering, and the ability of caregivers to maintain or increase support.

Three CCAC coordinators sat on the expert panel and compared with other BoC research across, asked more questions specifically related to RAI-HC data. This had the project run long with limited time for review of the care packages and thus the reason for a follow-up web-based teleconference with the panelists less than a month later. Expert panelists were also given the opportunity to hear preliminary findings in August 2009 prior to submitting them to the SW BoC Steering Committee.
Panelists from organizations providing SH were also asked at that time to identify vignettes that would meet eligibility criteria for their SH programs. While there was lengthy discussion and debate about the mix and intensity of services required for individuals in each vignette, consensus was achieved in every case. A follow-up teleconference with webinar technology was held with expert panelists on March 23, 2009 for further comment and to confirm care packages. Preliminary findings from the research were presented to the Expert panel in August 2009.

In addition, four Supportive Housing providers in the South West Region were presented with case profiles for each of the 14 vignettes as well as the H&CC care packages created by the expert panel. They were then asked to explain how the needs of typical individuals in each sub-group would be met by their SH programs on a daily or weekly basis. For confidentiality reasons related to a market competition, a list of SH providers cannot be provided.

2.3.7.4.2 Phase 2

In April 2009 four Supportive Housing providers in the South West Region were presented with the case profiles for each of the 14 vignettes and the corresponding H&CC care packages created by the expert panel. The SH providers were then asked to explain how the needs of typical individuals in each of the 14 sub-group would be met by their SH programs on a daily or weekly basis.

2.3.7.5 Step 5: Costing and Divert Rates

Direct costs to the Ministry of Health and Long-Term Care were estimated for each of the H&CC and SH service packages using cost data provided by the SW CCAC, and by two of the four SH providers interviewed (note: of the four SH providers only two were able to provide hourly unit costs which were then averaged for SH cost estimates). “Divert” rates were first estimated by comparing the costs for each of the H&CC packages over a 13-week period to the costs of a residential LTC bed for that same amount of time.

Estimate “divert rates” were based on two criteria: safety and appropriateness for individual and caregiver; equal or lower cost as compared to the direct Ministry cost of a LTC bed. To
ensure comparability, only direct LHIN costs were included; user fees and co-payments were excluded. Divert rates were then estimated for SH by comparing the costs for the SH packages over the same 13-week period to the costs of the corresponding H&CC packages as well as the costs of a residential LTC bed for that amount of time.

2.3.8 **Expert Panel Care Package Guiding Assumptions**

During the expert panel sessions, panelists identified a number of important considerations and guiding assumptions in the creation of H&CC care packages. These will be detailed further in chapter seven: *Balance of Care Findings*. Highlights of community based care package construction are listed below:

- Proactive and integrated approaches to care were applied even when current day practice restricts such efforts.

- Care packages were also created using a conservative approach so to address individual’s needs on their worst possible day/situation, and as such, panelists recognized that packages may be considered to be very “rich” in resource intensity.

- Care packages were constructed under the assumption that if clients would accept the recommended care packages, they should be able to remain in the community.

- Although current day practice cannot guarantee consistency of care workers/staff, expert panelist highlighted the need for such particularly for those with cognitive impairment as this was considered a crucial element towards the acceptance and continuation of care services.

- Despite regional disparities, an assumption that all Adult Day Programs would be able to offer on-site bathing was applied although this is not currently offered uniformly throughout the SW LHIN region.

- Although the expert panel acknowledged that in rural and more remote areas, transportation is often problematic, with relatively few providers that can be called on
to cover large areas; care packages were constructed under the assumption that clients can get around and that care support workers can also get around and visit their clients.

- Care packages were developed to formally address caregiver stress and burnout and the crucial contribution of both live-in caregivers and caregivers who live outside of the home.

Each of the 14 vignettes presented to the expert panel and supportive housing providers with final costings can be found in Appendices D and E respectively.

2.4 Balance of Care Strengths and Limitations

This methodology has been proven in the United Kingdom and more recently in Ontario. The BoC is particularly strong in that it combines best available administrative data with the “real life” knowledge and insight of experienced decision-makers and front-line case managers. These individuals understand population needs at a local level, and are knowledgeable about the local capacity to meet those needs.

Drawing upon front-line case managers understanding of client needs at the local level and local capacity to meet needs this research identifies care packages that should allow “at-risk” seniors, particularly those with frailty and/or cognitive impairment, to live as independently as possible in their own communities; avoid premature or inappropriate placement into LTC homes; and to avoid unnecessary or inappropriate use of acute care services.

Previous BoC research projects in Ontario have stimulated considerable interest across the province and have been used to inform policy planning including the work of the MoHLTC “Aging at Home” Strategy and other related provincial and local planning initiatives. To this end, the SW LHIN and the SW CCAC jointly sought out participation in this research to provide further insight for planning and integrating care for older persons in their region.

A weakness of this methodology may be that it is viewed through the lens of the provider and not from the perspective of PLWD or their caregivers (although a number of expert panelists had both personal and professional experience with dementia). If one were to convene panels
with PLWD and/or their caregivers, a comparison could be made of the impressions as to what is necessary to include in care packages for PLWD to remain independent in the community as safely and cost effectively as possible. This is a recommendation for future study.
Chapter 3
Conceptual Framework

Based on a number of aforementioned provincial reports on Ontario’s health care system and other supporting literature, this thesis argues that the acute based, medically focused and siloed nature of health care is contributing to a gap between what PLWD need to age at home (demand) and what is available in the community to help them do so (supply). While there have been attempts at responding to the chronic homecare needs of vulnerable populations such as the elderly and PLWD, this thesis aims to provide some explanation as to why we have gotten to a point where experts like Walker, Drummond and the Ontario government itself are saying that the system urgently needs to look at ways to respond to this growing gap (Walker, 2011; Drummond, 2012; Government of Ontario, 2012; MAS, 2008). To help explain the gap between needs of community dwelling PLWD and how the system responds to their needs this thesis draws upon Neo-institutional Theory to identify and understand relevant connections between broad system-level factors in determining individual-level outcomes (in this case, outcomes for PLWD). It highlights the influences that both State and societal institutions (their structural characteristics, formal rules, and informal norms) have on the ideas, interests, and the distribution of power in a policy field (Steinmo, Thelen & Longstreth, 1992).

Subsequent chapters will look at the needs of community dwelling PLWD (Demand Chapter), what is available to meet those needs (Supply Chapter), a review of the historical legacy of policy decisions affecting current care options for PLWD (Policy Trajectory Chapter), and how this legacy is played out at the frontline of care (SW BoC Findings Chapter), and where we can be in the future (Discussion and Conclusions Chapter).

3.1 Rationale for Theory Explored

Neo-institutional theory provides a framework to help understand factors that drive policy dynamics in the evolution of health care – in particular the policy sub-field of long-term community-based home care – and political factors involved in the policy legacy for dementia care in Ontario. Neo-institutionalism helps in understanding what brings about dramatic shifts
in policy, the influence of dominant institutions (for formal and informal), structural relationships behind policy decisions, and accounting for the pace and direction of policy change in this field. It is also useful for speculating under what conditions veering off of embedded historical pathways might be possible, and what will happen if the system remains unchanged.

### 3.2 Neo-Institutionalism

Neo-institutionalism is a high-level theory derived from political science that emphasizes the role that historical legacies play in shaping current health responses and resource allocations at the local level. “History matters” (Putnam, 1993 in Tuohy, 1999) such that past policy decisions “crystallize” dominant political relationships at key historical junctures, and create a policy pathway or “path dependency” which influences subsequent policy decisions and their outcomes (Pierson, 2000). Historical neo-institutionalism has been summarized by Stephen Krasner (1988, p.67) in Howlett and Ramesh as follows:

> “An institutionalist perspective regards enduring institutional structures as the building blocks of social and political life. The preferences, capabilities, and basic self-identities of individuals are conditioned by these institutional structures. Historical developments are path dependent: once certain choices are made, they constrain future possibilities. The range of options available to policymakers at any given time is a function of institutional capabilities that were put in place at some earlier period, possibly in response to very different environmental pressures.” (Krasner, 1988 in Howlett and Ramesh, 2003, p. 44)

Neo-institutionalism can be used to identify and understand relevant institutions, structural relationships, and vested interests that provide the context for, and shape current policy decisions affecting the pace of change in the H&CC sector in Ontario and its impact PLWD. Beland and Hacker (2004) state that:

> “Scholars who adopt the institutional perspective generally make three common arguments:

i. that state officials are not simply political referees or agents of outside forces;

ii. that political institutions are relatively long-lived and resistant to rapid change; and
Neo-institutionalism as a theory of policy development not only provides an analytic perspective that emphasizes the impact of formal institutions (e.g., state enforced laws, regulations, courts, bureaucracies, funding arrangements that exercise state authority in accordance with embedded values) and informal institutions (e.g., civic, religious or societal rules or conventions) (Brooks, 2000 in Baranek et al., 2004); it also incorporates their historical contexts for structuring political reality and influencing policy decisions and outcomes (e.g., defining the terms and nature of political discourse, state and societal interests, the distribution of power in a policy field, conduct of individuals and organizations to which they belong) (Brooks, 2000 in Baranek et al., 2004; Kumpers et al., 2005; Howlett & Ramesh, 2003; Immergut, 1998; Thelen & Steinmo, 1992; Steinmo, Thelen & Longstreth, 1992).

### 3.2.1 Institutional Mix and Structural Balance

Carolyn Tuohy (1999) in her book *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain, and Canada* notes that periodic episodes of policy change establish structural and institutional parameters (internal logics or contexts) which explain how decisions are made and the extent to which particular modes of policy action become institutionalized in a given policy arena affecting future decisions (Tuohy, 1999, ch. 4).\(^6\) Tuohy draws on historical institutionalism and rational choice approaches to explain the logic of decision-making in health care as requiring an understanding of the intersection between institutional mix and structural balance that exists between the state and societal actors.

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\(^6\) Note: Researchers Kumpers and associates (2005) also suggest cultural characteristics/parameters reflecting historically embedded organizational, professional, political, and public values, as well as attitudes and routines as also influencing current and future policy processes/decision-making in health and social care systems (Kumpers et al., 2005, p. 1202).
The **institutional dimension** refers to the ways in which human interactions and public policies are shaped (systemized, legitimized and institutionalized) within a broader framework of ideas for the purposes of social control and to structure thinking about what constitutes a public problem, the means available to deal with the problem, and what evaluations are made retrospectively (Tuohy, 1999; Manzer, 1994 in Baranek et al., 2004). The institutional mix also considers an assortment of hierarchical, market and collegial instruments used to arrive at various policy decisions (Tuohy, 1999). The **structural dimension** refers to the balance of influence across different types of actors and policy communities within health care decision-making, including the State (i.e., federal and provincial governments), health care professionals, medical associations and private (market) and each of their respective interests (Tuohy, 1999).

The preferences and values of policy actors are shaped fundamentally by their structural position within the system. Institutions are conceived as structuring political reality and as defining the terms and nature of political discourse (Coleman & Skogstad, 1990, in Baranek et al., 2004).

While there are many different approaches to defining and applying neo-institutionalism as a theory, its basic underpinning and strength is that while it considers the importance of institutions of the State (including bureaucratic structures, laws, regulations), it also draws attention to the importance of key stakeholders/societal actors (including organized interests, the general public, and consumers) in the development of public policy.

### 3.2.2 Path Dependency

Path dependency is a key concept in neo-institutionalism describing ways in which institutions create their own historical pathways, thus shaping future decisions and outcomes. According to Deborah Stone (2002), certain types of decisions are easier to continue along the same path because repeated decisions require no new thought, and people are less likely to resist or even question orders and requests they have obeyed before (Stone, 2002).

A broad definition of path dependence offered by Sewell (1996) refers to the effects of events that occur at an earlier point in time as limiting the possible outcomes of a sequence of events occurring at a later point in time (Sewell, 1996 in Pierson, 2000). A narrower definition offered
by Levi (1997) suggests that path dependence implies that once a government/State has started down a path, the costs of reversal are high and entrenchments of certain institutional arrangements obstruct an easy reversal of the initial choice (Levi, 1997 in Pierson, 2000) – not to mention the many different institutions that come in to play as well.

Pierson conceptualizes path dependence as a social process grounded in the dynamics of “increasing returns” where the relative benefits of the current activity in a policy process, compared with other possible options, increase over time (Pierson, 2000). Metaphorically speaking, it is easier to get more development along the path of a city bus route than in the back roads of a city. Pierson also points to the critical nature of “sequencing” in these processes because earlier events play a large role in shaping policy decisions and outcomes. Beland and Hacker (2004) further highlight the importance of sequencing noting that while different policy dimensions factor into decision-making and outcomes, a central reality of politics is that the sequence and timing of an event is perhaps the most crucial element to policy change:

“If factor A comes before factor B, the effect may be very different to that if B precedes A, even though the same basic factors are involved. Similarly, the effect of particular events or decisions within one institutional or policy context may be fundamentally different than their effect in another context. In these cases, it is the path of policy development – when events and decisions occur relative to previous events and decisions or to large-scale institutional and policy changes – that ultimately provides the most convincing explanation of outcomes.” (Beland & Hacker, 2004, p. 46)

Because path dependency can be a very strong force, theorist Charles Lindblom (1979) suggests that when one sees or makes policy change, it will likely be incremental change. Incremental politics/change can look attractive because it:

\[\text{\footnotesize{\text{\textsuperscript{7}} A good example of this later described in the policy trajectory, was the ease with which the newly elected Ontario progressive conservative government in 1995 was able to implement its new vision for H&CC care services due to the enactment of Bill 173, An Act Respecting Long-Term Care by the previous government. While the act was intended to strengthen and protect home and community care services, “it removed one of the few remaining impediments to the passive privatization of health care in Ontario, calcifying that as care shifted out of hospitals, it would indeed be removed from the protection of the Canada Health Act” (Baranek et al., 2004, pp.150 and 284).}}\]
• “is intelligently exploratory when linked with sequences of trial and error
• reduces the stakes in each political controversy, thus encouraging losers to bear their losses without disrupting the political system
• helps maintain the vague general consensus on basic values (because no specific policy issue ever centrally poses a challenge to them) that many people believe is necessary for widespread voluntary acceptance of democratic government
• does not rock the boat, nor stir up the great antagonisms and paralyzing schisms as do proposals for more drastic change.”

(Lindblom, 1979, p. 520)

3.2.3 Policy Episodes and Windows of Opportunity

Neo-institutionalism provides a useful perspective that considers the effects of “policy episodes” and the specific “logic of the State” at the time when major policy decisions were made. Different policy episodes will exert different conditions under which the State will have relatively more or less capacity to assert its own internal logic and shape the broader context in which it exists rather than being shaped by this context (Baranek et al., ch. 2). According to Tuohy, policy episodes where major policy change occurs in a field such as health care are episodic and rare, only occurring when a coincidence of external forces is strong enough to overcome the resistance of interest within the arena to such change (Tuohy, 1999). She states:

“Episodes involving major structural and institutional change allow for opportunities to shift the balance of power across the State, the medical profession and private finance, and for changing the mix of hierarchical, market-oriented, or collegial instruments.” (Tuohy, 1999, p. 264)

However, for significant episodes of policy change to occur they usually require extraordinary mobilization of political authority and will within the political system. In addition, while policy

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8 Extraordinary is used to describe the necessary mobilization of political players because it is difficult to get those with influence and/or the necessary authority to agree to major change (regardless if evidence points to the need to restructure current health care practices, or existing mechanisms of organizing and financing health care); particularly if and when the change is perceived to, or likely to negatively impact any of the embedded/vested interests or go against widely held beliefs or ideas about the nature of healthcare.
episodes are likely to be shaped very much by the prevailing climate of policy ideas in the health care arena (the logic of the time), the window for change may actually be created and opened by factors in the broader political system (Tuohy, 1999).

As will be discussed in more detail in the historical trajectory, Canadian Medicare has largely fostered and maintained a focus on ‘medically necessary’ hospital and physician care – referred to as the **Medicare Mainstream** – as outlined in the **Canada Health Act (1984)**. This has set a path that embodies a fairly narrow, medical and curative based definition of what is involved in the maintenance of health, points of entry into the system, and the States’ responsibilities in providing publically funded health care. Institutions like the Canada Health Act (1984) and powerful hospital and doctor associations extend/perpetuate the logic of a medical model which can act as a barrier to getting the H&CC sector on the policy agenda. In addition, the dominant medical model of health care is more acute care oriented and outcome based (e.g., wait times for surgery, how many procedures were conducted, timely discharge) while other proximate policy fields like H&CC are guided by a more holistic approach to care (both health and social well-being). This can impact on the ability of H&CC to prove its value, acquire funding and gain greater recognition as a key component in the achievement of health and well-being.

Some windows of opportunity have opened to try and increase H&CC’s priority on the policy agenda however, as will be described in the historical trajectory, changing direction off of the familiar path of the Medicare Mainstream remains difficult. Such policy episodes are brief at best and any attempt at reform that threatens the funding or welfare of the dominant interests or ideas holding hospitals and doctors as the experts in achieving health (even though these entities do not really create health and remain largely designed cure illness and disease) is met with great resistance. A significant change away from the dominant medical model pathway would require extraordinary mobilization from community based interests (e.g., non-profit agencies, their associations, the interested public, non-government organizations), that are often not well funded, organized, and lacking power, and linkages with decision makers as other more established organizations (e.g., Medical Associations).
3.2.4 Getting on the Policy Agenda

John Kingdon’s (1984) work on agenda-setting has noted that the intersection of windows of opportunity with one of three streams of policy variables – problem stream (perceptions of problems as public problems requiring/that required government action); the policy stream (evidence based examination of problems and proposed solutions); and the political stream (national mood, administrative or legislative turnover and interest group pressure campaigns) – is key to any significant policy change (Howlett & Ramesh, pp. 135 - 137). He notes that some windows are quite predictable, but some are very unpredictable, rarely happen, and when they do, do not stay open long. While he notes three types of policy streams exist, he suggests that really only two principle types of windows come into play: the ‘problem’ and the ‘political’ windows:

“Basically a window opens because of change in a political stream (e.g., a change of administration, a shift in the partisan or ideological distribution of seats...or a shift in national mood); or it opens because a new problem [stream] captures the attention of governmental officials and those close to them.” (Kingdon, 1984, p. 176, in Howlett and Ramesh, 2003, p. 137)

Tuohy also describes two necessary conditions for windows of opportunity to occur (neither one on its own sufficient):

1) The political system must provide a consolidated base of authority for policy action – controllers of key levers of state authority must be willing and able to act in concert and different political systems will vary in their potential to consolidate authority (e.g., minority governments).

2) The substantial change in health care policy holds a high priority within the broader agenda of those who command the levers of authority – i.e., a commitment by key political actors to elevate the issue above the many other issues that would benefit from this type of effort (Tuohy, 1999).

An example of a window of opportunity that has opened in the United Kingdom (UK) would be the recent dementia care movement. This movement has captured the attention of Prime Minister David Cameron, his governmental officials and those close to them. A national
“Dementia Friendly Campaign” with over 1.8 billion pounds has been invested to this cause in 2012-2013. Not only is the campaign considered important due to the growing needs of PLWD in the UK, but also because the prime minister has a personal connection to someone with dementia. This helps to elevate the priority of dementia both within the broader agenda of government, and by key political actors (especially given that the British government has a great deal more authority and ability to assert its will on health care and its various actors unlike the weaker authority in Canada and the United States).

3.2.5 Three I’s of Neo-Institutionalism

The institutionalist lens is beneficial in highlighting the important role of not only institutions, but the combined effect of institutional and structural parameters with political values and ideas, elite and public interests, path dependency, and the sequencing of policy decisions in shaping legacies from which future relationships, interactions, and policy outcomes are formed (Bananek et al., 2004; Beland & Hacker, 2004; Steinmo & Watts, 1995; Tuohy, 1999). Using Tuohy’s conceptualization of neo-institutionalism, and building on the work of Baranek and associates, the following sections will highlight three key concepts known as the 3-I’s – institutions, ideas, and interests – used in both authors’ theoretical arguments to help understand the underpinnings of policy dynamics and historical pathways in health care.

3.2.5.1 Institutions

There are a number of ideological and practical considerations around the role of the State in its development or reform of health care including the many formal and informal institutions involved (e.g., legislation, funding arrangements; offices of government; global organizations) and the division of power within and amongst them.

The institutional dimension of neo-institutionalism refers to ways in which human interactions and public policies are shaped (systemized, legitimized and institutionalized) within a broader framework of ideas for the purposes of social control and to structure thinking about what constitutes a public problem and how to deal with it. It also recognizes an assortment of hierarchical, market and collegial instruments involved in arriving at various policy decisions (Tuohy, 1999; Manzer, 1994 in Baranek et al., 2004).
Institutions can range from broad notions/establishments like “the institute of marriage” to concrete structures like laws, or Parliament itself, that impose rules for which different actors can exert influence within a sector. “Past policy decisions can also be considered institutions as they can impact upon and shape the terms of future policy decisions” (Kay, 2005, p. 557). Steinmo and Watts surmise two central roles of institutions as follows:

1) **Political institutions can influence the political climate** by shaping how interests organize themselves, how much access and power interests are likely to have, and even the specific policy positions they are likely to take.

2) **Institutions can influence what is seen as achievable** critically affecting policy preferences based on their ability to shape the rules and giving priority to some interests and ideas rather than to others (Steinmo & Watts, 1995).

Thus, institutions play a crucial role in political decision-making processes and have an effect on:

- the interpretation of problems and possible solutions;
- the definition of actors’ interests by making certain alliances and outcomes more likely than others (Weir, 1992); and
- broadly held ideas that restrict, produce or reproduce policy choices and actions of governments and social interests (Baranek et al., 2004).

Although institutions play a crucial role in political decision-making processes (e.g., constraining or enabling decision-making processes; exerting influence in other conceptual dimensions such as ideas and interests) institutional factors alone do not cause action or fully explain policy dynamics (Immergut, 1998).

**3.2.5.2 Ideas (Paradigms and Framing)**

Ideas affect how we think about a public problem and how to deal with it. Canadian Medicare is often seen as a defining feature of Canadian Society both for individuals and for the State. Ideas about health care play a major role in defining the nature of illness/health and weigh
heavily as a topic of concern at every national and provincial election. According to Stone, people *fight with ideas* as well as *about ideas*, with every idea about policy drawing some kind of boundaries (Stone, 2002, p. 34). While the public feels health care is important, ideas about health policy related to aging are not straightforward; care of the elderly evokes mixed feelings both in individuals and society, and can get caught up in broad political (e.g., ideology, research evidence, values) and economic debates (e.g., external events like a recession) and about the appropriate roles of different institutions in solving problems related to the aged.

Two overarching paradigms (sets of ideas) exist in Canadian health care that specify how problems of the day are to be perceived, which goals might be attained through policy and what sorts of techniques can be used to reach these goals (Baranek et al., 2004). They provide a framework for thinking through problems, framing issues, and ultimately decision-making. The earlier mentioned medical model is considered the dominant paradigm in the development of Canadian Medicare and has a predominantly clinical/curative focus. A lesser known paradigm is the broader *Social Determinants of Health Model* (often associated with the term population health model) which considers a range of factors spanning across the larger health and social care continuum including, but not limited to, income support, poverty, food security, education (Epp, 1984). The determinants of health paradigm was highlighted in 1974 by Mark Lalonde, the then Minister of National Health and Welfare, in his “ground-breaking” report *A New Perspective on the Health of Canadians*. The report examined the historical developments that resulted in a “doctor and hospital” centred Canadian health care system and suggested the need for expansion of the idea of health and of the government in promoting and maintaining it:

> “The role of the Federal Government is necessarily circumscribed by its powers, but the Health Side of the Department of National Health and Welfare now finds itself, thirty years after its creation, with numerous, varied and important activities which have been developed over time, in collaboration with the Provinces, to cope with evolving changes in the health needs of Canadians.”

(Lalonde, 1974, p. 46)

Lalonde went on to describe a number of programs and activities which he defined within the context of the *Health Field Concept*, that are important to general health and well-being including medically based *Human Biology*, while also recognizing an expanded role for other
broader social determinants of health such as *Environment, Lifestyle*, and *Health Care Organization* (Lalonde, 1974). Related to this, the World Health Organization (WHO), identifies determinants of health as being “those factors that can enhance or threaten an individual’s or a community’s health status (e.g., matters of individual choice or social, economic, and environmental factors beyond the control of individuals).

Although one may conceive of many different ways Medicare services can or even ‘should’ be offered (e.g., expanding basket of “medically necessary” services to include long-term home care), and why (e.g., an increased demand for care and reliance on home care as a lower cost alternative to acute and long-term institutional care, fewer family caregivers due to changing family structure, and greater emphasis on self-management), any substantial change in the policy parameters of our current health care system or rebalancing the administrative structure and resource mix would meet with strong resistance and require a major *paradigm shift*. Effecting such change would involve the signatures and hence agreement of the provinces and territories to make any real changes to the CHA. Paradigms like the Medicare Mainstream, having become so well entrenched change very slowly/incrementally especially when they become tied to the socialization and education of experts/physicians and their associations who may subsequently have a strong voice in changing the policy agenda9 (Doern & Phidd, 1992). This helps to explain why major policy shifts require extraordinary mobilization of political authority to occur and the need for any new idea (in this case that aging in place constitutes a public problem) to be supported by a sweeping current of public opinion to establish the broad outlines of the agenda for change (Tuohy, 1999).

Beyond the need for significant political authority and sweeping public opinion, a paradigm shift could also involve a much wider range of forces (economic, social, environmental, and political) which would have an impact on the health of individuals and on broad populations. In

9 For example, physicians are reimbursed for their services on a fee-for-service basis through a fee schedule negotiated between provincial governments and provincial medical associations (Maioni, 2002, p 184)
H&CC in Ontario the debate often involves strong government ideology (e.g., cost-efficiency/cost-restraint tactics), powerful medical institutions and interests (e.g., Medical Associations, Colleges of Physicians and Surgeons, Hospital Associations) and community interests (e.g., disease specific interest groups). Characteristics of the policy under consideration will determine what is at stake, who will become involved, and how conflictual the issue will be (Lowi, 1964 in Kellow, 1988).

The groups that weigh in and to what extent often relate to whether the policy being considered is **distributive**, **regulative**, or **redistributive** (Lowi, 1964 in Kellow, 1988). Generally, distributive policies are not conflictual and everybody tends to win because they all get something in the policy. Regulative policies are considered conflictual and involve behavioural rules formulated at the level of the economic sector and then implemented on a firm-by-firm or case-by-case basis. Redistributive policies are considered very conflictual because they explicitly redistribute resources from one social group to another. Because there are potential losers involved with redistributive policies, opposition is guaranteed (Lowi expected both winners and losers to mobilize on redistributive issues, generating struggles that approach class conflicts) (Lowi, 1964 in Kellow, 1988). In the case of H&CC, the earlier mentioned powerful medical and hospital organizations will engage heavily into any debates about health care if and when possible reform occurs as this can threaten their power and processes (e.g., a redistribution of hospital or physician resources).

### 3.2.5.2.1 Scope of Conflict

Related to the Lowi’s “Policy Theory” (Lowi, 1964) and notion of how and to what degree different interests engage in policy development is Schattschneider’s *Scope of Conflict Theory*. This theory suggests that policy debates are often determined by who participates, how many interests participate, and under what “ground rules”. Who bears the cost and who gets the benefits is dependent on how many people, and which people are at the table in relation to policy development. Schattschneider outlines three key factors that determine the nature and scope of conflict:

- **Visibility** – whether the group has the information about the policy so it knows that it will need to participate and be organized to acquire access
to this valuable information (e.g., what type of policy is being discussed; how to access information; where is policy being discussed and how accessible it is to them; issues of stigma affecting participation – tied in with notions that this is a “private matter” etc.)

- **Intensity** – how attached the group is to the policy issue whether they will participate or not (e.g., concentrated or diffuse interest)

- **Direction** – agenda of individuals and whether they see this as an important enough conflict to be involved in (note: people’s interest can shift).

(Schattschneider, 1960 in Kellow, 1988)

In the case of getting and keeping dementia on the policy agenda, multiple factors come into play including stigma by PLWD and their caregivers and a related reluctance to become identified or attached to the issue; the symptoms of the disease itself for those with dementia causing difficulty in organizing to convey their message; public and private notions that the locus of responsibility is with family in the support and care of PLWD. These and other factors can limit the voice of those experiencing the disorder and their partners in care. As will be discussed in a later section, their voice/interest has been elevated by such national, provincial and local Alzheimer Societies and other concerned Associations (e.g., mental health, caregivers associations) who to varying degrees involve consumers and family members in their efforts. The influence of interest groups and consumer advocates will be discussed further in Section 3.2.5.3.

### 3.2.5.2.2 Framing Ideas

The manner in which something is defined or “framed” plays a large role in an idea getting attention, how it is perceived, determining who is involved in decision-making processes, the priority various actors/stakeholders and interests will place upon the idea, the degree of conflict amongst them, possible policy solutions, and the rules by which the decisions are made (Schattschneider, 1960). Tversky and Kahneman (1981) contend that decision framing is also influenced by the problem itself and who frames it.

In the case of dementia, it has been framed in many different lights depending on the actors and their interests in framing the issues. Historically, we have seen changes in the way people
refer to dementia from “senility” to “senile dementia” to “dementia” and now a move towards referring to dementia as a “neuro-cognitive disorder.” Definitions and labels can greatly influence how “problems” are perceived. Dementia has long been considered through the biomedical lens based on neuropathology – a pathology which tends to show itself later in the manifestation of the disorder when there is a greater degree of incapacity. From this perspective, PLWD are described as ‘suffering from dementia’, ‘victims’ of the disease, and ‘incompetent dementia patients.’ As such, professionals and even family members often perceive PLWD as being incapable of many things, including living independently in the community. Biomedical framing of dementia as a pathology perpetuates a reliance on physicians as ‘gate keepers’ for PLWD to hospital, clinical, and home care services. This type of framing contributes to an ongoing medical mode of thinking about the issue and desired policy outcomes to help PLWD.  

An additional issue with framing dementia is that it is often set within a context of ‘risk,’ ‘risk mitigation’ (e.g., protection from unsafe wandering or from being taking advantage by others) and potentially ‘dangerous behaviours.’ Risk is frequently “defined in terms of its negative elements, namely, harm and danger rather than as a chance to gain benefits in a situation [like remaining in one’s own home] where harm is also possible” (Alaszewski, 1998 in Waugh, 2009, p. 206). Linking dementia primarily to risk and seemingly ‘abnormal’ or ‘challenging’ behaviours associated with the progressive and unpredictable nature of dementia contributes to the framing of people with mental illness/dementia as posing risk to one’s self or risk to others (Standing Committee, 2006, 7.3.1). Such framing has important ethical and practical  

10 It is curious that interventions often considered to be helpful to PLWD may actually impose limitations on that person’s individual liberty in an effort to provide security to those at risk (self or others). The Charter of Rights and Freedoms applies to all on Canadian soil, however can be trumped by Federal and Provincial Mental Health Acts as well the Consent and Capacity Act based on medical presumption of risk. In further relation to the traditional medical model of doctor as expert and patient as benefactor, provider-driven care is generally structured to suit primarily the needs of individual and institutional service providers not their clients (e.g., traditional office hours, short appointments, hospital/doctor office). Current dementia health interventions do not well suit such time-constraints and locations of this model.
implications for perceptions of need, policy and practice and can lead to serious consequences for this vulnerable group (e.g., denying them of certain rights and privileges based on potential risk). For example, who is to say that just because risk exists it needs to be entirely contained (e.g., would one stop eating because they might choke and die on a piece of food?).

In the case of policy making, it is easier to generate interest when one is able to frame something more visible and easier to recognize (physical health issues/disabilities) as they can be more difficult for people to ‘deny’ as posing a problem. In contrast, cognitive/mental health issues can be less obvious as needing assistance and thus the health policy field struggles with generating interest and recognition of dementia as a pressing problem.

3.2.5.3 Interests (Interest Groups and Policy Communities)

There are many different ways to describe interests such as policy preferences, areas-of-interest, motives or objectives that someone, some organization, or even a state holds dear – to the actual individuals, organizations or state institutions themselves. Interests may be implicit or explicit; openly declared or hidden; vested or public (Howlett & Ramesh, 2003; Bryant, 2004). Deborah Stone (2002) “Public Interest” can mean many things including:

a) *Individual interests held in common, things everyone wants for themselves*

b) *Goals on which there is a consensus, things favoured by the majority*

c) *Things that are good for a community as a community (e.g., some sort of governing process to ensure order and “fair play”).*  

(Stone, 2002, pp.21-23)

3.2.5.3.1 Interest Groups

*Interest or pressure groups* may form around a particular policy issue to give it more visibility and credibility (Pross, 1992) in the hopes that the voice of many will more powerful than the voice of few. According to Doern and Phidd (1992) these groups will range in scale and scope and play an integral part of the democratic policy process. They are also seen to compete with political parties, the media and others “for the privilege of interpreting the public will to key decision makers” (Doern & Phidd, 1992, chapter 5). They further note that in Canada, interest
groups perform two major politically relevant functions in the role of policy formulation: **communication** (providing technical data, conveying the intensity of the members’ views which can range from apathy, concern or anger, and express the concerns of policy makers to the members) and **legitimation** (the role they play in broadening the base of information and the number of people involved in discussing policy problems. Governments use these groups to test policy ideas, to obtain visual support, and defuse extreme resistance. (Doern & Phidd, 1992, ch. 5).

While pressure groups are not part of the government, many departments of government must deal with a variety of such groups and many of these will be consulted if they are considered key stakeholders in an issue and if there is a need for them to cooperate with organizations to get public buy-in (e.g., provincial Alzheimer’s Society for dementia related issues). Some groups, such as non-governmental organizations, may actually be provided with public funding in order to intervene in the policy process\(^{11}\) (Ibid, 1992). It is important to consider the impact that such an arrangement can have on consultations and the cardinal rule that ‘thou shalt not bite or embarrass the Ministry hand that feeds you’. Depending on the issue at hand and structural balance, some interests will have a stronger influence than others at the policy table and as such, powerful and cohesive interest groups may actually be considered a form of institution because of their formal organization and ability to structure relationships and outcomes (Pross, 1975). This is highlighted in Baranek and associates (2004) book “*Almost Home*” where a number of organizations in the field of LTC, many of which have biomedical underpinnings (e.g., Ontario Nursing Association, Ontario Hospital Association, Ontario Medical Association, Ontario Nursing Home Association, Ontario Association of Non-Profit Homes and Services for Seniors), are almost seen to form what amounts to a sub-government.

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\(^{11}\) Although allowed to conduct awareness activities, if receiving with government funding by law they may not have more than 10% of their regular activities be related to advocacy work.
The LTC policy community also includes many grassroots and consumer driven organizations (e.g., Ontario Community Support Association, Ontario Coalition of Seniors Citizens Organizations, Advocacy Resource Centre for the Handicapped, Ontario Home Help Providers Association, Concerned Friends) who while lacking the same power and financing of the earlier mentioned associations, will be seen as possessing great ‘moral authority’ on an issue. Depending on the issue, one might also see specialized interest groups with a stake in the outcome of a policy decision such as disease specific organizations (e.g., Alzheimer Society, Arthritis Society, Centre for Addictions and Mental Health) join in the policy community for a time (Baranek et al., 2004).

3.2.5.3.2 Policy Communities

Related to interest groups, one might also see the emergence of policy communities that take an interest in dementia. Doern and Phidd describe policy communities as:

- A network of private (non-profits, for-profits, individuals) and public entities that have a continuing stake in/knowledge about, any given policy field or issue
- Comprising many different types of actors: interest/pressure groups, governmental departments/agencies with policy jurisdiction, media, consultants and experts in academe/private institutes
- Important to facilitate policy action in a policy field; their absence may make coherent (or meaningful) policy impossible (Doern & Phidd, 1992, pp.76-80).

Policy Communities in the field of dementia care often share a sense of policy history where members are repositories of technical and corporate knowledge, and have dealt with each other for many years – with many of the same players/actors (i.e., provider associations) included at the policy table. Typical players in this field include dementia and related mental health non-government organizations (NGO’s), and depending on the issue at hand, associations which comprise family physicians, psycho-geriatricians and neurologists. These might include the federal, provincial or regional Alzheimer Societies, Colleges of Family Physicians, Medical Associations, Psychiatric Associations, Mental Health Associations and Alliances, and Regional Geriatric Programs. Other related interests may include disease specific organizations that focus on specific types of dementia (e.g., Lewy Body, AIDS), Parkinson’s Society, Palliative Care Associations and possibly to a lesser extent, consumers/individuals.
receiving or having need of dementia services. These institutions provide a forum for the voice/interests of those experiencing brain health issues, are also considered public goods\textsuperscript{12} because of the large amount of research and/or direct service provision they provide in the field. The earlier mentioned LTC, Hospital, and Professional Associations may also enter into a policy community depending on the relevance of the topic to their vested interest or intensity as described by Schattschneider (1960).

Sometimes the scope of a policy issue will cross jurisdictions such that other seemingly unrelated organizations become involved (e.g., the police, court systems, or legal aid). Another group which has more recently taken a public position on improving the health system for vulnerable seniors in Canada is the media – in particular *The Globe and Mail* and *The Star* (two of the Canada’s most influential national newspapers). Each continues to run articles on aspects of brain health and it’s intersections for those with dementia and their families living in the community, receiving hospital care, or living in residential LTC homes.

### 3.3 Summary

This conceptual framework has used neo-institutionalism to provide an understanding of key factors to look for historically to better understand the importance of historical policy decisions on current day reform (or lack thereof), and as a means to predict what one might see happen in the future. Neo-institutional theory points out that substantial or sweeping change in health care is tough to accomplish due to deeply embedded ideas, institutions and interests and resistance to transformation on any of these fronts. The longer one is on a certain path the more difficult it is to move off of it (inertia), thus leading to only constrained or small incremental changes when change does actually occur. In the eyes of the State incremental change is often considered safer to avoid big mistakes and because going in a new direction can become more costly to leave than staying on the familiar path; there is always some risk

\textsuperscript{12}“The benefit to society as a whole” – it is not an issue of who owns what, but what is best for society (Stone, 2002, p.398).
involved with change such as cessation or alteration can involve considerable legal, bureaucratic, financial and political expense (Howlet & Ramesh, 2003). In the eyes of PLWD, some incremental steps can be helpful as compared to no change as will be highlighted in the following chapters.

In this research, if neo-institutional theory is correct, we can expect to see the policy mismatch between the needs of PLWD and the ability of the system to respond to those needs will continue along the same familiar path (hospital use and LTC placement as default options for PLWD).
Chapter 4
Dementia and Demand

This chapter provides a background on the topic of dementia and many unique characteristics related to its progression that affect the ability of PLWD to age at home as independently, safely, and as long as possible. It also describes the complexities of growing demand by PLWD due to an aging population with greater numbers of people affected by dementia and possible interventions needed to treat or care for them. The subsequent chapter will highlight supply factors affecting system capacity to provide needed community based care options for PLWD and their informal caregivers and their influence on the ability to age at home in the community.

4.1 The Uniqueness of Dementia

Like other older adults, PLWD desire to age at home for as long as possible (ASUK, 2011)\(^\text{13}\); however, dementia is noted as the primary cause of long term institutional placement among elderly Canadians (CIHI, 2011a) with more than half of those residing in long-term care (LTC) homes (“three out of five) having some form of dementia (CIHI, 2010a; ASO, 2007; Forbes et al., 2008). While institutional LTC is an appropriate setting for those in need of high level care, many community dwelling seniors living with dementia are vulnerable to premature or inappropriate institutionalization. PLWD often have complex, ongoing needs (e.g., progressive memory loss, confusion, functional impairment and cognitive related behaviours), that may not fit traditional curative responses to health care. Furthermore, care systems focused on episodic, acute care and fragmented service provision are ill-suited to support PLWD safely and cost-effectively in the community.

\(^{13}\) 83% of caregiver and PLWD who responded to a questionnaire in the UK said being able to live in their own home was very important to the person with dementia; 59% of caregivers and PLWD who responded believe being active in the community is very important to PLWD (Alzheimer’s Society UK, 2011, p. x - xi).
As mentioned in the Introduction, age is the greatest risk factor for experiencing some form of dementia, a long-term chronic and ultimately fatal disorder of the brain, with one in thirteen persons over the age of 65, and one in three over the age of 85 estimated to experience one of its many forms (ASC, 2012). Contrary to popular belief, dementia is not a normal part of aging; however, the aging population means that there will be more older adults at risk for developing dementia (Chertkow, 2008; Volicer, 2001). Not only will more people develop dementia than ever before due to population aging, they will also live longer with dementia due to advancements in health care, technology and pharmaceutical interventions. This new phenomenon is expected to place additional demand on an already fragmented system of health care services including hospital based health care, rehabilitation, residential LTC, and H&CC support services (ASC, 2010). The World Health Organization (WHO), Alzheimer Disease International (ADI) and the Alzheimer Society of Canada (ASC) have each warned of a pending “Dementia Public Health Crisis” or “Dementia Epidemic” and describe dementia as one of the most significant health issues of our time—set to overwhelm already stretched health care systems, increase the burden on caregivers, and to impose increased economic costs (WHO & ADI, 2012; ADI, 2011; ASC, 2010).

“PLWD who have severe functional disability receive far more services than those with mild to moderate disability. And, although the needs of PLWD and caregivers of dementia increase with increasing levels of patient disability, services remain underutilized in this population. Only 3.4% of dementia caregivers use respite services, a service identified by caregivers as a key formal support to alleviate the stress of caring. It has been documented that spousal caregivers use fewer support services than caregivers who are adult children. Despite the decreased utilization in services, dementia has a significant economic burden on the Canadian health care system. A main driver for these costs is the cost associated with caring for a dementia patient in LTC. In 1991, the total net costs of dementia in Canada were $3.9 billion (Cdn) with 2.18 billion coming from LTC.” (MAS, 2008, p.23)

While dementia in and of itself can be difficult to manage and accommodate by PLWD and their caregivers, the experience becomes even more debilitating when one factors in possible age-
related declines\(^{14}\) (e.g., vision, hearing, mobility): and that PLWD often experience one or more additional chronic conditions\(^ {15}\) (e.g., diabetes, chronic obstructive pulmonary disorder, chronic heart failure, hypertension, angina), and/or terminal illness (e.g., cancer). In this connection, dementia is associated with more years with disability than many other chronic diseases (ASC, 2010; WHO & ADI, 2012). Moreover, dementia often hinders management of other chronic diseases resulting in frequent visits to hospital EDs, hospitalization of PLWD (driving up ALC bed rates), and premature placement in residential LTC. In fact, PLWD account for almost one quarter of ALC hospitalizations and more than one third of ALC days. Using dementia as the primary diagnosis, PLWD had a median ALC length of stay of 23 days compared with 10 days for ALC patients overall (Walker et al., 2009). This is often attributed to limited options for discharging PLWD back to the community, and/or long wait-lists for placement to residential LTC; however, an additional explanation may be that had appropriate interventions been introduced earlier in the progression of the dementia, unnecessary visits to the hospital or institutional placement may have been avoided.

As noted in the introduction, the Walker report echoes this citing that current models of care continue to rely on acute care hospital resources and institutional LTC placement without appropriate consideration of a patient’s potential to improve, recover, and be cared for at home with support (Walker, 2011). In this connection, the Canadian Healthcare Association (CHA) cites that “home care can permit individuals to live at home with independence and dignity, and is part of the solution to some of the challenges facing our health system, such as lengthy wait times for placements and procedures, pressures on EDs, inappropriate use of hospital beds, and a shortage of LTC beds” (CHA, 2009, p.9). Long-term H&CC support services

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\(^{14}\) Remembering that most PWD are 65 years of age and older.

\(^{15}\) In a study comparing community dwelling PWD receiving formal homecare services provided by the 14 Community Care Access Centres (CCACs) across Ontario with other long stay (term) homecare clients: of the 28 disease diagnoses that the Resident Assessment Instrument for Homecare (RAI-HC) records during assessments and reassessment, CCACs long stay homecare clients with dementia had on average 3.9 conditions, compared to other long stay homecare clients who had 3.3 (Alzheimer Society of Ontario, 2007a).
and interventions targeted to the needs of PLWD and their caregivers can often delay, substitute for or prevent unnecessary admission to acute care hospitals and LTC facilities; however as will be discussed below, these interventions are often limited in supply, or not accessed in a timely matter due to gaps in the system.

### 4.1.1 About Dementia

In the recent past dementia has been used as an umbrella term referring to a large class of disorders of the brain that can be both reversible (e.g., medication induced dementia/polypharmacy; depression; malnutrition) and irreversible (e.g., Alzheimer’s disease; Vascular dementia; dementia with Lewy Bodies). Since less than 10% of cases are reversible (Clarfield, 2003), these cases can be easily mistaken for irreversible dementia (Chapman et al., 2006). Both types of dementia can also be present at the same time (e.g., Depression and Dementia). Alzheimer’s disease is the most common form of irreversible dementia and possibly accounts for 60-70% of cases. Determining which of the dementias a person has, generally relates to the speed and type of progression; however, mixed forms often co-exist, making it difficult to distinguish between the sub-types (ASC, 2010; WHO, 1992 in WHO & ADI, 2012; Chapman et al., 2006). At the time of data collection the definition provided in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* for dementia was used broadly for a host of commonly and less commonly occurring cognitive impairments, and was used for the purposes of this thesis.

> “The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR), defines dementia as multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia (language disturbance), apraxia (impaired ability to carry out motor activities despite intact motor function), agnosia (failure to recognize or identify objects despite intact sensory function), or a disturbance in executive functions (e.g., planning, organizing, sequencing, abstracting). The cognitive impairment must be sufficiently severe to cause impairment in occupational or social functioning, must represent a decline from a previously higher level of functioning and the deficits do not occur exclusively during the course of a delirium.” (American Psychiatric Association DSM-IV-TR, 2000)

It is important to note that in 2013 the *Diagnostic and Statistical Manual (DSM)* was updated in a fifth edition (DSM-V) whereby there was a significant change where the term “dementia” is
no longer used and has been replaced with the term “Major or Mild Neurocognitive Disorder” (American Psychiatric Association DSM-V, 2013). The new term focuses on the decline from a previous level of functioning as opposed to a deficit and is believed to be less stigmatizing towards those with the condition. In addition, the old dementia terminology required the presence of memory impairment for all of the dementias. It has been recognized that memory impairment is not the first domain to be affected in all of the other diseases that cause a neurocognitive disorder. For instance, in frontal temporal disorder, language could be affected first. This change in terminology will now require that all diagnosing health care professionals first establish the presence of a neurocognitive disorder and then determine whether the neurocognitive disorder is minor or major (American Psychiatric Association DSM-V, 2013).

4.1.2 Diagnosing Dementia

Dementia in general is characterized by the chronic and progressive deterioration of thinking ability, judgment, reasoning, orientation, comprehension, calculation, learning capacity, language, and memory as the brain degenerates, eroding functional independence to a state of complete dependence and eventually, taking life (ASC, 2010; WHO, 1992 in WHO & ADI, 2012). As a dementia progresses, a person’s disability\(^\text{16}\) increases as does their need for support and care (CIHI, 2010a). To determine if the declines are attributable to a dementia, a person will undergo a battery of physical, clinical, and cognitive evaluations. Consensus Guidelines from the 2006 Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia, suggest a diagnosis of dementia involves a combination of:

- taking the patient’s history
- interviewing a caregiver or family member
- physical and functional status examinations

\(^{16}\) Dementia is also considered one of the major causes of disability in later life accounting for 11.9% of the years lived with disability due to a non-communicable disease (WHO Global Burden, 2008 in WHO & ADI, 2012, p.8).
• neuropsychological/cognitive evaluations (e.g., screening tests like the MMSE or MOCHA)
• basic laboratory tests (e.g., blood work, urine) and
• structural/diagnostic imaging (CT scan) for patients meeting certain criteria

(Feldman et al., 2008; ASC, 2010; Husband, 2000)

Other important considerations when diagnosing dementia are any deficits in a person’s vision or hearing, their level of education, mother tongue, culture, financial (in)security, social networks, and emotional status as each factor, alone or in combination, can affect the state of wellness and their ability to understand and answer questions appropriately (Nicholl, 2009; WHO & ADI, 2012; Morton, 2010).

It is worth noting that the aforementioned considerations and declines may also present as symptoms that mirror those of dementia (e.g., not hearing questions properly or not understanding the meaning of certain common terms or phrases in the English language thus answering incorrectly; not asking for clarification for fear of looking stupid resulting in doing something incorrectly; diagnosis of dementia because a translator was not available).

Diagnosis of dementia is typically made by a family physician or by a geriatrician, neurologist or psychiatrist most often when PLWD’s cognitive abilities are no longer adequate for them to cope with their environment (i.e. well into the early to middle stages of dementia). “While family physicians tend to be the first point of contact for a diagnosis of dementia, family physicians often do not recognize cognitive impairment” (Iliffe & Manthorpe, 2002 in Lee et al., 2010) with estimates of one-quarter (25%) to two-thirds (66%) of people with [dementia] not receiving a formal diagnosis or treatment (Feldman et al., 2008; Callahan et al., 1995 in Lee et al., 2010). Other factors are the lack of physician confidence in their diagnostic skills, poor patient and physician communication (Bradford et al., 2009 in Lee et al., 2014), and beliefs that diagnosis requires specialist consultation (Connolly et al., 2011 in Lee et al., 2014).

Missing this diagnosis or misdiagnosing a reversible dementia (e.g., depression, thyroid issues, urinary tract infection) can lead to inappropriate admission to hospital and/or LTC placement.
This is unfortunate at both an individual and at a system level because unrecognized dementia or treatable conditions with dementia-like symptoms (e.g., confusion caused by infection, medications, electrolyte imbalance) increases the risk for tragic situations such as delirium, motor vehicle accidents, medication errors, financial difficulties, caregiver burnout, early/inappropriate institutionalization, and health care use and elevated health care costs (Sternberg et al., 2000; Steele et al., 1990 in Lee et al., 2010, p. 2197). Specialized programs, memory clinics, and collaborative approaches to dementia diagnosis and management have been recommended as significant opportunities to improve dementia recognition and increasing capacity for dementia care at the primary-care level (e.g., improved and timely access to specialized inter-professional assessments and early interventions which provide an opportunity to reduce crises and caregiver burden) (Lee et al., 2014).

4.1.2.1 Reversible and Co-Morbid Dementias

Prior to determining a diagnosis of an irreversible dementia it is important to rule out possible reversible dementia. While there is no cure for an irreversible dementia, there are treatments available for many reversible dementias. Two of the most common forms of reversible dementia are delirium and depression.17 “Delirium, dementia and depression are often unrecognized among the geriatric population, due to their complexity and multi-faceted nature. This lack of recognition impacts upon the quality of life, the morbidity and the mortality of the older client” (Registered Nurses Association of Ontario (RNAO), 2003, p. 20).

Much like dementia, depression among the elderly is often under-diagnosed and under-treated since other health problems can mask its symptoms or the symptoms may be considered as part of the normal aging process (National Advisory Council on Aging (NACA), 1999 in Canadian Coalition on Seniors Mental Health (CCSMH), 2006). Next to dementia, the most common

17 Other reversible forms of dementia may include: Thyroid issues; Vitamin B-12 deficiency; or Medical conditions (e.g., heart disease, diabetes, kidney disease, lung disease or any combination of these) (Ladika & Gurevitz, 2011)
mental health problem among seniors is depression (Elderly Mental Health Care Working Group, 2002). Missing this diagnosis can be costly not only to the individual, but also to the system as it can result in excessive use of health care services, increased length of stay during hospitalization, decreased treatment compliance, and increased risk of medical illness and suicide (Conn, 2002). For those experiencing dementia and depression together, the latter can bring additional disability to [PLWD] and their caregivers while if treated can help better manage the dementia. For this reason it is recommended that depression be screened for routinely to help improve many dementia-related outcomes (Boustani & Watson, 2004).

Symptoms of depression (e.g., mild to severe affective, cognitive and somatic or physiological manifestations such as apathy, difficulty with memory and word finding) and the symptoms of a delirium (temporary disordered mental state, characterized by acute and sudden onset of cognitive impairment, disorientation, decline in level of consciousness, disturbances in attention, speech, and/or perceptual disturbances) can be similar to those of a person experiencing a dementia; however, their underlying pathology can be quite different (e.g., bladder infections, adverse medication reactions or poly-pharmacy, trauma)(RNAO, 2003; Canadian Coalition of Seniors Mental Health, 2006 a,b).

Making the distinction is important as interventions will differ. “Left untreated depression can lead to increases in mortality, morbidity, and suicide rates and a higher incidence of comorbidity with [other] medical conditions” (RNAO, 2003, p.21). Hospital-acquired delirium, particularly post-operative, is a disease of the elderly with a prevalence of up to 40.8% (Inouye 2006 in Liu et al., 2010). This contributes to increased lengths of stay in hospital, cost of care, functional decline, mortality and morbidity (Lui et al., 2010).

According to the Canadian Coalition for Seniors’ Mental Health (CCSMH) National Guidelines For Seniors’ Mental Health: The Assessment and Treatment of Depression:

“Depression often complicates dementia, including Alzheimer disease and vascular (post stroke) dementia. Eleven to 24% of patients diagnosed with Alzheimer-type dementia meet diagnostic criteria for depression, while an even greater percentage (43%) are considered depressed by their family. The association between stroke and depression has also been well documented with up to one third of stroke patients developing major depression. It is therefore not
surprising to encounter depression during the course of vascular or mixed dementia. Depression may be more common early in the course of dementia. However, the lower incidence of depression reported in later stages of the illness may be attributed to the difficulty of diagnosing depression in patients with severe dementia.” (CCSMH, 2006, p.44)

A summary of features of the three conditions (often referred to as the “3 D’s”) can be found in the table below. While the three conditions are not synonymous with aging, prevalence increases with chronological age (RNAO, 2003). They may also present with overlapping clinical features and may co-exist such that PLWD may also experience delirium and/or depression at the same time (RNAO, 2003 & 2004; Ladika & Gurevitz, 2011).

<table>
<thead>
<tr>
<th></th>
<th>Delirium</th>
<th>Dementia</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset</td>
<td>Acute</td>
<td>Insidious</td>
<td>Variable</td>
</tr>
<tr>
<td>Duration</td>
<td>Days to weeks</td>
<td>Months to years</td>
<td>Variable</td>
</tr>
<tr>
<td>Course</td>
<td>Fluctuating</td>
<td>Slowly progressive</td>
<td>Diurnal variation (worse in morning, improves during day)</td>
</tr>
<tr>
<td>Consciousness</td>
<td>Impaired, fluctuates</td>
<td>Clear until late in the course of the illness</td>
<td>Unimpaired</td>
</tr>
<tr>
<td>Attention &amp; Memory</td>
<td>Inattentive Poor memory</td>
<td>Poor memory without marked inattention</td>
<td>Difficulty concentrating; memory intact/minimally impaired</td>
</tr>
<tr>
<td>Affect</td>
<td>Variable</td>
<td>Variable</td>
<td>Depressed; loss of interest and pleasure in usual activities</td>
</tr>
</tbody>
</table>


4.1.3 Treatment of Dementia

At present there is no cure for an irreversible dementia; however, there are some prescription drug therapies that can help treat the symptoms of dementia. For those with dementia of the Alzheimer’s type, they may be prescribed Cholinesterase inhibitors (for cognitive function, functional impairment) if the PLWD is in the mild to moderate stages of the disease. Memantine is also used in the case of moderate to severe dementia; however, is not covered under the Ontario Health Insurance Plan (OHIP) and can be financially out of reach for many without private insurance (Chapman et al., 2006; ADI, 2011). While these treatments can be beneficial for some, they do not fundamentally alter the course of the disease (ADI, 2011). In addition, non-pharmacological interventions, (therapies which do not involve drugs) such as psychological (e.g., cognitive stimulation) and psychosocial interventions (e.g., counseling, support groups, behavioural interventions) have also been shown to improve cognitive function in PLWD, delay institutionalization, reduce caregiver strain and psychological illness, and improve quality of life (ADI, 2011; Chapman et al., 2006).

Unfortunately relatively few families access services early in the disease course with many waiting until they face a crisis to seek support from a range of general to dementia-specific community services (Pratt, Clare, & Kirchner, 2006; McAiney et al., 2008; Tootab et al. 2013). For example, commonly cited reasons by caregivers of PLWD for inadequate H&CC services include a lack of consistency in staff and the consequent need to train and retrain new workers. In addition, caregivers cite the need for multiple reassessments by new professionals or case managers visiting the home (Smale & Dupuis, 2004a,b; Dupuis, Epp & Smale, 2004). Other considerations include lack of awareness of services or early interventions to better manage and accommodate the progression of dementia, the need for respite care to be provided at non-traditional hours (evenings and overnights), and a lack of ethno/cultural/linguistically appropriate care providers (Morton, 2010).

Not accessing community support early in the disease process is unfortunate because while there is no cure for an irreversible dementia, timely diagnosis and interventions allow for:
Dementia and Demand 70 Frances Morton-Chang

Chapter 4

• early treatment of symptoms to lessen the effects of the dementia (e.g., early stage medications for the most common dementia, Alzheimer’s Disease; better monitoring of comorbid conditions)

• more time to put life, finances, and advance directives in order

• preparatory education and even preparatory grieving for the person and their family

• improved quality of life for longer period of time

• avoidance of excess disability/medical complications and devastating social, financial problems, and

• reduced crises and caregiver burden.

(McAiney et al., 2008; ASO, 2012; ASC, 2010; WHO & ADI, 2012; Lee et al., 2014; Lee et al., 2010; ADI, 2011; Chapman et al., 2006)

4.1.4 Progression of Dementia

The face of dementia is changing because people are living longer with the disorder, especially when they have access to pharmacological and non-pharmacological interventions to manage and accommodate the symptoms of the illness. While PLWD are not homogeneous, for ease of reference the complexity of progression for many dementias is often categorized into three stages based on typical patterns of onset and course of progression – early, middle and late stages. A brief description of common symptoms and losses experienced by PLWD in relation to these stages is provided in Table 4.2 taken from the World Health Organizations’ report Dementia: A Public Health Crisis (WHO & ADI, 2012). Simplifying the stages of dementia into three general categories helps to provide common reference points for the dementia journey (as compared to normal age related changes); however, it is important to note that the timing, severity and overlap of symptoms will vary considerably from person to person and between types of dementia (e.g., faster decline for those with frontal-temporal dementia than with Alzheimer’s disease). Also, the simplified use of three stages does not reflect the growing body of research on Mild Cognitive Impairment (MCI), known in some cases to be a precursor to Alzheimer’s disease (ASC, 2010; Chapman et al., 2006; Morton, 2010) as a potential pre-stage, nor does it take into consideration that PLWD are living much longer with the disease than
before, therefore extending the late stage into total palliative care at the end of illness’ progression (WHO, 2012; ASC, 2012; Morton, 2010).
## Table 4.2 Common Symptoms Experienced by People with Dementia Syndrome

<table>
<thead>
<tr>
<th>Early Stage</th>
<th>Middle Stage</th>
<th>Late Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The early stage is often overlooked. Relatives and friends (and sometimes</td>
<td>As the disease progresses, limitations become clearer and more restricting.</td>
<td>The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical</td>
</tr>
<tr>
<td>professionals as well) see it as “old age”, just a normal part of ageing</td>
<td>• Become very forgetful, especially of recent events and people’s names</td>
<td>side of the disease becomes more obvious.</td>
</tr>
<tr>
<td>process. Because the onset of the disease is gradual, it is difficult to be</td>
<td>• Have difficulty comprehending time, date, place and events; may become lost at home as well as in the community</td>
<td>• Usually unaware of time and place</td>
</tr>
<tr>
<td>sure exactly when it begins.</td>
<td>• Have increasing difficulty with communication (speech and comprehension)</td>
<td>• Have difficulty understanding what is happening around them</td>
</tr>
<tr>
<td>• Become forgetful, especially regarding things that just happened</td>
<td>• Need help with personal care (i.e. toileting, washing, dressing)</td>
<td>• Unable to recognize relatives, friends and familiar objects</td>
</tr>
<tr>
<td>• May have some difficulty with communication, such as difficulty in finding words</td>
<td>• Unable to successfully prepare food, cook, clean or shop</td>
<td>• Unable to eat without assistance, may have difficulty in swallowing</td>
</tr>
<tr>
<td>• Become lost in familiar places</td>
<td>• Unable to live alone safely without considerable support</td>
<td>• Increasing need for assisted self-care (bathing and toileting)</td>
</tr>
<tr>
<td>• Lose track of the time, including time of day, month, year, season</td>
<td>• Behaviour changes may include wandering, repeated questioning, calling out, clinging, disturbed sleeping, hallucinations (seeing or hearing things which are not there)</td>
<td>• May have bladder and bowel incontinence</td>
</tr>
<tr>
<td>• Have difficulty making decisions and handling personal finances</td>
<td>• May display inappropriate behaviour in the home or in the community (e.g. disinhibition, aggression)</td>
<td>• Change in mobility, may be unable to walk or be confined to a wheelchair or bed</td>
</tr>
<tr>
<td>• Have difficulty carrying out complex household tasks</td>
<td></td>
<td>• Behaviour changes, may escalate and include aggression towards carer, nonverbal agitation (kicking, hitting, screaming or moaning)</td>
</tr>
<tr>
<td>• Mood and behaviour:</td>
<td></td>
<td>• Unable to find his or her way around in the home</td>
</tr>
<tr>
<td>– may become less active and motivated and lose interest in activities and hobbies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– may show mood changes, including depression or anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– may react unusually angrily or aggressively on occasion</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: WHO & ADI 2012, p. 7 based on work by ADI, 2009 and WHO, 2006
### 4.1.4.1 Dementia Interventions by Stage of Progression

For PLWD to remain at home for as long as possible, they and their informal caregivers require a wide range of health and social support services. These services need to be sensitive and responsive to changes in the PLWD’s cognitive and physical health throughout the lengthy progression of the dementia, as well as those of the caregiver (especially as most informal caregivers are also elderly spouses). As a dementia progresses and PLWD’s disability increases, so too does the need for their support and care (CIHI, 2010a, p. 2) and care for the caregiver to help alleviate or mitigate the stress of caregiving. Services to address these needs may span medical, rehabilitative, and psychological care (outpatient physician/specialist, inpatient, emergency) and community care (home health care, adult day programs, meal preparation, transportation, medication monitoring, education, counseling, support groups, respite care, physical or occupational therapy, behavioural interventions) (Weber et al., 2011; Morton, 2010; MAS, 2008).

While dementia meets the criteria of a chronic disease, interventions and care practices in the home are often episodic and reactionary due to earlier mentioned issues around late or inappropriate diagnosis, a lack of awareness and education about preventative measures by both the public and by health professionals, issues with system navigation, medically based eligibility criteria and others. More common are those practices largely focused on the mid to late stages of the care continuum, neglecting proactive and preventative interventions at pre-diagnosis and early stages of the continuum. Research indicates PLWD will frequently use the full spectrum of [higher intensity] medical services yet less frequently use [lower intensity] community resources (Weber et al., 2011) which largely relates to PLWD first interfacing with the health care system at a point of crisis (Samaras et al., 2010; McAiney et al., 2008; Dupuis, Epp & Smale, 2004; Tootab et al., 2013). The cause of such a crisis can be as simple as a person not remembering to take their medications due to progressive memory loss and result in a hospitalization, when a service as simple as medication monitoring with interventions such as blister packs or preloaded dosettes from the pharmacy, telephone reminders, and/or visits from personal support workers from community agencies likely preventing such a crisis. It is beneficial for PWD to feel in control of their lives and recommended to put these and other
mechanisms (e.g., setting up automatic banking for the depositing of cheques, bill payments and lowering limits on credit cards) in place as early as possible to help them manage their progressive memory loss.

Potential interventions and strategies for community dwelling PLWD by progression of dementia, are briefly outlined below and summarized in Tables 4.3 – 4.5. These interventions include a variety of care practices, programs, clinical and non-clinical services, and environmental adaptations that help to promote independence (e.g. monitoring and home modifications); maintain cognitive function (e.g., cognitive therapy; reminder technology; pharmacological treatment in the case of Alzheimer’s with cognitive enhancers); and improve health and social well-being (e.g., occupational therapy, physical therapy, exercise, speech language pathology, and home modifications/adaptations to improve safety (Czaja, Eisdorfer & Schulz, 2000 in Dupuis, Epp & Smale, 2004; Marquardt et al., 2011; Elliot, 2011; Morton 2010; ASC, 2010b; Snyder, 2001; Alzheimer Knowledge Exchange, 2014; Brawley, 2006; Canadian Mortgage & Housing Corporation, 2009; Rushford, ND; Topo, 2009; ADI, 2011; Chapman et al., 2006; McAiney et al., 2010; Lee et al., 2010.).

4.1.4.1 Early Stage Dementia

Generally a healthy person with MCI or in the early stages of dementia, regardless of late or early onset, can live relatively safely and independently in the community with limited to no assistance or monitoring. In fact, this is often the safest and most comforting place for many PLWD due to their reliance on “the familiar” and an increasing, albeit insidious, dependence on their environment to help compensate for increasing frailty, decreasing endurance, and/or sensory and cognitive losses (Brawley, 2001). The procedural memory of PLWD is often spared until the end stages of the disease whereby familiar objects and routines can contribute to improved perceptions and interpretations of one’s environments (Elliot, 2011). Increased distress can occur with advancing age if a senior’s increasing reliance on the “familiar” is interrupted. In a familiar setting, PLWD are often able to adapt based on their retained cognitive capacity, long-term memory, and sense of routine. Their ability to manage in their home can become compromised if reliance on short term memory and abstract thinking
complicates important tasks related to the maintenance of other health conditions or home safety (e.g., keeping track of medication regimens; using the stove/oven appropriately). Some people are not aware that they have dementia during this stage, and they may not be diagnosed until they have progressed past it (ASC, 2012). For others, the onset of early stage dementia marks the start of a process of negotiating access to a wide range of health and social services in order to find practical and emotional support in the face of the changes that dementia brings (Pratt et al., 2006) and assist in their ability to remain in their own home.
### Table 4.3 Early Stage Interventions

<table>
<thead>
<tr>
<th>Group</th>
<th>Possible Interventions</th>
</tr>
</thead>
</table>
| PLWD            | • Early diagnosis, First Link® programs, Memory Clinics  
|                 | • Education (e.g., about dementia, coping strategies, advance care planning; system navigation)  
|                 | • Counselling/support groups (e.g., Alzheimer’s Society First Link® program)  
|                 | • Symptom control drug therapies (e.g., cholinesterase inhibitors/cognitive enhancers)  
|                 | • In-home services (e.g., homemaking, medication monitoring/reminders, meals on wheels)  
|                 | • Professional health care services from occupational therapists, physiotherapists  
|                 | • Consistent routines and support staff / volunteers  
|                 | • Accessibility aids for physical impairments and frailty (e.g., installing grab bars or ramps)  
|                 | • Orientation/memory cues used around the house (e.g., labelling rooms, drawers, cupboards)  
|                 | • Falls prevention techniques (e.g., clutter-free home; stable furniture with rounded corners)  
|                 | • Adequate lighting and visual aids (e.g., clearly marked and well-lit pathways for walking; colour contrast used to identify obstacles/depth perception)  
|                 | • Early entry into Assisted Living (e.g., supportive housing, retirement home)  
|                 | • Cognitive training  
|                 | • Therapeutic Recreation (e.g., art, music, dance, movement, horticulture animal-assisted therapy)  
|                 | • Telephone reassurance (e.g., volunteer programs that contact PLWD living in their own homes)  
|                 | • Proactively registering with MedicAlert® Safely Home® program in case of wandering  
|                 | • Supportive technology (e.g., automatic shut off kettle, stove, faucets)  
| Informal Caregivers | • Education (e.g., about dementia, coping strategies, advance care planning; system navigation)  
|                  | • Early introduction of in-home respite services  
|                  | • Home modifications/assistive devices as indicated above  
|                  | • Counselling/support groups  
|                  | • Proactively registering PLWD with MedicAlert® Safely Home® program in case of wandering |

Sources: Czaja, Eis dorfer & Schulz, 2000 in Dupuis, Epp & Smale, 2004; Marquardt et al., 2011; Morton 2010; ASC, 2010b; Snyder, 2001; Alzheimer Knowledge Exchange, 2014; Brawley, 2006; Canadian Mortgage & Housing Corporation, 2009; Rushford, ND; Topo, 2009; ADI, 2011; Chapman et al., 2006; McAiney et al., 2010; Lee et al., 2010; Elliot, 2011.
4.1.4.1.2 Middle Stage Dementia

As a dementia progresses from the latter part of the early stage and into the middle stage, PLWD will experience more and more losses in their cognitive and functional abilities, and need help with many daily tasks including instrumental activities of daily living (IADLs) and eventually basic activities of daily living (ADLs). IADLs are activities that involve a person’s ability to maintain their independence in day-to-day living such as the ability to cook for oneself, go grocery shopping, or pay the bills. ADLs include bathing, dressing, toileting, ambulating and eating that are part of daily routine and a person’s functional ability is measured by the ability to perform such tasks. According to the Canadian Institute for Health Information (CIHI), 98% of informal caregivers provide some form of emotional support and 90% provide a wide range of informal and formal activities of daily living such as meal preparation, medication management, shopping, dressing, bathing and toileting (CIHI, 2010b; Canadian Caregiver Association, 2009). This highlights the importance and relevance of the four key variables (cognition; presence of a live-in caregiver; IADLs; and ADLs) in the BoC framework used in this research.

The middle stage is also a point where an inability to concentrate/pay attention and memory loss become quite noticeable and may account for increased repetitive behaviours. For example, PLWD may phone the same phone number many times to ask the same question to someone, or may feed their dog or cat 12 times a day because they have forgotten they had already done so. The opposite can be true as well such that they forget to make phone calls or to feed their pet or themselves thinking that they have already done so (because that is what they ‘normally would have done’). Cognitive losses will also lead to further declines in the ability to provide self-care or to recognize the need to complete important activities without cueing such as dressing, bathing and even remembering to go to the bathroom.
### Table 4.4 Middle Stage Interventions

<table>
<thead>
<tr>
<th>Group</th>
<th>Possible Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PLWD</strong></td>
<td>• Symptom control drug therapies (e.g., Memantine for those with Alzheimer’s)</td>
</tr>
<tr>
<td></td>
<td>• Increased in-home services (e.g., homemaking, medication monitoring/reminders, meals on wheels, grocery shopping)</td>
</tr>
<tr>
<td></td>
<td>• Professional health care services from occupational therapists, physiotherapists, speech language pathologists, nursing</td>
</tr>
<tr>
<td></td>
<td>• Counselling/support groups</td>
</tr>
<tr>
<td></td>
<td>• Consistent routines and support staff/volunteers</td>
</tr>
<tr>
<td></td>
<td>• Therapeutic Recreation (e.g., art, music, dance, movement, horticulture, animal-assisted therapy) offered at home or at Adult Day Programs</td>
</tr>
<tr>
<td></td>
<td>• Accessibility aids for physical impairments and frailty (e.g., installing grab bars or ramps)</td>
</tr>
<tr>
<td></td>
<td>• Orientation/memory cues used around the house (e.g., labelling rooms, drawers, cupboards) and avoidance of abstract art</td>
</tr>
<tr>
<td></td>
<td>• Falls prevention techniques (e.g., clutter-free home; stable furniture with rounded corners)</td>
</tr>
<tr>
<td></td>
<td>• Additional/adequate lighting and visual aids (e.g., clearly marked and well-lit pathways for walking; colour contrast used to identify obstacles/depth perception)</td>
</tr>
<tr>
<td></td>
<td>• Move into Assisted Living (e.g., supportive housing, retirement home)</td>
</tr>
<tr>
<td></td>
<td>• Precious and/or dangerous items removed (e.g., internal and external settings)</td>
</tr>
<tr>
<td></td>
<td>• Dementia-specific programming (e.g., Dementia-Based Montessori; Spaced Retrieval/Cognitive training using spared capacity)</td>
</tr>
<tr>
<td></td>
<td>• Sheltered transportation programs</td>
</tr>
<tr>
<td></td>
<td>• Dementia specific adult day programs</td>
</tr>
<tr>
<td></td>
<td>• Music therapy</td>
</tr>
<tr>
<td></td>
<td>• Registering with MedicAlert® Safely Home® program in case of wandering</td>
</tr>
<tr>
<td></td>
<td>• Supportive technology (e.g., automatic shut off kettle, stove, faucets)</td>
</tr>
<tr>
<td><strong>Informal Caregivers</strong></td>
<td>• Education (e.g., about dementia, coping strategies, advance care planning; system navigation)</td>
</tr>
<tr>
<td></td>
<td>• Home modifications and assistive devices</td>
</tr>
<tr>
<td></td>
<td>• Supportive Technology (e.g., monitoring technology, bed sensors)</td>
</tr>
<tr>
<td></td>
<td>• Counselling/support groups</td>
</tr>
<tr>
<td></td>
<td>• If a senior, community based transportation programs for PLWD and self for appointments</td>
</tr>
<tr>
<td></td>
<td>• Registering PLWD with MedicAlert® Safely Home® program in case of wandering</td>
</tr>
<tr>
<td></td>
<td>• Supportive Housing</td>
</tr>
<tr>
<td></td>
<td>• In-home respite services to help with burden of care</td>
</tr>
<tr>
<td></td>
<td>• Nursing home respite bed or adult day programs for caregiver relief</td>
</tr>
</tbody>
</table>

Sources: Czaja, Eisdorfer & Schulz, 2000; Dupuis, Epp & Smale, 2004; Marquardt et al., 2011; Morton 2010; ASC, 2010b; Snyder, 2001; Alzheimer Knowledge Exchange, 2014; Brawley, 2006; Canadian Mortgage & Housing Corporation, 2009; Rushford, ND; Topo, 2009; ADI, 2011; Chapman et al., 2006; McAiney et al., 2010; Lee et al., 2010; Elliot, 2011.
As memory continues to decline, PLWD may lose awareness of things like their personal history, have difficulty recognizing friends or family, become disoriented about time and place and experience declines in judgment that may lead to poor decision-making. Wandering also presents itself as an issue at this point where people may head out to a destination with purpose only to forget somewhere along the journey where they were going and how to get back to their current residence. Eventually basic language skills will be affected and PLWD that speak more than one language will lose all but their mother tongue (which later in the progression will also be lost). Confusion will increase and they may even experience altered perceptions or suspicion or paranoia. Despite these progressive cognitive losses, many PLWD will still be somewhat aware of their condition which can be distressing for PLWD (ASC, 2012), but as the disease progresses, they may not realize that there have been changes (they don’t know that they don’t know).

For families and caregivers, the middle stage is the point where they may increasingly need to provide care thus making this stage seem the longest (ASC, 2012). The well-being of the caregiver can inversely affect the well-being of the PLWD and their ability to remain in the community; it is very important to also attend to the needs of the caregiver’s state of physical and emotional health (Smale & Dupuis, 2004a,b,c; Dupuis, Epp & Smale, 2004; Snyder, 2001; Mittleman et al., 1996). While much research points to the need for a wide range of sensitive and responsive health care and social support services for those with a chronic disease or life threatening illness, these services are also vital to informal caregivers, especially seniors experiencing frailty or chronic conditions themselves (HCC, 2010 in HCC, 2012; CIHI, 2010a,b). With all of the extra care and monitoring being provided in the middle stage of dementia, this is also a time that many caregivers are encouraged to consider placing the PLWD on a LTC wait-list to avoid caregiver burnout (Note: when this happens caregivers need to be willing to willing to place them as soon as a bed is offered). While fatigue, caregiver health, and feelings of distress are important factors in the decision to place a PLWD on a LTC wait-list, such a decision is also made in combination with other factors including physical, personal, social, emotional, and financial circumstances. These and other factors are discussed further in chapter five, section 5.2 Informal/Unpaid Caregiving and Dementia.
4.1.4.1.3 Late Stage Dementia

The late stage of dementia may also be called "severe" or "advanced." People in the late stage have diminished mental ability, cannot communicate verbally\(^{18}\) and become more physically frail. Most PLWD by this stage are receiving the support of a 24-hour LTC home. The goal of care at this stage is to continue to support the person to ensure the highest quality of life possible \([\text{regardless of care location}]\) (ASC, 2012). In both middle and late stages of a dementia, the level of decline the PLWD is experiencing becomes quite significant and many informal caregivers will experience anticipatory or latent grief for the loss of the person that “once was”, knowing there will not be improvement in the condition (Boss, 2006; Dempsey & Baago, 1999).

At the end, or palliative stage of dementia, PLWD begin to shut down physically (e.g., sleeping more, refusing to eat, skin break-down from spending more time in bed). The goal of end-of-life care, as with any other individual, is to focus on quality of life and comfort, rather than on lengthening life and giving treatment. After the PLWD dies the family may feel a sense of loss, but also a measure of guilt that they are relieved of the responsibility of care. To help deal with these conflicting emotions, post bereavement counselling and/or support groups may be helpful resources during this time of grief and loss. Drug therapy may also be recommended if the person experiences ongoing depression (Czaja, Eisdorfer & Schulz, 2000 in Dupuis, Epp & Smale, 2004; Morton 2010; ASC, 2010b).

\(^{18}\) While PWD may not be able to communicate using the words they want to, they may still be able to use vocalizations and noises to convey emotions and needs.
## Table 4.5 Late Stage Interventions

<table>
<thead>
<tr>
<th>Group</th>
<th>Possible Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLWD</td>
<td>• Dementia-specific programming (e.g., Dementia based Montessori; Spaced Retrieval/Cognitive training using spared capacity)</td>
</tr>
<tr>
<td></td>
<td>• Meaningful engagement for behaviour management (e.g., music therapy)</td>
</tr>
<tr>
<td></td>
<td>• Symptom control of other comorbidities</td>
</tr>
<tr>
<td></td>
<td>• Increased in-home services (e.g., CSS based or live-in caregiver)</td>
</tr>
<tr>
<td></td>
<td>• Professional health care services from occupational therapists, physiotherapists, speech language pathologists, nursing</td>
</tr>
<tr>
<td></td>
<td>• Precious and/or dangerous items removed (e.g., internal and external settings)</td>
</tr>
<tr>
<td></td>
<td>• Removal of abstract designs to minimize confusion (e.g., artwork &amp; furniture coverings)</td>
</tr>
<tr>
<td></td>
<td>• Orientation/memory cues used around the house (e.g., labelling rooms, drawers, cupboards) and avoidance of abstract art</td>
</tr>
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<td></td>
<td>• Falls prevention techniques (e.g., clutter-free home; stable furniture with rounded corners)</td>
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<td>• Additional/adequate lighting and visual aids (e.g., clearly marked and well-lit rooms/pathways for walking; colour contrast used to identify obstacles/depth perception)</td>
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<td></td>
<td>• Home modifications and assistive devices (e.g., outdoor ramps, bed-chair lifts)</td>
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<td></td>
<td>• Dementia-specific adult day program</td>
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<td></td>
<td>• Nursing home respite</td>
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<tr>
<td></td>
<td>• Placement in LTC home</td>
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<tr>
<td></td>
<td>• Air pressure bed to help prevent bed sores</td>
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<tr>
<td></td>
<td>• Registering with /MedicAlert® Safely Home® program in case of wandering</td>
</tr>
<tr>
<td>Informal Caregivers</td>
<td>• Education (e.g., coping strategies, body mechanics, palliative care)</td>
</tr>
<tr>
<td></td>
<td>• Increased homecare and in-home respite or off-site respite</td>
</tr>
<tr>
<td></td>
<td>• Home modifications/assistive devices/technology (e.g., hospital bed, lifts)</td>
</tr>
<tr>
<td></td>
<td>• Counselling/support groups</td>
</tr>
<tr>
<td></td>
<td>• Drug therapy for caregiver (e.g., depression)</td>
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<td></td>
<td>• If a senior, community based transportation programs for PLWD and self for appointments</td>
</tr>
<tr>
<td></td>
<td>• Registering PLWD with MedicAlert® Safely Home® program in case of wandering</td>
</tr>
<tr>
<td></td>
<td>• Supportive technology (e.g., bed sensors)</td>
</tr>
</tbody>
</table>

Sources: Czaja, Eis dorfer & Schulz, 2000 in Dupuis, Epp & Smale, 2004; Marquardt et al., 2011; Morton 2010; ASC, 2010b; Snyder, 2001; Alzheimer Knowledge Exchange, 2014; Brawley, 2006; Canadian Mortgage & Housing Corporation, 2009; Rushford, ND; Topo, 2009; ADI, 2011; Chapman et al., 2006; Elliot, 2011.
4.2 Demand and Dementia

4.2.1 Demands of an Aging Population

Most industrialized countries are experiencing population aging, a phenomenon where the proportion of seniors increases more rapidly than all other age groups in a population. Many factors have contributed to population aging, most notably a significant decrease in fertility rates since 1945, and increases in life expectancy due to advances in medical science, technology, public health measures, and welfare state institutions. In 2011 Canadian seniors accounted for a record high of 14.8% of the population with the percentage expected to rise to between 23% and 25% by 2036 as the large baby boom generation (those born between 1946 and 1965), reach 65 years old and older (Statistics Canada, 2012; Statistics Canada 2010). Projections for the province of Ontario mirror national percentages. The number of seniors aged 65 and over is projected increase from 13.9 % of the population in 2011 to 23.6 per cent by 2036 using a medium growth scenario (Ontario Ministry of Finance, 2012).

In addition to the sheer volume of seniors, the age range among the senior population will change as well. There will be far more very elderly people aged 80 years and older who, also according to a medium growth scenario, could number 3.3 million by 2036 and the number of centenarians projected to possibly triple or quadruple (Statistics Canada, 2010). According to the Canadian Institute for Health Information (CIHI) Canadian seniors age 65 and older:

- Account for less than 14% of the population yet those in need consume nearly 44% of provincial and territorial government health care dollars (CIHI, 2011b)
- Are [considered] heavier users of hospital services (CIHI, 2011d)
- Stay longer once admitted to hospital (e.g., seniors’ overall average length of stay in acute inpatient care is roughly 1.5 times that of non-senior adults (nine days versus six) (Ibid)
- Comprise 95% of those receiving care in residential LTC from 2009–2010 (CIHI, 2011c)
- Comprise 85% of those receiving hospital-based continuing care from 2009 – 2010 (Ibid)
- Comprise 82% of home care clients in 2009–2010 (CIHI, 2011c)
These numbers can however be misleading as “the effects of population aging have evolved slowly where the share spent on Canadian seniors has not changed much in the last decade (from 43.6% in 1998 to 43.8% in 2008)” (CIHI, 2011b, pp. 16-17). Population aging has been a relatively modest contributor to health care costs given that the greatest concern for costs appears to be older seniors and not all seniors. On average health care spending per person is highest for those 80 years if age and older largely as a consequence of two factors: the cost of health care in the last few months of life [proximity to death], and the minority of the population with [multiple] chronic illnesses that tend to require more intensive medical attention with age (Ibid).

While older Ontarians generally report being in good health, there exists a minority of seniors that experience chronic and complex conditions (Sinha, 2012). The Health Council of Canada (HCC) cites 41% of Canadian seniors are dealing with two or more select chronic conditions (HCC, 2012 p.8) and many are experiencing a decline in physical and/or cognitive functioning (CIHI, 2011c). The multiple and often inter-related health and social care issues of these seniors has become an important concern to the health care system as those with heavier care needs or inadequate support drive up costs using more expensive and intensive types of services, particularly in acute care settings (Gill et al., 2011). Dementia, a chronic progressive neurological condition whose greatest risk factor of development is age, will also have an impact as the population ages. Statistics Canada as far back as 2002 cites that “diseases with the most serious impact on health-related quality of life [have been] identified as Alzheimer’s disease [the most prevalent form of dementia], stroke [which can cause vascular dementia], epilepsy, bowel disorders and urinary incontinence” (Schultz and Kopec, 2002 in Statistics Canada, 2006, p.47 & 48). As mentioned earlier, these declines coupled with other possible age-related declines in hearing, vision, learning, and mobility can further restrict a senior’s activities and/or require supportive care. In trying to cope with challenges, seniors may limit or withdraw from previously enjoyed and even essential activities (e.g., housekeeping, cooking, going to the doctor, hairdresser, social or religious services). When one combines normal age related changes with declining neurocognitive abilities and other possible comorbidities, managing at home becomes increasingly difficult for seniors with dementia.
4.2.2 Dementia Demographics

The WHO & ADI report that in high-income countries like Canada the growing numbers of PLWD will continue to increase, particularly among the oldest old (e.g., those over 80). The report warns that this growth will inevitably become an urgent political priority and impact the provision and financing of the LTC needs of those with dementia and their family caregivers (WHO & ADI, 2012).

In Canada the rising incidence of dementia\(^1\) for those 65 and older is expected to increase 2.5 times from 2008 to 2038, and the number of Canadians of all ages with dementia is projected to increase 2.3 times that of the 2008 level (1.5% of the Canadian population) by 2038 (2.8% of the Canadian population) (ASC, 2010). In Ontario it was estimated 181,000 Ontarians had dementia in 2010, a number expected to rise to 255,000 by 2020, less than a decade from now (ASO, 2010). Evidence of this can be seen in an increase in dementia prevalence across each of the 14 Local Health Integration Networks of Ontario (ASO, 2010).

It is important to note that these statistics may be under-estimates for a variety of reasons and as a result, health planning may have been undertaken using data which does not truly reflect the real impact of dementia. One of the most common reasons for under-estimating the impact of dementia is that most prevalence studies in Canada have focused on adults 65 years of age and older with an a diagnosis of dementia (CSHA, 2000 in Dupuis, Epp & Smale, 2004). Studies in high income countries show that only one-fifth to one-half of cases of dementia are routinely recognized and documented in primary care (ADI, 2011, p. 7). In addition, prevalence rates often do not reflect those with early onset dementia (experiencing dementia prior to age 65) as this is considered rare and few population-based surveys have been carried out, since large

\(^{19}\) Dementia prevalence and the prevalence of major subtypes (Alzheimer’s disease and vascular dementia) in Rising Tide were estimated from a combination of data from the 1991 Canadian Study of Health and Aging (CSHA) and European data from the EURODEM studies provided in Berr et al., 2005, p.118. Dementia incidence rates and the rates of major subtypes (Alzheimer’s disease and vascular dementia) were estimated from the 1996 CSHA follow-up study (ASC, 2010).
sample sizes are needed to estimate prevalence with precision (WHO & ADI, 2012, p. 15). Understanding the rates of early onset dementia in Canada is increasingly important because younger adults with dementia are likely to have very different needs than older adults with dementia and are often reluctant to participate in programs and services tailored to older populations (Dupuis, Epp & Smale, 2004; Morton, 2010). As a consequence our understanding of the prevalence rates of early onset dementia in Canada remains limited (WHO, 2012; Dupuis, Epp & Smale, 2004).

Underestimates for dementia may also occur because:

- It may go unrecognized, be misdiagnosed, or not be recorded due to
  - lack of physician knowledge or training about dementia, symptom recognition and screening
  - changes that can be insidious and missed or attributed to normal aging by the PLWD, their informal caregivers, and even their health professionals
  - stigma by the PLWD and/or their family about dementia and how it would be perceived if disclosed (e.g., fear of judgment or labeling; fear of placement)
  - avoidance of diagnosis for fear of placement
  - false beliefs that nothing can be done

- A condition referred to as MCI – which is thought to be a precursor to Alzheimer’s disease – is often not captured until it progresses into a full dementia

- Many PLWD are not in contact with health and social care providers that would lead them to a proper diagnosis until crisis, LTC home placement or death and therefore are not entered into an accessible database for epidemiological purposes.

( McAiney et al., 2010; Lee et al., 2010; WHO & ADI, 2012; ASC, 2010; NACA, 2004)

Under diagnosis, misdiagnosis and late diagnosis negatively affects the ability of policy planners and other decision makers to address issues from an individual and system level. Inadequate
diagnosis also plays a large role in the ability of PLWD and their caregivers to deal with the issues related to dementia proactively and in a timely way.

Despite a growing body of evidence pointing to issues of system sustainability and possible ineffective and disproportionate utilization of the health care system by those currently affected by, and projected to experience dementia, dementia continues to be “at the margins of care” having little public profile, limited mobilization of those with the condition, and a historical absence of direct sustainable funding. With no national or provincial frameworks to specifically address the needs of those affected by dementia, baseline services and standards of care targeted for this population, or mechanisms to insure that such services are delivered in a useful way, it will remain difficult to delay and avoid inappropriate institutional care in hospital or institutional LTC. These and other policy related issues will be discussed further in the historical trajectory of chapter six.

4.2.3 Aging at Home

The majority (87%) of Canadians age 55 years and older want to live at home as long as possible (Senate Committee on Aging, 2007) and in fact do. According to the 2006 Canadian census, the vast majority (93%) of seniors age 65 and older live in private households (CIHI, 2011c). Projected increases in the numbers of older adults currently affected by or expected to experience a dementia are causing increased concern about the potential strain this will put upon LTC, medical, social, and recreational services (WHO & ADI, 2012; ASO, 2010; MAS, 2008) which are currently inadequate to meet the growing demands of this population and their desire to age-in-place. As such, “there is a pressing and urgent necessity to address the needs of [the aging population] in new ways” (Walker, 2011).

While many seniors are able to live in their own homes with little to no support, some require formal home care services and/or informal support (e.g., family caregivers) to manage (CIHI, 2011a; HCC, 2012). In 2003, one in ten Canadian seniors aged 75 and over living in a private household needed someone else to help with their personal care such as washing, dressing, eating or taking medication (only one in 100 individuals aged 25 to 54 were in the same situation) (Statistics Canada, 2006). In fact, an estimated one
million Canadians receive formal home care supports at any given time and of these clients, about eight out of every ten (80%) are seniors (CIHI, 2011c). Informal care (about 80%) comes from unpaid family members, friends, volunteers, and neighbours. As the time they spend providing care increases, so does the strain and possible distress caregivers experience (CIHI, a,c,d; CIHI, 2010a,b).

With regards to formal home care services provided to seniors; these vary by age and need and include both home health and home support services. Of seniors receiving publically funded home care services:

- 40% are over the age of 85 (HCC, 2012)
- 20% were formally diagnosed with a dementia (excludes Yukon)(CIHI, 2010a; HCC, 2012)
- 95 to 98.5% have some difficulty with IADLs (HCC, 2012)
- 23 to 41% need help with ADLs (Ibid).

It is estimated that the majority of PLWD live in private households with 2008 estimates at 55% of Canadians with dementia 65 and older living in their own homes – most with the support of some kind of community care. It is also estimated that by 2038, 63% of Canadians 65 and older with dementia will be living in their own homes. This increase in the sub-population with dementia is expected to put additional pressure on an already strained and inadequate community care sector a stretched acute and LTC sector and have ramifications for increased caregiver burden (ASC, 2010).

### 4.2.4 Community Care and Dementia

To enable vulnerable populations like PLWD to remain at home, they and their caregivers require a network of formal and informal support services (MAS, 2008; Peckham et al., 2014; Williams et al., 2010; Williams et al., 2009a,c) that are sensitive and responsive to progressive changes in their cognitive and physical health; and are well-coordinated and integrated between the *Medicare Mainstream* (hospital and physician services) and the community throughout the whole continuum of the dementia. Diagnosing a dementia and implementing targeted inter-professional interventions and services as early as possible can help to minimize
the disabling impact of the condition, facilitate better care planning, reduce caregiver burnout, and the delay the need for institutional care (McAiney et al., 2008; Lee et al., 2014; Lee et al., 2010).

Even though the progressive declines of a dementia are relatively slow, as mentioned earlier many PLWD first encounter/interact with the health care system at a point of crisis (e.g., because the PLWD or their caregivers are no longer coping) and where the complexity of their needs is quite progressed. The symptoms of dementia later in the progression can place heavy psychological, emotional and physical strain on caregivers and PLWD alike, making them particularly vulnerable to crisis placement – even more so if and when PLWD live alone, as this increases their risk of economic insecurity, abuse, loneliness, depression, poorer health due to self-neglect, and vulnerability to malnutrition, falls, accidents and hygiene problems. This can leave relatively few choices for them to return or remain at home in the community leading to institutional placement. In a critical ethnographic study by Oona St-Amant and associates which examined how the context of the home care system revealed that even when connected to home care services, that the formalized home care system contextually imposes decisions upon PLWD and their caregivers that can contribute to pressured decision-making (St-Amant et al. 2012). They suggest that as the home care system works to meet the needs of many people and ensure that they receive at least minimal service; the system has compromised tremendously on quality (Ibid, p. 430). Furthermore, they suggest that the system’s wait-list approach exemplifies this point where PLWD and their families may be forced to make decisions for PLWD to enter into a LTC home prematurely or too late, or more importantly, not on their own accord (Ibid).

Related to this observation, when placement is considered at a point of crisis, it often involves a hurried decision.

“...rather than being considered carefully and planned in advance...Such admission frequently results in an inappropriate placement in an institution which may also be inconveniently located for visits from the person’s family and friends. This may compound the trauma often experienced by the elderly person who has his or her life and routine disrupted so abruptly.” (Grant, 1985a; Schulz & Brenner, 1977 both in Forbes et al., 1987, p. 51)
This trauma is not contained to PLWD. Findings of the St-Amant study found many negative consequences for both PLWD and their families when decision-making is pressured by time constraints (e.g., family conflict, caregiver stress and the psychological burden of uncertainty about where one’s relative will be placed) which they point out is “ironic as the system which is intended to promote health and provide health care contextually contribute to these threats to health and wellbeing” (St-Amant et al., 2012, p. 431).

While PLWD in the early stages may not need formal clinical/medical care, they may benefit from more practical assistance such as help with IADLs, monitoring of medications and nutrition, and homemaking. Furthermore, offering assistance earlier is preferable to trying to offer care to PLWD after they get to a point of not knowing they could use some help. The earlier the introduction to service providers and services, the better chance in getting PLWD used to such visits and helps to build trust. “Lower-intensity” community based services can provide a foundation on which additional community supports and/or more formal clinical services (e.g., nursing, allied health services, geriatric outreach programs; help with ADLs) can be integrated into the care plan as needed. In addition, due to the complexity and hidden nature of dementia, interventions for PLWD and their caregivers are best organized and provided by those with dementia training and expertise and, in cases where a caregiver is involved, research indicates care plans and interventions are best organized when PLWD and their caregivers are treated as a unit (MAS, 2008; Peckham et al., 2014; Williams et al., 2009a,b).

There is no “silver bullet” that can ameliorate the progression of dementia, however; when introduced in a timely fashion, preventative and proactive community interventions can maximize the person’s function, quality of life, and minimize stress, anxiety and caregiver burden (MoHLTC, 1999, p. 17). Despite research indicating the benefits of addressing the needs of PLWD as early as possible, PLWD frequently do not access lower cost/intensity community resources and use more high cost/intensity medical services (Weber et al., 2011) which in part has to do with the role of caregivers providing a great deal of support to PLWD until they can no longer sustain the levels necessary. It also may in part be due to PLWD, and partly because they often do not intersect with the system until some form of crisis ending up in hospital
emergency rooms. This is an important factor regarding how PLWD begin to interface with the health care system at a point of crisis and in the moderate to late stages of the progression (McAiney et al., 2008; Dupuis, Epp & Smale, 2004). When community dwelling PLWD come into contact with health care system well into the course of their dementia, the interventions and care practices for PLWD are often reactionary and based on physiological conditions as the primary reason for care, and dementia as secondary. Late or inadequate interventions can be both costly to the individual and to the system.

To help formal care providers, PLWD, and informal caregivers understand the nature of dementia and types of interventions, supports and services that might benefit PLWD, the WHO & ADI have suggested that countries develop care pathways (i.e., suggested plans of care) that are responsive to the intermittent and progressive changes of dementia with regular reassessment as a key element to improving the care of PLWD and their quality of life (WHO & ADI, 2012).

Care pathways can help to support the implementation of both tacit and evidence-based clinical guidelines and protocols, and improve the continuity and co-ordination of care across different disciplines and sectors. Although PLWD are not homogeneous and no one set of “best practices” is ideal for this large population (Interior Health, 2009; Morton 2010), evidence informed guidelines are helpful for basic understanding and classification purposes, while bearing in mind that dementia does not follow a linear description of disease progression, and can also be complicated by other comorbid conditions and life circumstances. With this in mind a Dementia Care Phased Pathway was developed by Interior Health British Columbia to

20 Quite possible given that the majority of dementias occur in those over 65 years of age.

provide some guidelines informed largely by the 2006 Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia Guidelines, and focus groups with PWD and formal and informal care providers. The Pathway is intended to help with understanding the progression of dementia and the types of care needs experienced by PWD and those caring for them. The original pathway was adapted and expanded (with permission by Interior Health) in a research project funded by the Toronto Central Local Health Integration Network (TCLHIN) on Dementia Services in Toronto. The adapted Toronto Dementia Care Pathway expanded the original pathway to include additional stages to reflect the new and emerging body of research on Mild Cognitive Impairment (MCI) as a potential precursor to Alzheimer’s disease, and modifiable risk factors that can help postpone the onset of a dementia. There is also more recognition of the people who have early/young onset dementia (prior to age 65), and that PLWD are living much longer than before therefore prolonging the terminal stage at the end of illness’ progression (WHO & ADI, 2012; Morton, 2010). The stages in the adapted Toronto Dementia Care Pathway include information the following: modifiable risk factors, mild cognitive impairment, early onset dementia, early stage dementia, middle stage dementia, late stage dementia, and the palliative care stage. The information contained within the Pathway is not specific to a location and can be applied to all Canadians/Ontarians living with dementia. This pathway is described in an Alzheimer Society of Toronto commissioned report to the TCLHIN titled Dementia Care: Diversity, Access, Coordination and accessed on the Toronto Dementia Network website at:


While more attention is being directed at interventions to get PLWD out of ALC beds by new and emerging CCAC programs (e.g., Home Stay and Wait at Home Programs), a more preventative planning and measures approach may prevent or mitigate the need for unnecessary or inappropriate use of hospital care, ALC and LTC beds. Most OECD countries have been encouraging the use of home care to delay or avoid the potentially higher costs of institutional care and to meet the preferences of the public (HCC, 2012). The Canadian Home Care Association (CHCA) defines home care as “an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and
teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the informal (family) caregiver” (CHCA, 2014). It is used for a range of purposes and durations (e.g., acute home care after hospitalization; palliative home care when someone is dying), and is geared towards special populations (e.g., maintenance home care for vulnerable seniors to stay in their homes independently; long-term home care to manage chronic conditions; children with disabilities; people with mental illness) (Canadian Health Care Association, 2009). Despite the growing recognition of the need for more home care, “the proportion of the gross domestic product (GDP) spent on home care is generally less than that spent on LTC institutions in most OECD countries with a few exceptions” (HCC, 2012 p.52).

While Canadian studies indicate that continuing community care services can be a cost-effective substitute for residential services and maintain clients at an optimal level of functioning preventing further deterioration in health status (Hollander, 2001 b & c; Hollander et al., 2009), there appears to be a lack of political and administrative will to make substantial change in the way the health system is organized and a lack of recognition that long term home care is a key vehicle for increasing the efficiency and effectiveness of the overall health care system (Hollander & Prince, 2002).

4.3 Summary

This chapter has focused on the pathology of dementia, types of interventions that are beneficial to PLWD, the rising numbers of those with, and expected to experience some form of dementia, and the impact this growing impact this unique and complicated disorder will have on PLWD, their caregivers and the larger health and social care system. While research is highly suggestive that there are ways to achieve further efficiencies and effectiveness for the greater health care system, including elevating the importance of continuing community care services, as will be explored in the next chapter, there remains a growing gap between the community based needs of PLWD and what is actually available to them to live in, and receive care in their own home for as long as possible.
While demand issues are often the starting place for health policy initiatives; less is known about the political and structural issues, or the system-level configurations that contribute to the way in which dementia care has been, or can be addressed in the community. The next chapter will examine supply side issues related to community based care for PLWD including the types of H&CC services available in Ontario, the role of informal caregivers of PLWD, integrating mechanisms for care such as Supportive Housing and Adult Day Programs, and LTC placement options when care is no longer viable in the community.
Chapter 5
Supply and Dementia

Dementia is complex and the demands of this growing population can pose challenges when working under current system configurations. While demand issues are often the starting place for health policy initiatives, less is known about the political and structural issues, or the system-level configurations that contribute to the way in which dementia care has been, or can be addressed in the community. Health policy research focused on the role that H&CC preventative and maintenance services might play as an alternative to placement of vulnerable seniors like PLWD in a LTC home or placement on a LTC wait-list is sparse. Conventional policy research and planning for care needs of seniors often assumes that a growing population of older persons will demand a proportionately greater number of residential LTC beds and, with PLWD being the largest consumers of these beds, this has affected their trajectory of care; however, the need for such beds is also determined by other supply-side factors. As will be described in this chapter, the ability of vulnerable populations like PLWD and their informal caregivers to successfully remain and receive care in the community requires timely and flexible formal and informal support services that are:

- targeted and responsive to progressive changes in their cognitive and physical health
- integrated between the Medicare Mainstream and the community
- case managed to improve coordination and communication between all care providers and disciplines
- accessible and available
- affordable/cost-effective

(Lee et al., 2014; MAS, 2008; Forbes et al., 2008; Smale & Dupuis, 2004c; Williams et al., 2009a,b,c; Daker-White et al., 2002).
While timely implementation and integration of targeted and “dementia friendly” \(^{22}\) interventions and services have also been identified to help to minimize the disabling impact of a dementia, caregiver burnout, and the need for institutional care (McAiney et al., 2008; Lee et al., 2014; Lee et al., 2010; Change-Ability, 2009); in many jurisdictions across Canada often-needed H&CC support services are often:

- non-existent
- in-flexible
- not-integrated
- hard to access
- restrictive with eligibility criteria or fees
- not culturally appropriate
- difficult to navigate (especially by people with declining cognitive abilities), and
- not dementia-specific


Even when a range of H&CC services are available at the local level, accessing a coordinated package of services may still be problematic, particularly for individuals with multiple chronic needs (Williams et al., 2009 a,b, in Kuluski, 2012a, p. 439). Furthermore, having a personal care need or medical requirement to qualify for government-funded home care can also limit the ability for PLWD to access supports as many in the early stages may only need help with instrumental activities of daily living (IASLs) like meal preparation and medication monitoring.

\(^{22}\) Dementia-friendly is a term whereby health and social care providers understand dementia and can manage and accommodate for the uniqueness and peculiarities of caring for PLWD (e.g., may not remember appointments due to memory loss; may not answer the door or try to send providers away because they think they are managing well on their own, when in fact they really do need some assistance)
and not so much with basic activities of daily living (ADLs) like bathing. When they do need help with ADLs they may refuse help with personal care because they believe they are able to bathe themselves when they actually do not have the insight or ability to remember to do so. PLWD can also face barriers to community supports as many helpful seniors programs such as adult day programs are often unequipped or unwilling to accept cognitively impaired clients (Morton, 2010). Difficulty accessing services can be further exacerbated if the PLWD experiences early onset dementia and does not qualify as a senior for some H&CC services (older than 60 or 65 years of age)(Ibid). 23

This chapter will focus on a number of general and dementia-specific community-based options in Ontario for PLWD and their caregivers, provide a profile of PLWD receiving home care, identify the needs of informal caregivers in supporting PLWD, and highlight gaps or areas of need in Ontario that can contribute to LTC placement as a default pathway.

5.1 Health Care and Dementia

Health care in Ontario is noted to be fractured and fragmented such that “the health care system more closely resembles a collection of health care providers in different health care sectors (e.g., Hospital, LTC home, H&CC) providing a series of disjointed services and working in many different silos” (Drummond, 2012, p. 152). As documented in previous chapters, this patchwork of providers and services can negatively impact the ability of individual to navigate, access, and maintain consistent and reliable care in the community – and likely more so for PLWD experiencing memory issues, confusion, and other possible symptoms of the dementia. The Walker Report (2011), Drummond Report (2012) and Ontario MoHLTC Seniors Strategy (2012) amongst others underscore the necessity to identify new ways of addressing the needs of those with chronic and complex health issues beyond the current (non)system of care of

23 Those with early onset dementia may also not be aware of, or be able to access other important forms of government pensions or disability assistance when they can no longer work (Alzheimer’s Association, ND).
relying on hospital and placement in LTC homes as a solutions for these populations (Walker, 2011; Drummond, 2012; MoHLTC, 2012). The Drummond Report suggests that in order to address the current fragmentation and patchwork services, the Ontario MoHLTC work with its health care providers, administrators and stakeholders to integrate silos of care, co-ordinate roles, reduce administrative red tape that impedes efficient and effective service, simplify the pathways of care, and improve the overall patient experience (Drummond, 2012, p. 152-153). His report also notes that the health care system is only part of the picture and that health outcomes can also be attributed to many other factors related to social determinants of health such as: education, income, biology, genetics, and the physical environment. “These combined factors should be taken into account when looking to bring forward any meaningful reform in the health care debate” (Drummond, 2012, p. 155).

One step that the province has taken to help address this system fragmentation is the move to regional oversight of health care through 14 Local Health Integration Networks (LHINs) in spring of 2007 (MoHLTC, 2007b). While the LHINs were intended to address health system needs at a local level, to date, there has been little change to the fragmentation of the system. Community based services and offerings continue to vary across the 14 LHINs and even across different communities.

While the progressive and changing needs of PLWD can make both care planning and policy planning challenging, all PLWD share a need for accessible, appropriate (dementia-specific), flexible (dementia-friendly), and timely interventions, drug therapies, and services to help in the maintenance of functional status and independence. The following sections highlight H&CC services that are available in varying degrees across the province to PLWD and their caregivers and typical patterns of usage.

5.1.1 Home Care in Ontario

A range of H&CC services and care options exist across Ontario offered by public, non-profit, private, provider organizations and volunteer agencies. Community based services and housing options can serve three important functions:

- **Substitution**: services that are also provided in hospitals and LTC facilities
• **Prevention**: services and monitoring which, over time, lead to overall lower costs of care and an improved quality of life for clients and,

• **Maintenance**: allowing clients to stay independent in their current living environment instead of having to move to a more expensive situation.

(Anderson & Parent, 2000)

Some home care services are publicly funded [though CCACs in Ontario] based on eligibility while others are cost shared between government and consumers, provided by private insurance or paid directly out-of pocket by the consumer (Commission on the Future of Health Care in Canada, 2002). In Ontario, government funded professional and para-professional home care services may be accessed through 14 provincially funded, regionally based, not-for-profit Community Care Access Centres (CCACs). Some CCACs are also the gate keepers to other important H&CC programs like Adult Day Programs and all CCACs have legislated responsibilities for determining eligibility, wait-list management for all LTC facilities in the province.

To qualify for publically funded services within a person’s own home, CCAC case managers conduct an assessment, and if the person is found eligible, they then arrange for contracted and purchased services based on assessed needs of the clients and within budget allowances. CCACs, however, have limited to no involvement with community support agencies outside of purchased services in their plans of care. CCACs do not provide services directly to clients but use global budgets set by the province to purchase mostly professional services as well as some community supports on a competitive basis from for-profit and not-for-profit providers (Kuluski et al., 2012a, p. 439). The types of formal care services most often coordinated and contracted out by CCAC case managers include:

• Nursing (RN)
• Personal support (e.g., help with bathing, dressing, respite care)
• Physiotherapy (PT)
• Occupational therapy (OT)
• Speech-language pathology (SLP)
• Social work (SW)
• Nutritional counselling
• Medical supplies and equipment

(Community Care Access Centre, 2012)

CCAC case managers complete in-depth assessments on all adult (age 18 and over) home care clients using a standard form called the Resident Assessment Instrument for Home Care (RAI-HC). This assessment uses information from all available sources, such as the client themselves, family and other informal caregivers, paid caregivers and other health care professionals (ideas for health, 2005, p. 3). Data collected in the RAI-HC provides information on the level of client needs through the MAPLe prioritization system which evaluates characteristics of home care clients based on such factors as the degree of physical limitation, cognitive impairment, and behavioural and the cognitive function items in the RAI-HC. The MAPLe is used to help health care professionals prioritize clients’ needs, allocate home care resources and are often used as screening tools for placement in long-term care facilities (MAS, 2008).

Starting in the late 1990’s to present day, there has been a strong trend in Ontario towards earlier discharge from hospital. This trend fundamentally changed the focus of home care services from maintenance services to more short-term acute care services (although the government continues to fund some maintenance services through the CCACs). CCACs must work within fixed budgets and provincial caps on service hours to meet the growing demands of special populations like the frail elderly and others with chronic and complex care needs. This has led to increasingly strict CCAC eligibility criteria to qualify for and retain home care supports and resources. According to research by Hollander and Tessara (2001), the trend toward shorter hospital stays was:

“designed to result in cost-effective savings in acute care by substituting less costly home care services for more expensive acute care services by facilitating reductions in the length of stay in hospital. Even assuming investment in short-term home care proves to be successful, they still only deal with the output (discharge) idea of the equation. They do not deal with the input side
While [this] may [be] more efficient at taking people out of the hospital, these efficiencies may well be swamped by an ever increasing number of persons making demands on hospitals and LTC facilities.” (Hollander, M.J. & Tessara, A., 2001, p. 1)

For clients receiving care from the CCAC that have needs beyond that which the CCAC is able to cover, CCAC case managers may recommend clients privately pay to ‘top-up’ care with additional hours from formal care providers and/or recommend services provided by Community-Support Service agencies (CSS). If left to cover costs on their own, this may be difficult to impossible for many seniors on fixed incomes. Financial constraints aside, trying to navigate and arrange extra/top-up care is especially difficult to understand, navigate and organize by those with diminishing cognitive capacities and experiencing difficulty managing finances; and almost impossible for PLWD in later stages experiencing a limited understanding of any need for assistance.

The types of community support services a CCAC case manager might recommend that are offered to some extent in most regions in Ontario and they are aware themselves of the service, include:

- Adult/Alzheimer day programs (ADP) (e.g., general and dementia-specific)
- Attendant care (e.g., for those with physical disabilities that can direct their care)
- Caregiver relief (e.g., respite in the home or through ADP or overnight stay programs)
- Care giver support and education (e.g., through the Alzheimer Society)
- Client intervention and assistance (e.g., occupational therapy, social work)
- Foot care
- Friendly visiting, security checks, telephone reassurance
- Meal delivery and community dining programs
- Personal support / homemaking (e.g., assistance with bathing, dressing, cooking, cleaning)
• Home maintenance (e.g., housing repairs, modifications, or adaptations to help support PLWD in the community and lower the risk of accidents and forced moves to institutional setting)

• Social, recreational and intergenerational programs (e.g., drop-in leisure centres, exercise programs, organized group outings for frail older adults)

• Transportation services (e.g., paid/volunteer drivers getting seniors to medical appointments, grocery shopping bus)

• Specialized Geriatric Services (e.g., Regional Geriatric & Geriatric Psychiatry Community Services)

• Supportive housing (e.g., housing with care services available 24/7)

• Volunteer hospice/ palliative care (e.g., end of life care in or out of the home)

(Community Care Access Centre, 2012; Ontario Community Support Assoc., 2001; Community Navigation and Access Project, 2010; Morton, 2010; Sinha, 2012)

While some CSS programs will offer assistance with basic activities of living such as personal care, their focus is often on supports for instrumental activities of daily living (IADLs) such as transportation, meals preparation, monitoring/security checks which according to Hollander (2001) “IADL support has been shown to play a crucial role in preventing or delaying LTC and hospital admissions” (Hollander, 2001 in Kuluski et al., 2012, p. 439).

Although many CSS are charitable in nature, and many of their programs are reliant on volunteers, they often must charge user fees, (usually on a sliding scale geared to income or offer subsidies based on eligibility requirements) because of funding models (it is a 70/30 split as compared to 100% funding for CCAC). To help offset the costs of offering important community based services CSS will often receive partial provincial funding for their programs and some will have contracts with CCAC for specific services such as personal support. There is no single point of access from which CSS services are accessed and offered (Kuluski et al., 2012a) and coordination of care between CSS and CCACs is limited to non-existent – especially
if individuals are only referred to CSS and do not receive any CCAC funded services. In fact, a critical issue for PLWD is that some people never go to the CCAC and will go directly to CSS for help (or not at all). The lack of integration or assistance with system navigation has PLWD and their caregivers often dealing with multiple health and social care providers and provider organizations that span multiple sub-sectors, each bound by different rules, assessments, eligibility criteria, and who receive funding in different ways. In addition, different medical and allied health professionals will often make (sometimes conflicting) recommendations which can be confusing. While there is potential for H&CC to be helpful for PLWD and their caregivers, and potentially substitute for more costly institutional LTC, it can instead become overwhelming and unpalatable.

As described in the previous chapter, PLWD respond best to H&CC services that are offered by consistent dementia-trained staff in a flexible manner that can adapt to their needs. Given the current fragmentation of the system and the way the H&CC is set up (based on a competitive model to be described in the next chapter) there can be high turnover of frontline staff (nurses and personal support workers) due to unsatisfactory working conditions including low wages, lack of hours and little guarantee over hours and clients (Denton et al., 2006; Caplan, 2005). This can pose problems for the care of PLWD and respite care for informal caregivers. In addition, because one agency may not provide all of the required care services, to get the coverage they need it is not unusual to have many different people coming in to conduct assessments and provide the care in the home. This often contributes to reluctance by PLWD and their caregivers to utilize lower intensity community care services (Smale & Dupuis, 2004a,b,c). Disparities between settings (urban, rural, and remote) and across LHIN boundaries in Ontario and even across provincial borders can also contribute to differences in care. It is possible that two PLWD with similar needs may have very different community care options to remain independent depending on where they live – even within the same city (Kuluski et al., 2012a; Morton, 2010). In order for the full potential of H&CC to be realized, it would “require building capacity in this sector, particularly in rural areas, which are currently underserviced…if resources are not available in the community, ‘upward substitutions’ [to higher cost services are likely] to occur” (Kuluski et al., 2012a, pp. 438 & 446).
As consistency and routine are vital elements in dementia interventions, the above mentioned inconsistency and unpredictability is harmful to the PLWD and their caregiver (e.g., having to train new people at each visit or dealing with the “aftermath” of an agitated family member with dementia who is exasperated by all of the people and disruption to their routine). If appropriate H&CC services are not available or accessed, PLWD and their caregivers will often resort to more ‘high intensity’ services basically triaging up to cover off the missing pieces in their care; however substitutions do not work well for the individual (unnecessary visit to hospital or physician) or the system (financial costs and interruptions with patient flow). These and other factors can contribute to premature or inappropriate placement of PLWDs on institutional LTC wait-lists.

Integration of services between all systems of care is therefore considered a critical piece to addressing system fragmentation experienced by PLWD and successful implementation of individualized interventions early in the dementia continuum. However there remains no formal mechanism for CSSAs to coordinate efforts with CCACs around the care of shared clients (Williams et al., 2009a). According to MacAdam (2008) integration can take many forms, occur on many levels, and can be targeted to many different populations with different needs. Common characteristics leading to successful integration often incorporate the use of case managers and facilitated access to a range of health and social care services in order to achieve their desired outcomes. Other key features such as self-management and payment systems may vary (MacAdam, 2008).

The role of family physicians is often a crucial aspect in achieving goals for patients (in this case PLWD), and possible reduction in hospitalization and nursing home use (Lee et al., 2014; Lee et al., 2010; McAiney et al., 2008). Lack of integrated community care services, insufficient information on services, lack of collaboration between health professionals, lack of communication between patient and physician, and the frequent absence of a reliable caregiver are also considered important barriers to the effective support of people with dementia in health care settings (Lee et al., 2014; Lee et al., 2010; McAiney et al., 2008; Cantegreil-Kallen, et al., 2006).
5.1.2 Profile of PLWD Receiving Home Care

In 2010 the Canadian Institute for Health Information (CIHI) published *Caring for Seniors with Alzheimer’s Disease and Other Forms of Dementia*. Key findings from this research brief indicate that:

- One in five seniors (20%) receiving publicly funded home care had a diagnosis of Alzheimer’s disease and/or other dementia. The rate was nearly three in five (57%) for seniors living in a residential LTC home.

- There was an overlap in the populations served by the community and the LTC home sector. One in six (17%) seniors with dementia and high impairment—those experiencing moderate to severe difficulty with basic cognitive and self-care functions—were living at home with home care. At the other end of the spectrum, the same proportion of seniors with dementia and low impairment—or little difficulty with cognition and self-care—was living in residential care.

- Among the low-impairment (higher-functioning) seniors with dementia, those newly admitted to residential care were twice as likely to be unmarried (defined as widowed, separated, divorced or never having been married). This highlights the critical role of the spouse in helping seniors with dementia stay at home.

(CIHI, 2010a, p.1)

These findings along with factors associated with informal caregiver distress, a common reason for seniors’ admission to residential care suggest that there are key factors related to why some seniors with dementia, even those with relatively mild symptoms of impairment, struggle to remain in the community.

In 2007 the Alzheimer Society of Ontario commissioned a report, *Profile of Ontario’s Home Care Clients with Alzheimer’s Disease or Other Dementias*, which highlighted common characteristics of PLWD receiving formal support from the CCAC based on RAI data. Research for this report was conducted by *ideas for health* at the University of Waterloo based on the over 177,000 RAI-
HC assessments completed in 2005. Some home care clients had two or more assessments completed in that year so findings of the report were based on the last assessment for each individual that year, for a total of 127,151. The report focused only on those individuals residing in private home/apartment or retirement/congregate care settings and home care clients assessed in hospital for placement purposes. Those in LTC homes were excluded from the report’s analyses. According to this report:

- “Home care clients who are assessed with the RAI-HC represent individuals with longer term health and care needs that are, on the whole, beyond what informal care (i.e., unpaid family, neighbours, and friends) can provide. Within this group of persons with high needs, those with [dementia] represent a distinct group who:
  
  o receive somewhat larger amounts of paid care
  o receive much higher amounts of informal care
  o have nearly 10 times the rate of responsive behaviours
  o show higher rates of mood disturbance
  o have much higher rates of memory and executive function problems
  o have greater physical dependency in everyday tasks such as dressing or eating
  o show acutely higher rates of incontinence
  o [had on average 3.9 conditions, compared to other long stay home care clients who had 3.3]

- Caregivers, who are mostly spouses and adult children or children-in-law:
  
  o provide greater amounts of care [75% more care than other caregivers], and on a proportional basis receive weaker support from formal care compared to other home care clients experience much higher levels of stress, especially where the clients are showing behaviour problems [nearly 20% higher levels of stress].

Note: Dementia related behaviours can increase in frequency, duration and intensity as a dementia progresses. They may include: pacing and wandering, general restlessness and agitation, exit seeking, repetitive sentences and questions, complaining, cursing, making strange noises or screaming, and grabbing onto people or physical aggression (Dupuis, Wiersma, Loiselle, 2004). Behaviours are best described as responsive and not challenging or difficult, to better reflect that they are an attempt by PLWD to respond to their current situation or unmet need in the context of their changing abilities to think, perceive and remember. The term does not however, dismiss the fact that many caregivers feel challenged or difficulty in trying to managing and accommodate for them (ibid).
• **Characteristics of PLWD tend to look different depending on their living arrangement.** Those who live alone tend to be more capable of doing so (i.e., lower levels of dependency), while those living with others both need and receive higher levels of care. Not surprisingly, community-dwelling individuals with dementia who reside in congregate care settings show the highest levels of dependency.

• **Individuals with Alzheimer’s disease or other dementia tend to show higher rates of receipt of many services after becoming home care clients, although the rates of service generally remain low. Informal care time was not withdrawn, on average, once home care services were in place.**” (Ideas for Health, 2006, p. 15).

### 5.1.3 Dementia-specific Services

In 2010 a report by Morton commissioned by the Alzheimer Society of Toronto for the Toronto Central LHIN titled *Dementia Care: Diversity, Access, Coordination, Final Report* researched “dementia-specific core services” offered in the Toronto Central LHIN region. Building on the foundation of general H&CC services available to community dwelling PLWD in this large urban setting, the report identified trends, barriers and enablers to accessing dementia-specific programs and services throughout the entire continuum of a dementia. Two key components distinguished core services for PLWD from other general H&CC service definitions:

1) Core dementia services are central to the care and well-being of people with dementia and their caregivers.

2) Core dementia services are delivered throughout the continuum of dementia by staff with dementia-specific training, knowledge and skills. (Morton, 2010)
Seventeen core dementia services were identified in this report, and are identified below. Many of these services overlap between community dwelling PLWD and those receiving institutional care (e.g., respite or full-time care in LTC homes; in-patient behavioural assessment units).  

1) Adult day programs for PLWD  
2) Adult day programs with overnight stay for PLWD  
3) Assisted living for PLWD  
4) Dementia-specific case-management  
5) Dementia-specific counselling  
6) Dementia-specific education  
7) Support groups for families caring for PLWD  
8) Support groups for PLWD  
9) Dementia-specific personal care / personal support  
10) Dementia-specific homemaking / home help  
11) Dementia-specific respite  
12) Dementia-specific friendly visiting  
13) Psycho-geriatric mental health services  
14) Memory clinic for PLWD  
15) In-patient behavioural assessment unit for PLWD  
16) Dementia unit in a long-term-care facility  
17) Behavioural unit in a long-term care facility  

(Morton, 2010)

25 Note: Some dementia-specific services are only offered largely in urban settings (e.g., Memory Clinics; In-patient Behavioural Assessment Units) yet can serve the larger community.
This report and others note that while general and dementia-specific community based services can be helpful to assist PLWD to age in place, many issues affect the ability of PLWD and their caregivers to search out and or obtain them. Many PLWD and informal caregivers often find it difficult to ask for help or access these services for reasons that may include:

- stigma (e.g., fear of others perceptions about them or reluctance to admit a brain health issue)
- lack of awareness about services by PLWD, informal caregivers, primary care and case managers
- poor linkage channels between the individual and the system of care
- lack of availability (e.g., differences in offerings in urban, rural, remote locations)
- catchment areas/LHIN boarders (e.g., services exist but provider cannot cross boundaries)
- wait-lists for services for both government-funded and CSSA services
- poor accessibility (e.g., fragmentation of the system, strict eligibility criteria, affordability of services)
- lack of flexibility with program offerings (e.g., programs offered during traditional business day/week when services often needed afterhours, evenings and on weekends)
- inconsistency of formal caregiving staff
- transportation issues (e.g., cost, location of destination, purpose for drive, drivers without dementia training)
- ethno-cultural-language appropriateness (e.g., limited to no choice of services, programs or information in one’s mother language, familiar customs, multilingual staff)

(Morton, 2010; ASC, 2010; BSO, 2010; McAiney et al., 2008; Lee et al., 2010; Dupuis, Epp & Smale, 2004).

Furthermore, dementia itself is complex and PLWD are not homogeneous such that one type of program may not fit all PLWD in need (the needs of PLWD in the early stages of Alzheimer’s will
differ from those with Frontal Temporal dementia or Lewy Bodies Dementia). This is an important consideration when working towards care interventions for different sub-groups.

5.1.4 Supportive Housing

In addition to personal supports and home adaptations, another supply factor that is important to PLWD is access to affordable housing with care; however, according to O’Mally and Croucher (2005) the housing needs and preferences of PLWD and their caregivers has received relatively little direct attention in care planning (O’Mally & Croucher, 2005). While remaining in one’s own home (house or apartment) or that of a relative or friend may be considered desirable for PLWD, community living situations may also include a variety of housing arrangements which can include Supportive Housing (SH) programs (e.g., community based service configurations for managing and integrating care across the continuum for high-risk populations provided on a 24 hour per day, seven days per week basis), Group Home Living (e.g., non-licensed congregate housing for a small number of residents and staff grounded in a philosophy of community inclusion), and Retirement Residences (e.g., privately owned and operated (although some are owned and operated by a municipal government or non-profit organization) that for a fee, offer accommodation together with some combination of meals, housekeeping, laundry, and recreational and social programs).

Key factors that influence transitioning from one’s own home or apartment to a community-based congregate setting often include health and safety issues related to having a dementia, the needs of their caregiver(s), and others that may be affected (e.g., PLWD at risk of theft or mistreatment from neighbours/strangers, caregiver stress, neighbours that might be at risk for encountering behaviours of PLWD) (HCC, 2012; Aminzadeh et al., 2009; Morton, 2010; Rushford, ND). The level of supervision and care required by the PLWD, particularly as the disease progresses, will also influence the decision to move to another form of housing or LTC home, especially if and when the PLWD does not have an informal caregiver to assist them. Financial issues, cultural values and practices, family and friends’ ability to contribute to care, relationships with health professionals, and the supply (accessibility, availability and
appropriateness) of care in the current situation can also factor into a decision to move to a more supportive care setting (HCC, 2012; Morton, 2010; Aminzadeh et al., 2009).

Of particular relevance to this thesis research is the model of SH (also referred to as assisted living). It generally offers more independent living than that which is possible in a LTC home (Housing and Dementia Research Consortium, ND) and according to the Canadian Mortgage and Housing Corporation (CMHC), SH with a high level of support services available to its residents can be an alternative to residential LTC placement (CMHC, 2012).

SH as a model of care is unique in that it is neither fully independent living, nor institutional LTC. It is noted for its flexibility to allow people to maximize their independence, privacy, decision-making and involvement, dignity and choices and preferences and reduce caregiver burden for those residing with the client or elsewhere (Lum et al., 2006). Other benefits of supportive housing include:

- Promotion of good mental and physical health by encouraging independence
- Supportive physical environments (accessible, flexible and safe indoors and outdoors)
- Integrated care with access to necessary support services that are flexible as residents need change over time with proximity to and possible internal programming
- Providing opportunities for socialization and regular contact with staff and other residents who would be aware of changes in a resident’s well-being and
- Ensuring a secure residential living environment yet less restrictive than a LTC home
- Potential reductions in use of higher intensity health care services

(Goodwin et al., 2014; Hyde et al., 2014; Verbeek et al., 2009; Williams et al., 2009a; Lum et al., 2006; Morton; 2010; Lum et al., 2005; CMHC, 2000).

Type of programs that may be offered in SH may include, but are not limited to:

- care coordination and assistance with system navigation (arranging Meals on Wheels or transportation)
- preparing light meals
• assistance with basic ADLs such as grooming
• assistance with instrumental activities of daily living
• social activities
• 24 hour support services (either on-site or within a specific timeframe)
• security checks
• light homemaking
• emergency response systems

(CMHC, 2002; Lum et al., 2006; Lum et al., 2007; Verbeek et al., 2009; Morton, 2010)

SH has been praised for its perceived ability to support and meet the needs of diverse populations (e.g., dementia, frailty, mental health); improve the health status, functional independence and quality of life for individuals and their carers while also moderating demand for inappropriate use of “high-intensity” hospital and institutional care. It has also been speculated that SH can achieve cost-efficiencies that produce favourable outcomes for at-risk seniors including PLWD (Lum et al. 2007; Williams et al., 2009b); however, to date these models have received relatively little systematic research or evaluations to verify these results.

In Canada, SH has many different definitions and approaches, with some models being “linked” (housing and care staff provided by the same organization) and others “delinked” (housing offered by one provider and supportive services offered by another like a charitable/not-for-profit CSA) (Lum et al., 2006). SH apartments/bedrooms are considered private dwellings yet often with some shared or communal space. SH may take specific populations (e.g., seniors, PLWD, homeless) or support a mix of populations. Mixed programs that support PLWD often only do so when the impairment is mild or in the early stages and the clients are still relatively independent and able to direct their own care (Morton, 2010). In these programs SH providers may serve PLWD who do not have an official diagnosis. Regardless if clients are drawn from mixed or dementia-specific populations, both SH approaches less often assist those with middle or late stage dementia, unless they are “grandfathering” clients they are already familiar with.
Those with more progressed dementia then transition to LTC institutions.

In 2009 Verbeek and associates looked at cross-national variation in characteristics of SH models noting that the types of settings ranged from larger ones resembling LTC home type settings (e.g. “Residential groups” in Germany) to stand alone facilities (e.g. “Green Houses” in the United States or “Special Care Facilities” in Canada). They also noted differences within specific projects such as “small-scale living” in the Netherlands/Belgium and “group living” in Sweden can be located in ordinary houses in the community or may be part of a larger assisted living facility. Their findings also indicate that stand-alone facilities may provide some protection against more institutional characteristics and institutional feel of the home environment (Verbeek et al., 2009).

Despite many common characteristics of SH, there is currently no one comprehensive legal framework at the federal level under which SH is regulated across Canada. The responsibility for setting legislative frameworks for both the housing and services aspect of supportive housing rests with the provinces. In Ontario the MoHLTC defines SH as a combination of permanent housing with access to the 24-hour availability of personal care and homemaking services (Lum et al., 2006). Other definitions view SH as “integrating housing with access to a comprehensive and coordinated package of services and programs necessary to support individuals to maintain their optimal level of health and well-being” (Ibid). In Ontario, support services for seniors fall under the MoHLTC and Housing falls under the Ministry of Municipal Affairs and Housing with provincially funded service models largely offered in municipal social housing settings to ensure affordability for low income seniors. This has set a pathway that has makes it difficult to consider other models of care and has impeded the ability of the province in responding to high risk seniors who do not live in social housing. Further issues with availability and accessibility also relate to the lack of standardized eligibility criteria which varies across the province for SH; some programs accept adults 55 years of age and older, others 60 and over, and some will be for those with physical or intellectual disabilities – populations known to age faster than the general population. Criteria can become particularly restrictive when SH is offered in municipal housing buildings as clients need to already be living in one of
these buildings to qualify and the MoHLTC does not control social housing admission. Moreover, for many municipal homes (e.g., in Toronto) need for SH services are not identified as a grounds for prioritization. In Toronto-based study of dementia services by Morton (2010), respondents indicated that wait times can range from 6 to 12 years to getting to subsidized housing, creating a situation where people will not be able to access such integrated services in time to benefit those with progressive dementia either presently in need of assistance or those at risk of placement in a LTC home. Even for those already in the municipal housing system, and in a building where SH services are provided, accepting new clients with a recognized dementia becomes restrictive when people live alone without family support, have ongoing co-morbid medical conditions, or dual diagnosis with underlying mental health issues, communication barriers (aphasia from stroke or dementia; English as a second language), or require “two-person transfers” or palliative level care (Morton, 2010).

For PLWD, SH would appear to be well suited as a mechanism to address the progressive nature of their illness where there is flexibility to “ratchet-up” services when needed most, and “ratchet-down” when they are coping relatively well; however, previous BoC research (Peckham et al., 2014; Williams et al., 2009a,c) notes that there is great variation in providers’ views about the acceptability of risk in for people with cognitive impairment in the community (e.g., risk of forgetting to turn off taps, stove elements). Another benefit of the integrated care offered in SH buildings is that monitoring of PLWD is possible to a greater degree as supports can be more individualized than with traditional CCAC visits in PLWD’s private dwellings. A consequence however of such enhanced models of care is that turnover of clients tends to be slow, thereby limiting availability for more people in need.26 Clients with dementia can also experience barriers to more general SH programs (as opposed to dementia-specific) as some of

26 In a 2010 Toronto-based study, one organization had 450 people waiting for 134 rooms and on average only experienced a ten-person turnover per year, with the average age of those moving to a LTCH being 94 (higher than the average provincial age).
these programs require an ability to direct one’s own care (McGrail et al., 2013) and their capacity to make decisions may be questioned (St-Amant, et al., 2012).

In Ontario the Assisted Living Services for High Risk Seniors Policy, 2011 has replaced the provisions of the Assisted Living Services in Supportive Housing Policy, 1994. This updated policy continues to target high risk seniors (frail or cognitively impaired seniors) whose needs cannot be met in a cost-effective manner through H&CC services provided solely on a scheduled visitation basis, but who do not require admission to a LTC home (MoHLTC, 2011). The historical review of this thesis ended in 2012 and the impact of this broader focused policy has had much impact on the earlier described restrictions for PLWD and accessing SH programs.

5.1.5 Institutional Long-Term Care

Institutional LTC homes are designed for people with high care needs who require ongoing supervision and assistance with basic ASLs (e.g., toileting and personal hygiene), are no longer able to live independently in the community, and sometimes require a secure environment. More than 76,000 people in Ontario live in LTC homes, many of them with complex health conditions requiring specialized 24 hour care offered through a range of services including nursing care, personal care, medical treatment, physiotherapy and rehabilitation, special diets, and recreation therapy (MoHLTC, 2014a). LTC homes are regulated by provincial governments, require a license to operate, and receive some form of government provincial subsidy, often calculated on a per diem basis, to provide food, accommodation and health services. In most cases, residents pay for the room and board costs (unless they qualify for subsidies which are calculated based on income, and income plus assets in Quebec) and for an additional fee, many LTC homes offer optional services such as semi-private or private accommodation (CMHC, 2012).

A recent meta-analysis (broad evidence-based literature review and consultation with experts) of approaches to lengthening and maintaining people's ability to age in the community
conducted in Ontario by the Medical Advisory Secretariat (MAS)\textsuperscript{27} identified dementia as one of four key drivers to LTC admission:

- cognitive decline linked to dementia (Note: this was one of the most commonly cited reasons for institutionalization with approximately 90\% of individuals diagnosed with dementia being institutionalized before death)
- falls and fall-related injuries
- urinary incontinence, and
- social isolation

(MAS, 2008, p. 21)

Each of these on their own can be devastating; however, PLWD often experience many or all of these issues over the progression of their illness which can hasten their path towards institutionalization. Further to this, an American-based meta-analysis by Gaugler and associates outlined that three or more ADL impairments coupled with cognitive impairment were among the strongest predictors of admission to a LTC home (Gaugler et al. 2007 in Kuluski et al., 2012b).

Impairment with IADLs such as transportation, medications management, meal preparation, and housekeeping have also been identified as critical factors for LTC home placement of those with or without cognitive impairment (Williams et al., 2009 a,b; Kuluski et al., 2012a. These are activities that most seniors, especially PLWD struggle with well before they lose the ability to manage their basic activities of daily living (ADLs) such as bathing, dressing, or feeding themselves which also eventually become important triggers for LTC placement (Gaugler, et al., 2007). These activities are vital to maintaining independence and can trigger the need for and avoidable use of high end health care resources. For example, if a PLWD cannot remember

\textsuperscript{27} Conducted in Ontario by the Medical Advisory Secretariat (MAS) for the Ontario Health Technology Advisory Committee (OHTAC)
how to cook or even to shop for food, they can experience malnutrition, dehydration, and/or compounded confusion leading to an avoidable visit to the ED, a preventable admission to hospital and/or premature placement in a LTC home.

“Caregiver factors that can trigger LTC placement of PLWD included level of caregiver burden, old age, poor physical health, no first-degree kinship of the caregiver with the patients, use of services [or lack thereof], and desire to institutionalize” (Hebert et al., 2001 in MAS, 2008, p. 21). The decision to institutionalize is also impacted by many other contextual and psychosocial factors such as family dynamics, interactions with health care professionals, and the caregiver’s perception of their ability to provide care (MAS, 2008, p.21). The CSHA and other studies reveal that caregiver burden often results from behavioural problems by PLWD in their care and that caregiver burden and distress is often associated with depressive mood for the caregiver (Hebert et al., 2001; CIHI, 2010a,b; Smale & Dupuis, 2004a,b).

Additional factors that contribute to this PLWDs’ risk for institutionalization include:

- Individual barriers to accessing H&CC support services (i.e., difficulty navigating the system, progressive memory loss, diminishing cognitive capacity and awareness of need for help, increasing confusion, inappropriate behaviours resulting from unmet needs and incorrect perceptions of reality)
- System barriers to accessing H&CC support services (i.e., system navigation difficulties by professionals, fragmented approach to service provision, restrictive or clinical only eligibility criteria, long wait-lists)
- Fixed/low-income of PLWD with limited ability to purchase necessary/top-up services
- Stigma and shame about how dementia is be perceived (both internally for PLWD and externally by others)
- A lack of, or misinformed understanding of dementia by care providers and decision-makers alike
- Homelessness
- An inability to speak English or French to better access or understand services and providers
A lack of solid interest groups advocating for their needs in the community (i.e., as a consumer group PLWD do not have much voice limiting policy development)

(Morton, 2010; ASC, 2010)

As outlined in the previous chapter, issues related to a progressive dementia can lead to PLWD landing in the Medicare Mainstream or on a LTC placement wait-list at a point of crisis. When PLWD land in hospital or a LTC bed, it is often due to seemingly simple issues related to health and social care (e.g., medication errors on the part of PLWD, forgetting how to cook or not remembering to eat) that could have potentially been avoided with some proactive and preventative H&CC services. The outcomes of hospitalization for older patients with pre-existing cognitive impairment can be very bad (Liu et al., 2009) as hospitals are not designed to meet their special needs. Furthermore, once in the hospital, if H&CC options are not available or insufficient to discharge PLWD back to the community, they will often remain in hospital in an ALC bed until LTC placement can be arranged. When being placed from placed in to a LTC bed from an ALC bed, PLWD have fewer choices regarding which LTC home they may chose and have had to take the first bed that comes available even if it is not near their community or that of their informal caregivers. Failure to access lower level supports (e.g., dementia friendly H&CC services, primary care/family health teams) early in the progression of dementia thus can lead to complications (both health and social) setting a path to higher level, more costly institutional care in hospitals and LTC homes (Kuluski et al., 2012a; Williams et al., 2009a,b; Hollander, 2001; ASC, 2010).

An interesting phenomenon can occur when some PLWD are placed in a LTC home. Once issues such as medication monitoring or nutritional concerns are well met, they can sometimes return to a level of competency that would allow for them to be independent enough to return home with supports in the community; however, once placed in a LTC home what often happens is their power of attorney has already sold the persons home, released their retirement home residence or given notice to their landlord and there is no place for the PLWD to return to.

In principle there are a number of dementia friendly long-term H&CC services, interventions, and integrating mechanisms like SH that would appear to well suited to help PLWD in the
community independently and safely in the early to moderate stages of a dementia and assist with factors associated with informal caregiver distress, another common reason for seniors’ admission to residential LTC care” (Brod et al., in CIHI, 2010a). However, in practice the literature points to a system response that is fragmented and stretched and often inadequate H&CC sector that pick PLWD up only reactively when physically ill (acute based needs), and not proactively in the earlier in the progression when cognitive needs (chronic needs) are more easily managed and accommodated for. This suggests that the triggers for LTC placement of PLWD are therefore related to both demand issues and supply issues which can push those with even relatively mild symptoms of impairment to become unable to stay at home and experience premature or inappropriate placement.

“One series of studies led by Challis and Hughes focusing on supply-side factors determined that the extent to which individuals residing in or at risk of facility-based LTC, could age at home if given access to H&CC found that up to 36% of individuals residing in LTC facilities in one community in the United Kingdom could potentially have aged at home at a similar or lower cost if given access to needed H&CC. These individuals were characterized by low levels of functional and cognitive impairment, and had an informal caregiver in their home (i.e., a family member of the care recipient). Given such low impairments, these individuals were deemed to be the least appropriately placed.” (Hughes & Challis 2004; Challis & Hughes, 2002 in Kuluski et al., 2012b p 95)

As mentioned section 2.3.1 Balance of Care Methodology, Ontario BoC research has also noted that in many regions across Ontario between 20%-50% of similar types of individuals waiting for LTC placement in Ontario could potentially age at home, safely and at a lower cost than facility-based LTC, if given access to H&CC, including supports for IADLs. Access to an informal caregiver in the home varied and, as might be expected, became increasingly important when functional and cognitive impairments increased (Williams et al. 2009a,c)

5.2 Informal/Unpaid Caregiving and Dementia

Further to the supply and availability of H&CC services and housing options, the ability of PLWD to age at home is also largely related to the supply and availability of informal caregivers to assist them. Informal caregivers play a crucial role of in the management of care for PLWD given the high levels of dependency and morbidity that are associated with the condition.
Informal caregivers are “typically” unpaid and largely nuclear family members, but may also be extended family, friends, partners, and neighbours (MAS, 2008). Formal caregivers in home and community are those that are paid for their help. Care offered in the community is often provided by unregulated workers (e.g., personal support workers) who constitute the majority of formal care providers; however, care may also be provided by a range of paid and regulated professions including nurses, social workers, rehabilitation therapists, and so on. The Canadian Study of Health and Aging (CSHA), a longitudinal study originally released in 1994, is often used to base projections for the Canadian population. Calculations estimate the average for duration of care is approximately 5.8 years (6.7 years for women and 4.6 years for men) (CSHA, 2000). Further research on caregivers suggests that six in ten caregivers provide care to an elderly family member or friend for more than two years (Keating, Fast, Frederick, Cranswick, & Perrier, 1999 in Smale & Dupuis, 2004a), with one fifth of caregivers providing care for five years or more (Stone, Cafferata, & Sangl, 1987 in Dupuis, Epp & Smale, 2004, p. 2-3).

While there are many positive aspects related to informal caregiving of PLWD such as reciprocity of care, personal growth and personal satisfaction, the experience can also be very difficult. Caregivers of PLWD must deal with managing a progressive and unpredictable disorder that may also be complicated with: additional medical problems, managing their own health related issues, dealing with changes in lifestyle (e.g., being highly isolated), additional financial/time constraints, and provide all of this with little/inadequate recognition (Smale & Dupuis, 2004a,b,c; Dupuis, Epp & Smale, 2004).

Caregivers of PLWD experience high strain. The stresses include physical, emotional, social, and economic pressures for which caregivers require support from the health, social, financial and legal systems (WHO & ADI, 2012). To this point, a growing body of research including the Ontario MOHLTC Caring-About-Caregivers Long-Range Scenario Planning (LRSP) project by Change-Ability (2009); the Special Senate Committee on Aging – Canada’s Aging Population: Seizing the Opportunity (2009); the Canadian Health Services Research Foundation Health Systems Planning for the Aging Population: A Backgrounder; the Ontario Caregiver Coalition Initial Advocacy Strategy & Plan (2009) and; Canadian Health Care Association Home Care in
Canada: From the Margins to the Mainstream (2009) each recognize the vital role of informal caregivers in helping older persons manage their care and age at home for as long as possible and the need for the “formal” health care system to support caregivers in this role.

Regrettably, there is also a great deal of research that shows a continued under-valuing of informal caregiving, and that a decline in such caregiving reflects, in part, a failure of the formal system to provide informal caregivers with sufficient supports. This failure is seen to stem from multiple factors including capping of budgets/fiscal constraints, a continuing preoccupation with acute care, and the view that formal care should be provided only when families “fail” in their responsibility (Hollander, et al., 2007).

According to Health Canada, most family caregiving is provided in the caregiver’s home by either a spouse or an adult child (75 -77%) (Decima Research, 2002). While they may be providing care in the home, much of the work that caregivers do is often cross-institutional (from home to doctors’ offices to hospitals, to rehabilitation, to home, and often back into hospitals or rehabilitation). Untrained, under-supported, and unseen, family caregivers constitute a “shadow workforce,” providing physical and emotional support that moves constantly with their elderly care recipients (Bookman & Harrington, 2007; Levine & Murray 2004). They often act as geriatric case managers, system navigators, medical record keepers, paramedics, chauffeurs, and patient advocates to fill dangerous gaps in a health care system that is uncoordinated, fragmented, bureaucratic, and often depersonalized (Bookman & Harrington 2007; ASC, 2012). This is particularly vital when care recipients experience cognitive decline, coupled with increased IADL and ADL needs, decreased capacity to communicate needs, and increased resistance to dealing with unfamiliar faces. As such, informal caregivers may serve as the link to the formal system, and coordinate formal services and providers in the home (Peckham et al., 2014; Change-Ability, 2009).

According to data from the CSHA, approximately 50% of seniors with dementia are living in the community (at home or in an assisted living facility) and greatly reliant on informal caregivers (unpaid care provided by family, friends, and volunteers). Of these PLWD:

- 94% of them have a caregiver (family or friends)
• 2.4% have no caregiver
• 29% live alone but typically have a daughter living close by
• 8% have only one caregiver for support
• > 70% of the informal [unpaid] caregivers are women, most often wives (24%) or adult daughters (29%)
• Half of the informal caregivers are over the age of 60 with 36% being over the age of 70
• 92% have two or more relatives or friends beyond their primary caregiver who provide assistance
• Their spousal caregivers are less likely to have back-up support than others and yet are more likely to be caring for a person with severe dementia.

(CSHA, 1994a,b in MAS, 2008)

Peckham and associates (2014) identified that spousal caregivers provide more hours of informal caregiving than do adult children or other types of informal caregivers. Spousal caregivers are the most likely to provide personal care compared to adult children who tend to provide mostly IADL care. This difference in care provision was attributed to the functional limits a spousal caregiver may face when attempting to provide such IADL tasks (Peckham et al., 2014). While caregivers are often documented as being wives or daughters of PLWD, a recent report Caregiving for Caregivers prepared for the Ontario MoHLTC highlighted that early policy assumptions of caregivers being biological children or spouses, and that the caregiver of preference is female, are now being challenged by new demographic trends. The changing demographics of family include, but are not limited to:

• an uneven(decreasing) ratio of children to aging parents
• more children living away from aging parents (outward migration)
• more women having children later in life increasing the likelihood the “sandwich generation” will grow and that families will be caring for children and aging family members simultaneously
• divorce and re-marriage rates affecting the type and number of caregiving situations
increasing numbers of same sex partners/marriages

ethno-cultural considerations impacting the nature and type of care within a family

(Change-Ability, 2009)

The new realities and faces of caregiving will impact policy and regulations for accessing and assessing these caregivers and eligibility criteria for care and training supports. Additionally, caregiving is not limited to the nuclear family and may include extended family, friends, or volunteers providing a range of basic to very involved care. Caregiver needs, networks, resources, strengths and limitations vary from caregiver to caregiver.

As a care recipient’s ability to remain independent for as long as possible often relies on the ability and willingness of the caregiver to provide care – the two often need to be addressed as a unit, as well as considering the needs of the caregiver as an individual when creating care plans to ensure the services will be supportive to their needs (Peckham et al., 2014; Morton, 2010; Smale & Dupuis, 2004c). For example, if an older person has a live-in caregiver who is capable of providing instrumental support, services such as meals on wheels and meal preparation may be less crucial, while other services, such as caregiver counselling and respite may be more crucial (Peckham et al., 2014).

In a 2008 report by the Medical Advisory Secretariat (MAS) of Ontario two main categories of interventions for dementia caregivers were identified: respite care and psychosocial interventions. Respite care (defined as a break or relief for the caregiver) has been identified by caregivers as one of the key formal supports to alleviate the stress of caring (Rudin, 1994 in MAS, 2008). Respite can be provided in many different ways (e.g., caregiver relieve, housekeeping), in different settings (e.g., home, adult day program, institutions) and for different lengths of time (e.g., day, overnight, month) in an effort to temporarily relieve the caregivers from care responsibilities including but not limited to monitoring and/or engaging PLWD in daily activities, meal and medication monitoring, safety checks and social interaction (MAS, 2008; Morton; 2010). A number of individuals carry out respite care including paid staff, volunteers, family, or friends (MAS, 2008). Psychosocial interventions encompass a broad range
of interventions and have been classified in various ways in the literature. They may include educational, behavioural, dementia-specific, supportive, and coping interventions. Multicomponent interventions may also be used which include at least two of the above-mentioned interventions (MAS, 2008, p. 25). Further to this, access to H&CC services early in the progression of a dementia can not only help PLWD, but also help their caregivers to adjust to the caregiving role and establish supportive, enduring relationships with services providers (Gaugler, Kane, Kane, & Newcomer, 2005 in McAiney et al., 2008). Use of H&CC services and caregiver counseling has been found to delay institutionalization as well as death of care recipients (Brodaty, Gresham, & Lusombe, 1997 in McAiney et al., 2008), improve interactions between caregivers and care recipients (Corbeil, Quayhagen, & Quayhagen, 1999 in McAiney et al., 2008), and significantly reduce depressive symptoms in caregivers (Mittleman et al., 1996 in McAiney et al., 2008).

In 2004 the Ontario Dementia Caregiver Needs Project (herein referred to as the Caregiver Needs Project) was released by the Murray Alzheimer Research and Education Program (MAREP), University of Waterloo as part of the Provincial Alzheimer’s Strategy (1999 – 2004). This four part research project focused on the needs of caregivers of PLWD and identified common types of care provided by these informal caregivers, common stressors in caregiving for PLWD, and barriers to accessing formal care services amongst other factors.

Most caregivers in the Caregivers Needs Project provided assistance with a number of ADLs, IADLs as well as emotional and social supports. According to the MAREP report In their own voices: A Profile of Dementia Caregivers in Ontario - Stage 1: Survey Results, the types of ADLs that caregivers provided to PLWD included: “help with dressing (66.8%), bathing/showering (65.2%), personal hygiene (51%), Feeding (47.7%), Toileting (44.1%), general mobility (39.9%), changing incontinence products (35.8%), and bed/wheelchair transfers (22.7%)” (Smale & Dupuis, 2004a, p. 20). Smale and Dupuis (2004) point out that variations among assistance provided by caregivers may be explained by factors such as the progression of the dementia, the presence of other illnesses or disabilities, and/or the amount of help available from other sources (Smale & Dupuis, 2004a, p.20).
In this same report, over 75% of caregivers more commonly indicated providing assistance to PLWD with IADLs. Assistance included: “transportation (84.6%), money management (83.7%), attending medical appointments (79.8%), personal business and/or correspondence (77.3%), shopping and/or running errands (75.2%), laundry (67.2%), meal preparation (67%), household chores and/or cleaning (62.8%), arranging/supervising formal support services (60.8%), administering medications (60.2%), and yard work, outside chores (45.8%)” (Smale & Dupuis, 2004a, p.21). Other important and frequently occurring caregiving activities described in this study include: “emotional support (88.7%), recreational opportunities (82.9%), making social visits/providing companionship (79.9%), and telephone check-ups (47.2%)” (Smale & Dupuis, 2004a, p. 24). These supports highlight the crucial role of caregivers to meeting a constellation of needs for PLWD.

While many caregiving activities, supports, and responsibilities described in Caregiver Needs Project may seem generic and commonly offered by informal caregivers of seniors in general, those caring for PLWD face unique challenges. The burden of caring for the progressive debilitating nature of dementia (cognitive and functional declines), the increase in physical and psychosocial demands on a caregiver, hard to manage behavioural issues such as wandering or aggression (verbal or physical), the eventual need for 24/7 monitoring or supervision, and the long duration of intensive care (on average two – five years) causes more caregivers of PLWD to experience stress and in some cases distress than those providing care to seniors without dementia (Gill et al., 2011; CIHI, 2010a; Smale & Dupuis, 2004a; Dupuis, Epp & Smale, 2004).

According to the CSHA, this increased burden of caregiving contributes to chronic health problems seen among informal dementia caregivers with 16% of people caring for someone with mild dementia in the community reporting symptoms of depression. The rate is more than double for those caring for someone with moderate dementia (40%). The prevalence of depression in dementia caregivers is nearly twice that of caregivers of persons with other chronic diseases (CSHA Work Group, 1994c in MAS, 2008, p.25). While caregivers will often state they are doing very or generally well with caregiving, they also acknowledge it to be stressful (70%) and need a break either frequently (21%) or occasionally (47%) (Decima Research, 2002). Caregiver stress, if unaddressed, can lead to distress and burnout and...
potentially avoidable use of higher level care services. In a 2011 report by the Institute for Clinical Evaluative Sciences (ICES) one in five informal caregivers of PLWD reported distress, anger, depression or inability to continue care, which was even more marked in those cohabiting with the PLWD (26.7%) in contrast to 9.1% and 14.3% respectively for informal caregivers of older individuals without dementia (Gill et al., 2011, p.66). In addition, many caregivers do not feel prepared for the increasing challenges of dementia and while few receive any special training or dementia-specific linkages to support, they would benefit from them (McAiney et al., 2008).

The 2004 Caregiver Needs Project identified many sources of stress reported by caregivers of PLWD. Survey results from Stage 1 of In their own voices: A Profile of Dementia Caregivers in Ontario of the caregiver needs project reports a range of concerns that caregivers found to be very stressful including, but not limited to: “feelings of responsibility of caregiving (72.6%), concern about their PLWD’s future (70.0%), limitations on living their own life (63.7%), worries about leaving their PLWD alone (63.9%), and the exhausting nature of caregiving (61.3%)” (Smale & Dupuis, 2004a, p. 32).

In this connection, a 2010 CIHI study titled Supporting Informal Caregivers – The Heart of Home Care “nearly 20,000 informal caregivers (16%) of seniors receiving home care reported not just stress - but distress (the overall impact of physical, psychological, social and financial demands of caregiving related to their caregiving role) (CIHI, 2010b, p.2) The rates of distress were significantly higher among those:

- Providing more than 21 hours of care per week: 28%
- Caring for seniors with symptoms of depression: 32%
- Caring for seniors with moderate to severe cognition problems (most would be suffering from Alzheimer’s disease or other forms of dementia): 37%
- Caring for seniors displaying aggressive behaviours: 52%

(CIHI, 2010a, p.1)

Related to this, key predictors of caregiver distress include:
• Being a spousal caregiver (CIHI, 2010b)
• Lack of choice in taking on this responsibility (Decima Research, 2002)
• Level of cognitive impairment of the H&CC client and the number of hours of informal care received (CIHI, 2010b)
• Difficulty managing behaviours and or unstable health conditions (Ibid)
• Symptoms of depression in home care recipient (Ibid)
• Care recipient’s difficulty with IADLs and ADLs related to cognitive impairment (noted to be 3X greater than other caregivers of seniors) (Ibid).

Despite the potential for stress and distress, providing care is typically valued by caregivers and care recipients alike and, if given the help to do so (e.g., funds, tax credits), many caregivers would prefer to provide care themselves rather than to have paid care providers come into their homes (Hollander et al., 2009; Smale & Dupuis, 2004a). Research demonstrates that the majority of caregivers are able to cope, and they do not feel overly burdened, or if they do, it is periodic, not constant (Chappell & Dujela, 2008 in Chappell, 2011, p. 12). Furthermore, caregivers can experience self-affirmation, enjoyment and a sense of satisfaction in their caregiving role, and may not always feel there is benefit to the use of respite or other caregiver interventions for the many reasons including constraints within the system (e.g., if respite only offered in LTC homes and not in the persons home or homelike setting) (Braithwaite, 1998; Tarlow et al. 2004 in Chappell, 2011, p. 12).

Informal caregivers are critical to the success of PLWD who desire to live at home in the community given the many types of activities and forms of assistance caregivers provide. If and when caregivers reach a point where they are no longer able to meet the growing demands of providing support to PLWD, their withdrawal or absence from care will place even more strain on the current system. Many caregivers have identified ways they could use some assistance (predominantly IADLs and Respite), with 33% of caregivers citing the need for additional home care services (Health Canada, 2002). Despite this finding, less than one in four (23%) caregivers are currently receiving any type of formal home care services to assist them in caring for their family member (40% PSW; 34% RN; 26% homemaking; 10% other such as professional services
Commonly cited reasons by caregivers of PLWD for declining or refusing H&CC services include a lack of consistency in staff and the need to train and retrain new workers. In addition, caregivers cite impatience for multiple reassessments by new professionals or case managers visiting the home (Smale & Dupuis, 2004a; Dupuis, Epp & Smale, 2004). Other considerations include a lack of ethno/cultural/linguistically appropriate care providers and settings (Morton, 2010).

Among the barriers that might limit caregiver’s access to community support services, the inadequacy of the number of hours of support and the inadequacy of the number of services provided for both care receivers and caregivers were identified by approximately 50% of caregivers. While formal home care assistance is an important type of support to family caregivers (to reduce caregiver burden) – results from the Caregiver Needs Project (2004) indicate that it does not appear to significantly reduce the stresses that caregivers are experiencing in providing care for PLWD. This research found that:

- “Less than half of dementia caregivers in Ontario are making use of the formal community support services that are offered
- Caregivers are more likely to make use of informal support resources such as emotional support and help with caregiving tasks from other family members
- Among the barriers perceived by dementia caregivers in Ontario that constrain their access to or use of community support services, those identified most often were that the number of hours of formal support and the number of services to both caregivers and that care receivers were inadequate to meet their needs; that the health and social service system was too difficult to navigate their way through in order to receive services; and that they had little input into who provides in-home care.”

(Smale & Dupuis, 2004a, p.52)

Some of these barriers may also be an issue of timing as research suggests that:

“the period when a caregiver begins to assume a caring role, and the circumstances surrounding that transition, may have critical importance for long-term outcomes. Caregiver support, when accessed earlier, may allow caregivers to acclimatize more gradually and effectively to increasing care demands. They may, thereby, have more opportunity to make and implement plans and routines that may be helpful later in the disease course.” (ADI, 2011, p.22)
As mentioned earlier, even when formal supports are accessed, weekly maximums provided by the formal system may not be enough and financial barriers can inhibit paying for additional top-up services (Smale & Dupuis, 2004a; Morton, 2010). PLWD may also be eligible for other services such as Adult Day Programs; however, depending on hours of service, availability of transportation, appropriateness of fit, and a host of other factors, the effort caregivers must go through to have PLWD participate may not be worth it to them (Morton, 2010).

5.3 PLWD Default to Institutional Long-Term Care

Where individual needs of PLWD and their caregivers are important factors in determining the timing and setting in which they will age (community or LTC home), there is growing evidence that the supply-side variables are also important determinants and which options are more or less accessible. (Kuluski et al., 2012b; Williams et al., 2009a; Hughes & Challis, 2004). The tipping point for placement of PLWD tends to be low when cognitive needs, alone or in combination with other needs (e.g., physical, social) are coupled with a lack of available, accessible or appropriate community based interventions and itself may be considered a risk factor for placement. PLWD are particularly vulnerable to fragmentation and a predominant Medicare Mainstream focus on physician and hospital care and not proactive and preventative community care. Intersecting with the health care system at point of crisis often renders the health and social care system incapable of dealing with PLWD further impairing their ability to remain or return home without significant home support.

Some PLWD are placed in LTC homes with relatively low intensity care needs (CIHI, 2010a). Such needs might have been better dealt with using H&CC services and/or the coordination of informal supports (e.g., medication monitoring, requiring help with shopping and/or meal preparation). In fact, a growing body of international research suggests that frail seniors, including PLWD, can be diverted from LTC placement and avoid unwanted, inappropriate, and/or unnecessary use of acute care services when community care services and resources are (a) more accessible,(b) well integrated throughout the health care continuum, (c) case managed, and (d) targeted to those at highest risk of institutionalization (Kuluski et al., 2012a; Williams et al., 2009a,b,c; Chappell et al., 2004; Hughes & Challis, 2004; MacAdam, 2008; Onder
et al., 2007). Despite this growing body of knowledge, relatively little is known about tipping points between H&CC and facility-based LTC for those with cognitive impairment. So while there is no way to control who gets dementia “decision-makers have considerable scope to alter supply-side variables to tend to their needs through policies that make facility-based LTC beds and H&CC more or less accessible” (Kuluski et al., 2012b, p. 95). More on key policies that have set the balance between institutional and community-based resources for PLWD in Ontario will be explored in chapter six: *Historical Trajectory for Home Care in Ontario*.

Long-term home care is a key component to integrated care for the frail and cognitively impaired elderly in their quest to age-in-place in their own homes and community; however, the low tipping point for institutionalization of PLWDs also occurs in part because historically there has been no system or framework in place that addresses their specific H&CC needs. As will be described in the next chapter, prevalence data, census data and LTC home wait-list data have been used in the past to project and justify the need for building more LTC home beds. In the late 1990’s this encouraged financial assistance towards institutional development while neglecting more imaginative and integrative community support service options.

Institutional placement can benefit those in need of high-intensity care; however, there are others who appear to be placed due to a lack of community based alternatives or economic steering effects beyond their control. This is unfortunate as there is a growing body of international evidence suggesting that when appropriately integrated, targeted and managed, H&CC services can moderate the demand for more costly hospital and long-term residential care, while mitigating the human costs that a loss of independence can entail (Kuluski et al., 2012a; Williams et al., 2009a,b,c; Billings & Leichsenring 2004; Chappell et al. 2004; Hollander & Prince 2008; Leichsenring & Alaszewski, 2004; MacAdam 2008; Onder et al. 2007; Hughes & Challis, 2004; Challis & Hughes, 2002). Integration of services – where the most appropriate services can be selected from across the health and social care continuum – has shown a
consistent tendency toward “downward substitution,” that is, the use of lighter care IADL supports instead of medically based institutional health care” (Williams et. al., 2009a, p. 102).

The hidden nature of dementia, the fact that the disorder is often under-diagnosed or diagnosed quite late in the progression, or diagnosed by a doctor who is unresponsive or unaware of how to access supports coupled with a historical logic of caring for PLWD reactively, not proactively, all contribute to the use of high-intensity hospital based services and low tipping points for residential LTC with institutionalization becoming a default when other community based options are not available or are not pursued. Linking PLWD to integrated interventions early in the progression (e.g., timely access to memory clinics using a multi-disciplinary approach to care; First Link® programs) and lower-intensity community interventions and supports (e.g., medication reminders and monitoring to avoid poly-pharmacy or medical crisis; meal preparation to avoid poor nutrition/dehydration and possible resulting delirium) would appear to be a promising way to manage and accommodate other underlying conditions that can trigger hospitalizations or crisis placement (McAiney et al., 2008; Lee et al., 2010; Tootab et al., 2013). Avoiding hospitalization is key for many seniors (especially those with dementia) as it “can become a pivotal event (Inouye, 1993); either adding years or quality to their lives or placing them at risk of losing a great degree of independence. Hospital practices

28 Williams and associates site many examples of integrated models that do this. One such model is the On Lok/PACE (Program of All Inclusive Care for the Elderly) project in the United States, which showed that when multidisciplinary teams could use predetermined budgets to access the most appropriate services needed by frail older persons eligible for residential LTC, there was a progressive shift in resource use from healthcare (e.g., hospitals, radiography, laboratory tests, medications, medical specialists) to community supports (e.g. transportation, adult day programs) (Williams et. al, 2009a,c).

29 Consider, for example, the basic needs of a PLWD living alone in the community with a skin condition requiring the application of medicated ointment. Without someone to remind them, or apply the ointment for them, they may scratch the affected area(s) of their body to a point of inflammation or worse – infection, thus requiring medical treatment, a trip to the emergency department, and / or costly hospitalization. If this condition were to qualify for government funded homecare – because it is a medicated ointment, the person sent into monitor and apply it would need to be a nurse or someone trained by a nurse and signed off to perform the “delegated act.” While a simple issue – it involves much coordination and falls out of typical eligibility criteria for CCAC. If regular supports cannot be put in place in the community to help with the ointment, LTC placement is considered to keep the condition under control despite the person’s ability to negotiate other aspects of their life at home.
may cause significant harm to the elderly and include: prescribed immobility, unfamiliar surroundings, lack of sleep, under-nutrition, medications and interventions that predispose them to falls and hospital acquired infections” (Tsilimingras, 2003 in Liu et al., 2009, p.8).

5.4 Identified Areas of Need

As outlined above, the use of health services by community dwelling PLWD in Ontario is affected by many factors including variations in location, supply, and eligibility criteria of general and dementia-specific services. For example, two PLWD can receive very different care depending on where they live, if they have an informal caregiver or not, and if and how they link into the system of care. The current fragmented and confusing H&CC system is difficult for older persons without cognitive impairment to access and utilize, but becomes a more confusing and frustrating maze of services when viewed from the perspective of those with memory problems and/or caregivers experiencing a great deal of stress. Fragmented and siloed services in turn affect the capacity of the system to address a growing demand for services – especially proactive/preventative interventions that benefit dementia care the most. Four main areas of need have emerged in the literature as to the types of services and supports required by and for community dwelling PLWD throughout the progression of the disease.

1) The need for practical, accessible, appropriate, stable, and supportive community-based services and environments – to maintain the PLWD in the community, support the caregivers, and delay institutionalization for as long as possible (including respite for the caregiver). Practical community based and clinical services (memory clinics) and dementia-specific interventions (homemaking, personal care, hospice care, nursing, allied health services and respite care for informal caregivers) provided by as few organizations as possible, and consistent dementia-trained care providers are cited as beneficial to PLWD and to their informal caregivers. Adult day programs and SH are additional community based options cited as enhancing greater integration and monitoring of the needs and care of PLWD. (Lee et al., 2014; Goodwin et al., 2014; Hyde et al., 2014; Lee et al., 2010; Verbeek et al., 2009 Smale and Dupuis, 2004 a,b,c; Dupuis, Epp & Smale, 2004; Shuster, 2000; Snyder, 2001; Tariot, 2003).
2) **Flexible Individualized Interventions** – that use a person-centred approach focusing on empowerment and independence to maximize and maintain the individual’s abilities and minimize their disabilities for as long as possible in all care settings (including palliative care) are beneficial for PLWD, and where applicable, their caregivers. These dementia-friendly interventions adapt to the different and changing needs of individuals affected by dementia and help to minimize the stresses related to PLWD’s progressive loss of mental, physical and social competence. Intervention considerations include, but are not limited to, stage of disease, age of onset, living environment, and issues related to ethnicity, culture and language (Czaja, Eisdorfer & Schulz, 2000 in Dupuis, Epp & Smale, 2004; Morton 2010; ASC, 2010b; Snyder, 2001; Volicer, 2001; Volicer et al., 2001; Daker-White et al., 2002; Clare et al., 2003).

3) **Education and Skills Training** – of PLWD, their caregivers, and their health care providers to provide information and skills, both theoretical and applied, concerning diagnosis, prognosis, treatment, behaviour management, increasing coping skills, links to formal resources, individualized flexible care and the maintenance of a person’s abilities at the highest possible level (Lee et al., 2014; McAiney et al., 2008; Lee et al., 2010; Snyder, 2001; Sullivan, & O’Conor, 2001; Clare, L., 2002; Husband, HJ. , 2000).

4) **Integration of Services Across All Sectors** – to support PLWD to remain safely in the community for as long possible and avoid unwanted, inappropriate, and/or unnecessary use of acute care services or LTC placement. PLWD benefit most from: multidisciplinary care/case management approaches targeting those at risk of poor outcomes; support increased access to and case management of a range of general and dementia-specific health and social services; active involvement of physicians and geriatric teams in the care of PLWD early on in the progression; and infrastructure support such as decision tools, common assessment and care planning instruments, and the use of integrated data systems to avoid unnecessary duplication of effort and reluctance to receive care (Lee et al., 2014; Kuluski et al, 2012a,b; Williams et al., 2009a,b,c; Lee et al., 2010; McAiney, 2008; MacAdam, 2008; Chappell et al., 2004; Hughes & Challis, 2004; Onder et al., 2007; Williams et al., 2010; Goodwin et al., 2014).
5.5 Summary

The policy aspect of health care has a life of its own such that the current system is not matching up/responding to the needs of community dwelling PLWD and their caregivers. This gap between demand and supply continues to grow as the prevalence of dementia also grows (both locally and globally). This poses a serious problem with the ability of the current (non)system to address the gap and avoid upward substitution of high cost/resource intense health care services (e.g., hospital and residential LTC) in place of lower cost/resource intense H&CC options.

While PLWD and their caregivers can benefit from a wide range of interventions and H&CC services to help with aging in place for as long as possible, the current system is idiosyncratic, unreliable and inconsistent. As such, PLWD and their caregivers often experience great difficulty in accessing and navigating the current patchwork of services and coordinating care across siloed health care sectors. They also encounter issues with the amount of time available and timing of H&CC (e.g., early proactive interventions versus reactive care). Where other factors remain equal and H&CC is more accessible, this thesis predicts that the needs threshold for admission of PLWD to residential LTC will increase and a greater proportion of older persons will be able to age successfully in the community. In contrast, inadequate planning, investment in, and availability of long-term continuing home care and rehabilitation services can trigger premature or unnecessary institutionalization of individuals in need of LTC support.

“Failure to access the right care at the right time may lead to a deterioration of client (and informal caregiver) health outcomes, increasing the potential for preventable health related complications, recurrences, health system errors, a proliferation of negative client experiences, vulnerability to premature or unnecessary placement in long-term institutional care, and ultimately, greater health system costs downstream.” (Williams et al., 2009a)

This chapter notes that currently there is no coherent system of care – standards or standardization of care – for community dwelling PLWD. It also points to a number of individual (complexity of dementia) and system level barriers that pose challenges to accessing the types of supports necessary for PLWD to age at home and to care planning within the existing policy context. Using neo-institutionalism as a theoretical backdrop, the next chapter will explore
Ontario’s policy trajectory and how this seeming mismatch between demand and supply unfolded.
“Canadian Medicare was shaped during a ‘policy episode’ in the 1960s that essentially froze in place the health care delivery system that existed at that time” (Tuohy, 1999, p.31). As will be described in a later section of this chapter, the Canada Health Act (CHA) further set in place the logic – ideas and practices from the sixties – about health care and the role of the State and laying a foundation for medically based definitions of health and health care (e.g., hospital and physician acute focused health care deemed as “medically necessary”). This well entrenched path has seen other proximate policy areas (proximate to acute care), like H&CC, largely ignored and left essentially to the will of each province. When home care has received attention by policy makers it is frequently in the context of providing post-acute care to help free-up beds in hospitals and with an assumption that there will be assistance available by family and friends to fill in any gaps.30

This is not to say that the Medicare Mainstream of medically necessary hospital and physician care is bad for seniors. In fact, the guiding principles in the CHA have positively contributed to the care of many older adults, PLWD included, in providing a large measure of security with universal access to publicly funded medically necessary hospital or physician care, and equity where provision of care is based on need and not ability to pay.31 The success of modern medicine has seen the lifespan of PLWD living longer and on average will require care for approximately 8.5 years (Keene, Hope, Fairburn, & Jacoby, 2001). The issue that arises for policy makers is balancing the competing needs of the general population versus those with

30 For PLWD without such familial support or finances, few options remain beyond an extended stay in hospital or placement in a LTC home.

31 This would be relevant especially to low-income seniors, especially in light of prior to Medicare many people went without healthcare or experienced financial hardship to pay medical costs.
more complex and chronic needs (e.g., post-acute and chronic based home care), both from a fiscal and health outcomes perspective (Anderson & Parent, 2000). Aging is considered a cost driver: “as the population ages gradually health care costs also rise gradually with patients’ age” (Drummond, 2012, p. 148). Canada’s health care system has been “designed to address the hospital and doctor care needs of the majority of the population. However, as needs have changed the health care system has become overwhelmed and diverted by the special needs of the truly complex and expensive cases” (Drummond, 2012, p. 161). While the aging population is not a new phenomenon, policy change has been slow to address their chronic health and social care needs.

This thesis argues that where appropriate lower cost home care support services are available and accessible to PLWD, the need for higher intensity care resources (ED visits, hospital stays, and institutional placement) will decrease, or at least not increase as quickly. While high intensity care has merits for those in need (e.g., those further along in the progression of dementia and/or with physical conditions), many are prematurely placed in LTC homes often due to limited options (and finances) to retain their independence in the community.

Inappropriate placement of frail seniors, especially those with cognitive impairment, is not a new issue and was recognized as early as 1986 in a policy document known as the White Paper: A New Agenda issued by the Minister for Senior Citizens’ Affairs of Ontario (Ministry of Senior Citizens Affairs Ontario, 1986). Some of the strategies recommended in the paper specifically included a need to reduce inappropriate LTC institutionalization, improve access to long-term home care services, and coordinate a ‘one-stop’ approach to community-based care for seniors. These recommendations were particularly germane to PLWD then, and they are now. In fact, in a 2006 poll prepared by the Canadian Health Services Research Foundation (CHSRF) 91% of respondents said that publicly insured services should be extended to home care, long-term care, mental health care and drug benefits (Soroka, 2011 in Drummond, 2012).

Home care was also identified as important by both the Commission on the Future of Health Care in Canada (2002) lead by Roy Romanow (Romanow Report) and the Standing Senate Committee on Social Affairs, 2002 lead by Michael Kirby (Kirby Report). While not the specific focus of the two reports, the Romanow Report identified home care as the “next essential
service” and recommended the development of a Home care Transfer Fund to provide public coverage for three priority groups – end of life, mental health and post-acute care (Commission on the Future of Health Care in Canada, 2002), and the Kirby Report also recommended home care coverage through a national home care program for post-acute clients, a tax credit/deduction for home care consumers and insurance fund for home care and benefits/job protection for family caregivers (Standing Senate Committee on Social Affairs, 2002). A decade later a host of provincial reports such as those by the Medical Advisory Secretariat (MAS) of Ontario (2008), Walker (2011), Drummond (2012), Sinha (2012), and the Ontario MoHLTC itself in its Seniors Strategy (2012) and Government of Ontario 2012 Action Plan (2012) continue to highlight the need for a better response to the home care needs of Ontarians, in particular the chronic long-term care needs of an aging population.

The remainder of this chapter will provide a high level overview of the era between 1984 – 2012 in an attempt to understand why the policy sub-field of H&CC remains under-developed/resourced despite being identified as an area in need of attention and the interplay between key institutions, interests, ideas that have created a policy pathway where LTC placement has become a default option for PLWD. It will also describe four windows of opportunity that occurred where attempts were made to veer off this pathway including: Ontario’s Alzheimer Strategy (1999 – 2004) and subsequent Alzheimer Strategy Transition Project (2005 – 2007); the introduction of Local Health Integration Networks; Ontario’s Aging at Home Strategy (2007 – 2010), and the Behavioural Support Ontario Project (2007 – 2010). It will also consider the influence of recent provincial, national and international calls for government to address dementia as an area in need of attention (2010 -2012).

6.1 The “Institution” of Canadian Medicare

A key institution that has had a lasting impact on the way health care is viewed and delivered is the Canada Health Act (CHA), 1984, which has set a foundation for past, present, and future definitions of what constitutes health and related care. The Act was largely based on the Hospital Insurance and Diagnostics Services Act (HIDA), 1957 and the Medical Care Act (MCA), 1966 and established a framework of broad principles under which provinces must abide in
order to qualify for federal transfer payments, and within which subsequent provincial medical insurance plans continue to be based (Tuohy, 1999). Since the amalgamation of the aforementioned legislation, Canadian Medicare has seen relatively little change in the nature of health services provision and funding, and maintained a biomedical focus on health care practices and delivery of services. Given that the logic at the time from which the CHA is based was largely on acute and episodic care in hospitals and from doctors, it does not easily support collaboration and ongoing communication across different levels of care, sectors, and providers (Nasmith et al., 2010). The logic was established when few policy makers or even medical professionals would have been able to predict/envision the number or extent of outpatient services and care options that could be offered outside of hospital or doctor offices (e.g., professional H&CC services offered by regulated professional, and personal care by unregulated health care providers). Hence, provisions for the expansion of providing health care beyond the Mainstream walls were not incorporated, or easily applied.

The CHA does make mention of “extended health care services,” which include: (a) nursing home intermediate care services, (b) adult residential care services, (c) home care services, and (d) ambulatory health care services (Canadian Legal Information Institute, 2009a) with some federal funds provided for these extended health care services; however, no real rules or institutional constraints were attached to this money. Thus, the use of the money does not have to meet the qualifying five national conditions (Public Administration, Comprehensiveness, Universality, Accessibility and Portability). This has resulted in wide

32 The biomedical model is the model predominantly used by physicians in the diagnosis and treatment of disease and orientation of all phases of knowledge development and transfer practices

33 Public Administration (providers of provincially insured medically necessary health care services are publicly accountable); Comprehensiveness (medically necessary health services provided by hospitals and physicians are covered with some variation depending on in-hospital or out-patient services); Universality (all insured residents are entitled to equal access to medically necessary health services); Accessibility (medically necessary health care is based on provincial residency and not on ability to pay); Portability (coverage extended between provinces and territories).

34 Sometimes the money never makes it past the province’s general revenue stream to actual healthcare.
variations in eligibility, access and costs for long-term home care services across provinces, and provides provinces with much leverage in provincial decision-making about which services they are willing and not willing to go beyond in the CHA. Such variation produces and perpetuates fragmented and “siloed” systems, which can in turn hinder the organization and coordination of different medical, health care and social care services across the care continuum (Baranek et al., 2004; Deber, 2000; Williams et al., 2009b). As was described in earlier chapters, this fragmentation is particularly detrimental to PLWD and their caregivers in understanding and accessing the care needed to help them remain at home for as long as possible.

The CHA, serving as the foundation of the Medicare Mainstream (medically necessary hospital and doctor care), continues to affect ideas about what is considered health and health care, and the roles and responsibilities of different levels of government for each. Consequently, the biomedical model remains a key policy determinant not only in defining the nature of illness, health and health care, but in identifying the role of the State, the rights and the responsibilities of individuals, and a hierarchy of interests (Baranek et al, 2004). According to Henderson (1995), this dominant way of thinking and approaching health care continues to have enormous implications on the:

- Direction and organization of research priorities and trends
- Study and field of aging with a focus on scientific [biomedical] aspects
- Production and reproduction of public/lay knowledge
- Structure of professions and occupations, and
- Public policy

(Henderson, 1995)

35 “The fact that the division of federal and provincial jurisdiction is never settled means that these competing views are always in play and are addressed anew with new policy issues” (Tuohy, 1992, p. 52)
Lack of movement toward a greater presence for community-based care also comes from different ideas about the value attached to certain problems; whose responsibility it is to intervene (e.g., help keep seniors/PLWD at home) and how much the government (and thus society in general) is willing to pay for this to happen. Unlike Medicare Mainstream protected entitlements, H&CC services have been considered “soft services” or “light care services”; in the case of Ontario they have historically been dichotomized as falling either into the health care sector (e.g., home care offered by regulated health professionals) or into the social service sector (e.g., assistance provided mostly by non-professionals, and sometimes offered by volunteers). “Under fiscal pressure, policy makers may be tempted to treat H&CC more as a ‘heap’ substitute for hospital or LTC, ignoring its potential to mitigate the demand for these costly services in the first place” (Williams & Lum, 2011, p. 55).

With hospital and physician Mainstream services largely predicated on acute and curative care (both in the training of physicians and other health professionals and the purpose of hospitals), long-term home care of older people has also been shaped into a medical, rather than a social, health model – which may not fully meet the general needs of an aging population. The CHA legacy has firmly entrenched hospitals and physicians and their related associations and colleges as powerful interests (e.g., political actors and policy communities) which also influence/perpetuate the dominant idea that health care equates to “medically necessary” doctor and hospital care in past and current day health policy. As such, the mid-20th century is considered a critical juncture in time with a distinctive ‘logic' of the system thus created that allowed for policy change to occur. Once certain choices were made, they became embedded and remain difficult to change without a major shift off of the set path (Tuohy, 1999).

Neo-institutionalism has been used by Carolyn Tuohy (1999) to argue, in effect, that the institution of Canadian Medicare represents a hard-fought “implicit bargain” between the public, state, and the private medical profession, which cedes to the state authority to fund universal access to medical care, while guaranteeing the medical profession a considerable degree of clinical and economic autonomy. She argues that this bargain has proven very resilient politically, and as such it continues to constrain state capacity to enact health care reforms (Tuohy, 1999).
Neo-institutional theory has also been used in the Canadian context by Baranek, Deber, and Williams (2004), to argue that in contrast to Medicare’s mainstream of hospital and doctor care (which is protected largely by the CHA), policy-making in the proximate policy field of H&CC has been relatively unconstrained politically as these are not protected services or entitlements (Baranek et al., 2004). This has resulted in major policy shifts and reversals, and by the reinforcement of a highly fragmented, incoherent, and diverse delivery system characterized by a range of different services, providers, funding mechanisms, and eligibility criteria, which vary extensively at the local level (Ibid). This lack of an integrated system has made accessing H&CC services very difficult for the general population, but even more so for those with cognitive challenges and can result in unnecessary hospitalization or premature institutionalization by default (Williams & Lum, 2011).

In 1993 the Ontario MOHLTC policy document Putting People First: The Reform of Mental Health Services in Ontario and in 1998 Making it Happen: Operational Framework for the Delivery of Mental Health Services and Supports both identified the need for increased capacity in the provision of specialty geriatric mental health services (in-patient and outreach in the community) and recommendations on how core services should be delivered based on best practices and level of need (BSO, 2010). While this recognition has helped inform incremental change towards improved access to geriatric mental health services for community dwelling PLWD – services which can offer more intensive treatment and an associated increase in higher levels of coordinated care in both community and hospital settings – most PLWD and their caregivers still lack knowledge about such assistance either because they are not connected in the system. In addition, even when aware of such services, they often experience difficulty accessing and navigating them due to long wait-lists, siloed, fragmented, and capped nature of services, limiting geography and catchment areas. (ASC, 2010; Morton, 2010). While there is growing recognition of H&CC services as integral to a well-integrated health care system, and their potential to substitute for other chronic or non-curative based types of care such as care offered in nursing homes or hospice/palliative care (Hollander & Chappell, 2002), their priority on the policy agenda continues to be low.
The importance of long-term home care and its ability to help seniors to age in place has been recognized for decades. In the 1970’s and 1980’s the literature noted that:

“Although community LTC programs have not been in operation in Canada as long as they have been in many European countries, there is evidence that they have been successful in preventing or delaying institutionalization of elderly clients (Kraus & Armstrong, 1977; Kraus et al., 1982; Nocks et al., 1986), and in reducing LTC costs (Health and Welfare Canada, 1982). However the effect of these programs is that those who are eventually admitted to a residential facility are often older, more frail and disabled than hitherto. Partly because most people wish to remain in the familiarity and independence of their own home and communities for as long as possible (Connidis, 1983; Shanas 1979; Wister, 1985), an important question is the extent and nature of care likely to be needed by elderly people in the future.” (Forbes et al., 1987, p. 51)

While the desire to age in place for as long as possible remains the option of choice for most PLWD, a pathway has been set toward LTC placement largely based on a number of historical factors including but not limited to: retrenchment policies of the 1990s and early 2000’s, a shift in focus to acute-based home care, the introduction of the new CCAC model and “Managed Competition”, and a redevelopment strategy for LTC beds known as “Super Build.”

6.2 Pathway Toward Institutional Placement

6.2.1 Retrenchment Policies of the late 1990’s and early 2000’s

“Ontario began the 1990’s with a complex array of arrangements for institutional LTC and home care” (Deber & Williams, 1995 in Armstrong & Armstrong, 2006, p. 14). While responsibility for “these services was primarily with the Ministry of Community and Social Services (MCSS), there was no single regional authority responsible for this care, nor a history of direct government provision for most LTC services” (Armstrong & Armstrong, 2006, p. 14). The province mainly purchased the services through Placement Coordination Services (PCS) and regional home care programs negotiating visit fees and volumes of service with the same providers (primarily grassroots, not-for-profit and charitable organizations) (Armstrong & Armstrong, 2006; Baranek et al., 1999). In contrast, institutional LTC was dominated by the private sector (Armstrong & Armstrong, 2006).
In 1991 the New Democratic Party (NDP) of Ontario was elected and while in power passed Bill 173, *An Act respecting Long-Term Care* in an attempt to bring greater coherence to these services. The LTC Act received royal assent in 1994 and formally removed in-home nursing and personal support from the protection of the Ontario Health Insurance Plan (OHIP) with the intention of making home care services public and universal under a new Multi Service Agency Model, while also removing them from the sphere of medical dominance (Baranek et al., 2004). This however, set the stage for the succeeding Progressive Conservative (PC) government to take greater control of the H&CC and LTC sectors and push them further to the margins. The Act gave the State a large measure of freedom in making decisions and ability to limit its obligations in the provision of these services. This coupled with the lack of protection of H&CC in the CHA saw a general erosion of the preventative function of government funded home care. Restrictions were made to CCAC budgets and strict limits were imposed on the amount of home care individuals can receive and for what purpose (e.g., more acute care focus) based on the premise of rationing and cost containment for tax payers (Armstrong & Armstrong, 2006; Baranek et al., 2004). This reduced access to non-medical chronic care services and also reduced the number of hours available when access to government funded home care was granted.

The PC government also dissolved programs which had allowed clients access to in-home care without a direct medical referral36 or medically-based needs, although it did continue to direct some funding of CSAs to provide homemaking and respite on a non-medical referral basis. This funding continues to this day, yet to a much lesser degree and with user fees. Even when some agencies offer subsidies, in some cases even small user fees can be problematic for those in

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36 In Ontario, the medical referrals process to most homecare services has gone back and forth where under the NDP government, access to non-professional H&CC services was not dependent on the receipt of professional services such as nursing and physiotherapy and those in need of homemaking services could be referred to government funded homecare services directly by family or concerned friends as well as physicians. Under the PC government physician referrals became a requirement to be assessed for service. The present Liberal government has seen a return to a broader referral process.
need of assistance (e.g., frail elderly and the disabled) (Armstrong & Armstrong, 2006). Where accessing government funded H&CC supports became more difficult for seniors in general, it became very difficult for PLWD because as described in the Demand chapter, many of their needs in the early stages are non-medical requiring assistance with instrumental activities of living (e.g., cooking, cleaning, medication monitoring) in the early stages) than basic activities of living (e.g., bathing, eating). When they do require help with personal care many lack insight for needing this assistance and refuse help. As also discussed in chapter four, there remain a number of physicians in the community who experience difficulties recognizing, diagnosing and treating dementia thus making them ill-equipped as gatekeepers to home care services for PLWD.

Further containment policies by the PC government also saw a cancelation of provincial social housing programs but a continuation of limited housing funding available for existing supportive housing programs for the frail elderly, people with disabilities, individuals with acquired brain injury, and individuals with HIV/AIDs (Ontario Association of Non-Profit Housing Association, 2011). In 2011 a new policy, the Assisted Living Services for High Risk Seniors Policy, 2011 (ALSHRS policy, 2011) replaced the NDP’s former provisions of the Assisted Living Services in Supportive Housing Policy, 1994 (ALSSH policy, 1994) to address the needs of frail and cognitively-impaired seniors who do not need 24 hour nursing care and can reside at home with support, but whose care requirements cannot be met solely on a scheduled visitation basis (MoHLTC, 2013). As with the previous supportive housing policy, the assisted living policy incorporates a combination of personal support and homemaking services, security checks or reassurance services, and care coordination, around the clock, on a scheduled and as-needed basis.

6.2.2 New Community Care Access Centre Model and Managed Competition

During it’s time in power the NDP government maintained an existing mix of for-profit (FP) & not-for-profit (NFP) H&CC providers and protected the NFPs with an 80/20 rule in favour of 80% of care provision by NFPs and 20% by FPs. One year after the Progressive Conservative (PC) party was elected the government proclaimed the Community Care Access Centre Corporation
and implemented a new Community Care Access Centre (CCAC) model which replaced the old Homecare model to oversee government funded H&CC services. In 1996, 43 CCACs replaced the 36 Placement Coordination Services and the 38 Homecare Programs with a mandate to provide information on public services and programs, conduct assessments, determine eligibility, plan a program of care and ensure services are delivered to eligible clients (Armstrong & Armstrong, 2006). Under the new rules CCACs were not to provide direct service to clients and they divested themselves of the Homecare program’s own community services (e.g., physiotherapy) and dismantle specialty teams thereby losing much expertise in geriatric mental health.

The government also initiated a new procurement process which had community-based agencies competing with other service providers for their clients –and their very existence. This new model reflected a preference in favour of FP providers of care with no further protection for NFP (Baranek et al., 1999; Armstrong & Armstrong, 2006). The move towards a competitive market based model from a formerly cooperative model largely affected the ability of, and interest by NFP agencies (now competitors) to voluntarily work together to notice and bridge services and gaps where possible with other NFP and FP providers (Baranek et al., 1999). During the NDP government’s push for a Multi-Service Agency (MSA) approach to home care had brought H&CC providers together to oppose this vision of merging home care organizations into one MSA, the new competitive process between multiple formerly co-operative providers combined with vulnerable, hard-to-mobilize staff (including regulated professions, unregulated workers, volunteers), family caregivers and consumers, made them difficult to mobilize into action against this new model.37

More than a year after managed competition was in place Saint Elizabeth Health Care submitted a report to the Nursing Task Force citing:

37 Not to mention that FP providers were in favour of this new model.
“nurses were being pressured to “see more patients in less time” and “there was less ‘paid’ support for orientation, team time, on-going education and certification and preceptoring of students.” Part-time work had increased and “the nursing workforce experienced significant upheaval in the transition, when providers were unsuccessful and new providers enter the market.” (Saint Elizabeth Health Care, 1998 in Armstrong & Armstrong, 2006, pp.16-17)

Other consequences of moving to this competitive model included high turnover of home care frontline staff (nurses and personal support workers) due to unsatisfactory working conditions including low wages, lack of hours and little guarantee over hours and patients (Denton et al., 2006; Caplan, 2005).

6.2.3 A Focus on Acute-Based Home care

Cutbacks in H&CC ran parallel to reform and restructuring of the hospital sector in Ontario. In order to lower the level of public expenditures, and pressure to cut overall public expenditure, there was a shift in focus to shorter hospital stays, day surgery, and out-patient acute care services as a means reduce cost to hospitals and their provision of “medically necessary care”(Armstrong & Armstrong, 2006, p. 6). While the government worked to move people out of hospital faster using home care, there was no corresponding increase in funding to the H&CC sector. In a further effort to curb spending the government froze CCAC funding for the 2001-2002 and 2002-2003 fiscal years at the 2000 – 2001 levels and prevented CCAC’s from operating with a deficit by passing the Bill 46 and the Public Accountability Act. Ontario Regulation 386/99 also forced CCACs to reduce service volumes and tighten eligibility criteria (Caplan, 2005) further diminishing the preventative and maintenance services of the past. The combination of low budgets and increasing demands for acute care services no longer provided in the hospitals or other institutions meant CCACs had less money to provide traditional home care for the frail elderly and the disabled (Armstrong & Armstrong, 2006). As described by Baranek and associates “the policy direction of decades past – encouraging home care to promote wellness and discourage institutionalization – was effectively reversed by the new policies of the PC government” (Baranek et al., 1999, p294).

With such restrictions on community care and difficulty accessing and visiting family physicians knowledgeable in dementia care, PLWD and their caregivers were left with few options when
health issues arose. “For those who could manage, privatized services filled the care gap with both NFP and FP agencies charging for the necessary services no longer provided publically (with NFPs more likely to have a sliding fee scale that took income into account)” (Armstrong & Armstrong, 2006, p. 18). For those unable to access or afford home care or homemaking services many would turn to hospitals for care as their only remaining option. For PLWD, visits to a hospital ER or a hospital stay can be quite detrimental to their already fragile mental health. Those unable to return home would wait for LTC placement in a hospital which was costly to the health of the PLWD and to patient flow at the hospital.

It was during this time that the earlier mentioned Kirby and Romanow Reports cited a need to incorporate more funding for home care into the larger health care system albeit to a limited degree (Standing Senate Committee on Social Affairs, Science and Technology, 2002; Commission on the Future of Health Care in Canada, 2002). Any of their suggestions would have been helpful towards improved home care offerings, although they still would not address the issue of the more chronic needs of PLWD or the current fragmentation of the system with patchwork services that are difficult for PLWD and their caregivers to access, navigate, and qualify for.

In 2004, the First Ministers of Health across Canada crafted a health accord – “10 Year Plan to Strengthen Healthcare” – where they gave some mention to home care in the provision of funding for acute based home care (two-week post-acute care and two-week acute community mental health) and some palliative care provisions (Health Canada, 2004). Whilst there were some incremental changes towards the provision of home care, it was noticeably geared towards a medical model of short-term and/or post-acute medical care (CIHI, 2006). The Prime Minister and the premiers also agreed to a federal program – Compassionate Care Leave – covered under the Employment Insurance Act to provide family caregivers with six weeks of employment insurance benefits when caring for a relative who is dying within a predicted 26 week timeframe (Government of Canada, 2013). This is a useful provision for those with advanced terminal situations, but for those with dementia, the palliative stage of care can last months to years making this benefit rather ineffectual for families of PLWD unless there is a secondary terminal illness that expedites the process (e.g., cancer).
Despite a growing body of evidence-based research and tacit knowledge about the benefits of long-term home care services on the general health and well-being of the population, we see these services continue to remain outside of the national terms and conditions of medically necessary services for which provincial governments must comply to receive cash transfers from the federal government.38

6.2.4 Long-Term Care Redevelopment Project – “Super Build”

A perceived bed shortage was also being experienced in the LTC home sector in the 1990s resulting from growing wait-lists for LTC placement. To address this shortage in 1997 the PC government announced a Long-Term Care Redevelopment project, also referred to as “Super Build” and moved forward for the first time since 1988 the development or retrofitting of 20,000 new LTC home beds. The development of new beds further entrenched a belief that institutionalization is a necessary solution to a perceived bed shortage— and a resulting push to fill them once built. This solution also ignored other components of LTC such as community based options like the development of more supportive housing models for frail and vulnerable adults to age in place as considered in a 1997 report prepared for the Health Services Restructuring Commission (HSRC) titled Planning for A Restructured System of Long-Term Care for Ontario (HayGroup, 1997). This commission was established with a four year mandate (1996 – 2000) to provide advice to the Minister of Health and Long-term Care on matters relating to the development and establishment of an effective and adequate health care system (Canadian Legal Information Institute, 2014b). The HSRC had a mandate to shut or to amalgamate hospitals, advise on implications/impact such actions would have in the community and provide recommendations on how other sectors of the health care system could be restructured (Ontario Health Services Restructuring Commission, 2000). One year into their four-year mandate the HSRC described a vision of LTC for Ontario is described as follows:

38 There is actually no universal entitlement as even medically necessary services are not always covered when provided outside of hospitals by non-physicians.
“In our vision of Ontario’s health services system, LTC is an integral component of the overall system. LTC will be provided in different settings depending on the desires, level of dependence and care requirements of the individual and the availability of compensating informal and formal systems of support. LTC settings will include private homes, supportive housing and care facilities (Homes for the Aged, Nursing Homes, Chronic Hospitals and Units).

Individuals will have equitable access to affordable and appropriate long-term care services regardless of geography, income, age, gender or background. People in need of LTC services will be supported in their own homes and communities for as long as possible. Families will receive the support they require to make this possible. People who cannot be supported in their own homes will receive care in the least restrictive, least intrusive feasible alternative setting. In all settings, long-term care will focus on maximizing each individual’s health, functioning and quality of life.”

(HayGroup, 1997, p. 3).

This vision to support people in their own homes and communities for as long as possible, and designate funding based on LTC places (which could include both community and LTC homes) (HSRC, 1997 in Armstrong & Armstrong, p.21), was superseded with a singular focus of LTC bed development – Super Build. This in part reflects the influence of a coherent and powerful LTC home sector comprised of mainly large LTC home corporations (and an important site for profit-making) actively representing their interests which were in line with the governments’ pro market ideology moving bed development into the private market (Armstrong and Armstrong, 2010, p. 14) This powerful group was successful in having the majority of new beds allocated to FP developers (Ontario Health Coalition, 2005). Part of this decision to prefer beds over a more general category of LTC places may also have been seen as a means to off load responsibilities of the CCACs who were undergoing severe budget cuts and restructuring.

Once built, the new beds needed to be filled. According to Sandy Seary-McKinstry, former Senior Director of a community based multi-service agency for seniors, many CSS agencies lost clients that had “no business being in a LTC bed” but went because they were afraid to miss an opportunity to get in their LTC home of choice (Seary-McKinstry, 2014). Where once LTC wait-lists were years long for LTC homes considered to be of the highest quality and putting one’s name on the list was more like a reservation for when they might actually need care, wait-lists became very different. According to Seary-McKinstry, after Super Build the rules for LTC home
wait-lists changed and under the new rules of the CCAC, if a person refused a LTC bed twice they were told they would go to the bottom of the wait-list. Although there was a provision for those in critical need, many were afraid to refuse or misunderstood the rules. As such, when beds on the lists became available, regardless of location in many instances, individuals and their families had to be ready for placement or else go to the bottom of the list. People could no longer “wait-it-out” for their bed of choice in 10 years; not accepting an available bed was perceived as a risk for many. This had some clients without great need for such care accepting placement while there were others more suited to that level of care that could not get in because the lighter care needs individuals took the available beds (Seary-Mckinstry, 2014).

6.3 Windows of Opportunity for Change


A window of opportunity for dementia reform occurred in the 1990s through Ontario’s Strategy for Alzheimer Disease and Related Dementias (herein referred to as the Strategy).

The Strategy was the first of its kind in Canada spearheaded in the late 1990’s by Cam Jackson, then Minister of Health with responsibility for seniors (Mozel, 1999). A combination of personal interest and prompting from a number of advisors to his office (e.g., individuals interested in cognitive health) elevated Alzheimer’s disease and related dementias (ADRD) as a “problem stream” in need of attention. While dementia had not specifically stood out as an issue in and of itself to the Ministry of Health, at the secondary level the topic had arisen in other provincial ministries over years of planning around LTC and mental health systems and how best to support individuals with cognitive impairment, mental health, and addictions.

Starting in June of 1996 the Ministry of Health convened a three-year consultation process with caregivers, service providers, volunteers and professionals across the province and an Alzheimer Strategy Round Table that included membership from a diverse range of consumers and providers (MoHLTC, 1999). In 1999 the Alzheimer’s Disease and related dementias Strategy was formally announced in 1999 as a joint initiative between the MoHLTC and the newly created Ontario Seniors’ Secretariat (part of the Ministry of Citizenship and Immigration) and
run from 1999 – 2004 with a total of $68.4 million invested. Through this Strategy dementia became a specific issue for which various related initiatives already underway were brought together with new initiatives under one umbrella. Further funding was later provided by the succeeding Liberal government for a transition period running April 2005 – March 2007 to wind down or seek alternative funding for various legacy projects including a virtual repository of knowledge and information about provincial dementia initiatives (ASO, 2004).

Based on consultations and direction from the Alzheimer Society of Ontario’s *Blue Print for Action*, the initial idea was to push for system navigators for every PLWD; however, this did not receive traction (ASO, 1996). The final Strategy was comprised of a variety of initiatives many of which were already underway, and promises made at the Ministry level such that anywhere there was anything across the MoHLTC that touched on dementia ended up in the ten point strategy for a five year term. The major components of the Strategy initiatives were: education for health care providers, caregivers and the public; service enhancements and expansion; and research activities and knowledge exchange (McAiney, 2005). The ten separate but related initiatives of the Strategy aimed at improving the quality of life of PLWD and their caregivers in Ontario were:

1) Staff Education and Training
2) Physician Training (Mentor Programs)
3) Increasing Public Awareness, Information and Education
4) Planning for Appropriate, Safe and Secure Environments (Design Conferences)
5) Respite Services for Caregivers
6) Research on Caregiver Needs
7) Advance Directives on Care Choices (Education)
8) Psychogeriatric Consulting Resources
9) Co-ordinated Specialized Diagnosis and Support
10) Intergenerational Volunteer Initiative

(MoHLTC, 1999)
The initiatives that became permanent following the Strategy were investments in day hospitals, psychogeriatric resource consultants in LTC homes, public education coordinators at Alzheimer Societies, and to some degree, education for family physicians and others (primarily web-based).

According to the original Strategy document, *Ontario’s Alzheimer Strategy — Preparing for Our Future*, the government recognized the evolving needs of a growing and aging population and thus responded by enhancing access to LTC and health services, and expanding its investment in services for PLWD (MoHLTC, 1999). The Strategy document further cites:

“The statistics on [dementia], together with our aging population, while significant on their own, can only begin to tell the story of the far reaching impact that [dementia] has on individuals, on families, and others who care for, and about, people with the disease. The impact of this insidious disease on individuals, caregivers, families, health care professionals and the health care system is enormous. The social and economic impact of this disease will increase as the population ages.

*In response to this challenge, the Government of Ontario has made a commitment to work in partnership with the provincial and local Alzheimer Societies, service providers and numerous interest and consumer groups, to implement a comprehensive provincial Alzheimer strategy for the future, making the Province of Ontario a leader in this field.*”

(MoHLTC, 1999, p. 20)

While the Strategy was intended to enhance and improve access to health services for PLWD and their caregivers, during the course of the Strategy the PC government also moved forward a number of earlier described polices (e.g., managed competition, *Super Build*) that conflicted to some degree with many of the ideals of the provincial Alzheimer’s Strategy. Even so, the commitment by the government to provide permanent base funding to several of the initiatives

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39 Added Public Education Coordinators at Alzheimer Societies (one per chapter however some chapters cover a really large area therefore disproportionate); Psychogeriatric Consulting Resources; Staff Education and Training curriculum (PIECES and U-First); Alzheimer Knowledge Exchange (AKE); and funding for increased Respite Services for Caregivers.
was an important first step to integrate the achievements of the Strategy into the broader system on an ongoing basis. Specifically, these initiatives are the 40 public education co-ordinator (PEC) positions, the 50 psychogeriatric resource consultant (PRC) positions and the expanded respite services for people with dementia (ASO, 2004a). According to the Alzheimer Society of Ontario, the accomplishments of the original Alzheimer Strategy improved the quality of life in communities across the province by improving service and making life more meaningful for PLWD. However, due to the Strategy’s complexity and the extent of the multi-stakeholder involvement, it was not possible to achieve its full potential in the five years (Ibid). In this connection, prior to the end of the Strategy the newly elected provincial Liberal government agreed to a transition period to help partner groups originating from the Strategy with the sustainability of successful initiatives. The Alzheimer Strategy Transition Project 2004 – 2007 focused on four transitional initiatives including:

- Web-based Alzheimer Knowledge Exchange (AKE)
- Regional Dementia Networks across the province which as mentioned earlier, have largely merged into one larger provincial dementia network (DN) supported by the AKE
- Roundtable on Future Planning for People with Alzheimer’s Disease and Related Dementia which was completed and a recommendations report and toolkit were submitted on the pillars behind successful dementia reform
- Provincial Alzheimer Group which was convened and has since concluded.

(ASO, 2004b, p. 1)

A great achievement of the Strategy and its transition period was placing dementia on the policy radar of the province of Ontario; it moved forward a more holistic view of dementia that saw investments in research and education that went beyond medical research in search of a cure. Despite the Strategy receiving a very positive evaluation (McAiney, 2005), dementia has struggled to remain on the agenda. One lasting legacy project has been the development and implementation of a web-based Alzheimer Knowledge Exchange (AKE) to act as a clearinghouse/resource centre, an interactive exchange, support for change champions and end users, and supports to move innovations in practice forward. Another was one-time funding for
regional Dementia Networks – local entities that were created to bring together people and organizations that enhance the quality of life for PLWD, their families and caregivers with a goal of improving the system of care. Dementia Networks varied in structure and mandate depending on their level of maturity and the needs of their local community. In some cases, networks had a mandate that was broader than dementia (i.e. Specialized Geriatric Services, Seniors Mental Health) (ASO, 2004b). While these initiatives and others related to the five-year Strategy and transition period were valuable to the sustainability of sharing knowledge between different stakeholders in the field of dementia (i.e., researchers, health professionals and policy makers), they did not change the institutional or structural mix of the health care system or make large scale policy change for community dwelling PLWD.

In hindsight, the window of opportunity that opened for the Strategy had reasonable staying power as it was a good fit for the government of the day, had a policy leader in a powerful position dedicated to the issue, and was willing to act on its own and in concert with the new Ontario Seniors Secretariat. The Strategy initiatives tied together many relevant projects that were already in development or about to launch for which money and/or action was already promised. Yet money invested was also spent on short-term initiatives (chiefly exhortation projects like committee consultations, conferences, research, and educational initiatives) that while aligned well with existing patterns and perspectives and practices did not have staying power as people moved on and practical knowledge and skill sets moved with them.

The Strategy did, however, create a number of positions with long-term/sustainable funding (e.g., PECs in the community, PRCs in LTC homes) and encourage partnerships between private companies (e.g., Pharmaceutical), medical associations (e.g., Ontario College of Family Physicians), Researchers (e.g., Murray Alzheimer Research and Education Program at the University of Waterloo), and non-government organizations (e.g., Alzheimer Society of Ontario) which was mutually beneficial to all stakeholders including government. While these were beneficial to the “dementia cause” when the Strategy ended, there remained no concrete plan or dedicated funding to concretely deal with the tangible H&CC care needs of PLWD (e.g., system navigation, IADL supports) to support them in the community for as long as possible.
When the Ontario Liberal Party was elected in 2003 they continued to support the Strategy initiatives and granted funding for a transition period to wind down certain initiatives and build on successes of others by encouraging others to take the lead on these projects. During and after the transition period, support for disease specific initiatives however gradually phased out in order for the government not to look as favoring one disease/cause over another. In this connection, regional Dementia Networks originally established through the Alzheimer Strategy decreased in influence and relevance at planning tables as the government moved towards broader senior focused initiatives.

At the national level the National Advisory Council on Aging (NACA) researched dementia related initiatives happening across the country during the same period as the provincial Strategy was underway. In 2004 it released a report highlighting many of the serious issues faced by those dealing with dementia from the perspectives of PLWD, their families and caregivers, and from a broader perspective of the Canadian public. Building largely on the Ontario Alzheimer Strategy, the report put forth a number of recommendations looking towards improved prevention, support, treatments and eventually a cure, and a need for the federal government to collaborate with other key stakeholders across the country to develop a National Strategy designed and funded to diminish or eliminate the many challenges that make dementia such a devastating disease (NACA, 2004). While organizations like the Alzheimer Society of Canada (ASC) and other concerned interests advocated, and continue to advocate for a national framework, a decade later Canada remains without a national strategy to deal with the continuum of care for dementia despite prompting from NACA, the World Health Organization (WHO), Alzheimer Disease International (ADI), the Alzheimer Society of Canada, and other G7 nations. And where Ontario did have a Strategy, one no longer exists.

6.3.2 Introduction of the Local Health Integration Networks (LHINs)

In 2003 during the tail end of the Alzheimer Strategy the Liberal Party won a majority government and kept the CCAC model in place with some minor revisions. In 2006 the Liberals regionalized the health care system by enacting *The Local Health System Integration Act*, and fourteen not-for-profit corporations (LHINs) replaced former sixteen District Health Councils.
LHINs were created to plan, integrate, and fund local health services by working with local health providers and community members to determine the health service priorities in their regions. Their mission is to improve health care services and service delivery, making services more accessible, and help residents of Ontario achieve better health. While the MoHLTC largely retained policy power and budget control, the LHINS became responsible for the oversight of the following:

- Hospitals
- CCACs
- Community support service organizations
- Mental health & addiction agencies
- Community Health Centres
- LTC Homes

(MoHLTC, 2006)

During this time the CCACs reorganized to align with the geographic boundaries of the LHINs to create a more integrated structure for governing and managing the CCAC system. The system changes to the CCAC structure caused additional navigational challenges for PLWD as they redefined boundaries, teams, and often had to deal with new case managers and processes.

Local Dementia Networks (DNs) also merged to form regional networks that aligned with LHIN boundaries and began the process of forming a provincial dementia network due to many LHINs stating they did not want to appear as favouring one disease over another, and preferred to work with broader networks (all geriatric concerns combined even though dementia can affect younger adults as well). While the Provincial Alzheimer Society continued to put forth policy papers to the LHINs and MoHLTC, the push from the LHINs to dismantle regional DNs lessened the presence and dementia-specific voice in LHIN planning.
6.3.3 Ontario Aging at Home Strategy 2007 – 2010

In 2007, as the Alzheimer Strategy Transition Project was winding down, the Liberal government announced a three-year Ontario Aging at Home Strategy (A@H Strategy) which was overseen by the LHINs to address the home and community health needs of seniors in their respective regions to age in place. The intention of this strategy was a change in focus to more preventative care rather than post-acute care. The initiative aimed at supporting seniors to live independent lives in their own homes, avoid unnecessary hospitalizations and encourage faster discharges. Some of the funded programs served the dementia population, but not all LHINs targeted dementia specifically.

Mid-way through this strategy however, the MoHLTC changed its focus to address the growing struggles of hospitals with ALC bed use and the seniors filling these beds (a phenomenon known as “bed blocking”). Thus an attempt to veer off the pathway was again redirected by the constraints of the Medicare Mainstream becoming a reactive strategy to address seniors in hospital than a proactive H&CC strategy aimed at avoiding ending up in the hospital system in the first place. This change went largely unchallenged because the policy field of H&CC remains highly factioned with a diverse mix of services, providers, settings, needs populations which limits their ability and drive to assert any organized opposition to the change (Baranek et al., 2004, p. 23).

Some success was achieved for PLWD through the Aging at Home (A@H) Strategy however. In 2008 Ontario’s 38 Alzheimer Societies were funded to various degrees to offer First Link® Services across twelve of Ontario’s fourteen LHINs through A@H. First Link® is a referral program designed to help newly diagnosed PLWD get the help they need as soon as possible by ensuring that individuals and families are referred directly to a First Link® coordinator at their local Alzheimer Society at the time of diagnosis or as soon as possible after a diagnosis is made. Formal referral comes from physicians and other health-care providers (i.e. allied health professionals), diagnostic and treatment services, and community service providers (ASC, 2014a). This program works to integrate care and education for PLWD and their caregivers with both a community and a primary care focus. While this program provides only incremental
change to large system errors for PLWD, when accessed it can be life changing for their ability to age in place. If left unaddressed or poorly monitored, dementia will lead to premature or unnecessary use of the health care system and has been “identified as the primary cause of long-term care institutionalization among elderly Canadians” (Bronsick et al., 2011, p. 47). (Please refer to chapter four: Demand and Dementia for a more detailed exploration of the characteristics and needs of dementia and chapter five: Supply and Dementia as to options and services meet those needs). This program has since been endorsed in Dr. Sinha's 2012 provincially commissioned Seniors Strategy report Living Longer, Living Well (Sinha, 2012); however, the program remains voluntary for family physicians /primary care teams who also experience multiple competing initiatives seeking their time and attention which can cause barriers to awareness, training, and buy in to the program.

6.3.4 Behavioural Support Ontario Project

As mentioned earlier in this thesis, the media often portrays dementia in a negative light. In particular, the 21st century also brought with it rising attention and increasing concern regarding deaths of PLWD who wandered away from their private or retirement homes as well as a focus on abusive behaviours of a small minority of residents in LTC homes and actual deaths attributed to PLWD. Behavioural challenges that were associated with LTC pushed the envelope as a political issue. In 2010 the provincial government initiated the Behavioural Supports Ontario (BSO) program as a means to enhance services for older people with responsive behaviours linked to cognitive impairments, people at risk of the same, and their caregivers. According to an early BSO project summary:

“A behavioural support system is an integrated network of people, services and supports, across the continuum of care that provides quality care for those with behaviours associated with complex and challenging mental health, dementia or other neurological conditions... The Ontario Behavioural Support Systems Project aims to improve the lives of Ontarians with behaviours associated with complex and challenging mental health, dementia or other neurological conditions living in long-term care homes or in independent living settings.” (ASOa, 2010)

The BSO was originally created with the intention to develop a health care system for people with behaviours (largely PLWD) with both LTC home and community based specialized behavioural support units across Ontario (e.g., prevention and early detection, those in need of
community multiple agency support, high risk individuals in need of LTC specialty services), the implementation of this project saw it largely focus on meeting the growing needs of the LTC home sector (Dudgeon, 2010). Interestingly, the BSO initiative shifted focus at the same time an provincial election neared and promises had been made by the then Minister of Health (Deb Matthews) regarding more staff in LTC homes and training for registered nurses (RNs) to Registered Nurses Association of Ontario (RNAO) and the Provincial Nurses Secretariat (PNS). The BSO project built upon a foundation anchored on quality patient-centred care that is aligned with both Ontario’s Action Plan priorities and its aim of providing “Better Care...Better Health...Better Value” (Behavioural Supports Ontario, 2012). The BSO strategy when combined with earlier made promises to the RNAO and PNS grew from a pilot project of 70 staff to 700. In addition, the launch of four early adopter sites only had two month before the BSO become a provincial initiative (Behaviour Support Ontario, 2012). With the change to 700 staff comprised of personal support workers (PSWs) and RNs, the project was able to draw on two pots of money with the major pot of funding coming from the promise to the LTC home sector. The shift to the LTC funding envelope and a mandate to substantially invest in the LTC sector moved the original intervention away from a more balanced and integrated system approach with equal focus on early interventions to help manage PLWD in the community. While a valuable initiative, the focus again places care of PLWD in institutions with very little in the way of community support services; although those BSO community resources that do exist have received positive evaluations and may be an area for future development.

6.4 Continued Provincial, National and International Calls for Action
On a national level the Alzheimer Society of Canada has warned of a “Rising Tide” of people with and projected to soon experience dementia akin to a “tsunami” set to overwhelm our current system (ASC, 2010). Internationally the World Health Organization and Alzheimer Disease International are calling this increasing prevalence a “Dementia Public Health Crisis” (WHO & ADI, 2012). Despite these warnings Canada still lacks a coherent dementia strategy – although in 2014 there has been talk of a national plan of some sort to be developed. In Ontario, all LHINs show an increase in dementia prevalence; however, as indicated earlier, incidence and prevalence data, growing LTC wait-lists, and the desire for PLWD to age at home
are often irrelevant to whether an issue will be taken seriously enough to drive dementia related policy reform.

From 2007 – 2012, the Ontario Liberal government commissioned a number of reports concerned with the issue of health care sustainability. In 2008 the Medical Advisory Secretariat (MAS) of the MoHLTC produced a report titled *Aging in the Community* which was an evidence-based review of literature that identified four drivers of long-term care admission: falls and fall-related injuries; urinary incontinence; dementia (patient and caregiver-focused interventions); and social isolation (MAS, 2008). In 2010 the provincial Liberal government commissioned Don Drummond to review Ontario’s public services and provide recommendations for future implementation. The Drummond Report (2012) made multiple recommendations to address slow economic growth and rising public costs (including cuts of up to 30% in some ministries). Health care was the largest provincial expenditure therefore a big target (e.g., limit spending increases to 2%; shift people out of institutions quicker, deliver more services in the community)(Drummond, 2012). Drummond’s recommendations for health care largely built on the earlier released 2011 Walker report which focused on issues surrounding ALC bed issues in hospitals across the province and possible solutions. As described earlier in this thesis, these reports warn that the current health care system is unsustainable and that there is need to look at new ways to address the growing number of people using intensive and expensive health care resources (technology, pharmaceuticals, and ALC beds)(Walker, 2011; Drummond, 2012).

In 2012 the province of Ontario stated that it was looking again toward alternatives to a largely Mainstream system by launching *Ontario’s Action Plan for Health Care* as a means to establish a new direction for the province’s health care system, focused on equity, quality, access, value, and choice with a mantra of ensuring Ontarians receive the right care, in the right place, at the right time (Government of Ontario, 2012). The Plan speaks to the development of a *Seniors* 

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40 Note: PLWD often will experience each of these drivers in addition to a diagnosis of dementia making them particularly vulnerable to LTC admission.
**Strategy** to establish sustainable best practices and policies at a provincial level that could in turn support the local delivery of health, social, and community care services with a focus on helping older Ontarians to stay healthy and at home longer, addressing interlinked issues related to the health, social, and community care needs of older Ontarians (e.g., housing, transportation, and social inclusion) (Sinha, 2012; Government of Ontario, 2012); however, this is to be accomplished with no new funding.

These provincial reports, combined with multiple national reports from the Health Council of Canada and the Canadian Institutes for Health Information provide important evidence of the impact of the growing number of seniors living with complex chronic diseases like dementia, the utilization of health care by PLWD (home care services, ALC beds), and the toll caring for PLWD is taking on their caregivers where a caregiver exists, and put dementia back on the table (HCC, 2012; HCC, 2010; CIHI, 2012; CIHI, 2011a,c,d; CIHI, 2010a,b; CIHI, 2009). The 2010 *Rising Tide* report, the 2012 *Dementia: A Public Health Priority* report by the World Health Organization and Alzheimer Disease International, and the 2012 *Living Longer, Living Well* report by Sinha each highlight the need to address care options and navigational needs of the sub-population of PLWD to avoid unnecessary and costly use of health care services (e.g., inappropriate use of hospital beds and premature institutionalization) (ASC, 2010; WHO & ADI, 2012; Sinha, 2012).

While Ontario has lagged in developing a new and integrated dementia care strategy, there have been a series of incremental gains in the past two decades to improve the availability and effectiveness of services across the system – particularly and not surprisingly aligned with the Medicare Mainstream. There have been some tangible:

“...investments through the [provincial] Aging at Home Strategy in specialized geriatric psychiatry outreach teams, hospital Geriatric Emergency Management (GEM) nurses, behavioural support units in LTC homes, Alzheimer day programs with greatly enhanced service capacity. In a parallel process there have been new investments through Primary Care Reform such as Community Health Centres that have a seniors focus and Family Health Teams that engage mental health professionals in shared care have further improved access to health care for older adults.” (Ontario Behavioural Support System Project Team, 2010, p.7)
Less tangibly but importantly, prior to the Alzheimer’s Strategy there was little to no discourse about the real “lived experience” of PLWD and was always about diagnosis and the disease. During this era there has also been the introduction of more “person-centred” approaches to care, and the terminology has become part of the everyday lexicon and the promotion of more involvement by PLWD in decision-making and self-management of care (ASC, 2014b; National Institute for Care of the Elderly, 2006).

In this connection, there has been a growing movement in the 21st century by PLWD and interests that support them to frame dementia in a more empowering manner to avoid stigma associated with the condition (e.g., persons “living” with dementia versus “demented” individuals or persons “suffering” with dementia and capitalizing on remaining strengths versus only deficits). There has also been more recognition of dementia as a “chronic condition” in need of early and effective management much like other chronic conditions (ASC, 2014b).

This is a delicate balancing act as bringing change often requires creating a sense of urgency or pressing need to get on the agenda. This can be seen in recent efforts by the World Health Organization (WHO), Alzheimer’s Disease International (ADI), and the Alzheimer’s Societies of Canada and Ontario (ASC and ASO respectively) have all framed the idea of dementia as a looming “Public Health Crisis” and “An Epidemic” in an effort to convey dementia as an urgent problem in need of positive action or change. Interest or pressure groups such as ADI, ASC and ASO can “use such tactics to get messages out on behalf of their members to influence public policy that promotes their common interests” (Pross, 1992). So, while wanting to open a window of opportunity and get dementia recognized on the policy agenda with urgent messaging, interest groups also advocate for the use of more empowering language. Both of these activities are intended to promote the interests of those experiencing dementia and will be used according to the issue on the table and the actors sitting at the table (e.g., health care providers, bureaucrats, or interest/pressure) that they are trying to influence.

### 6.5 Summary

Guided by neo-institutional theory this chapter presents a historical picture pointing to a series of policies that impact the lives of PLWD wishing to age in place in the community. In doing so,
it highlights that there have been big problems for PLWD to access H&CC stemming as far back as the 1990s due to a patchwork of services and siloed sectors that compete and often do not communicate well with one another.

The CHA has embedded the Medicare Mainstream as a dominant idea of what constitutes health and health care, and as such provides rules that privilege certain types of actors and interests. The State, not being bound to provide home care, keeps deciding to stay on a familiar path and not to go beyond certain limits in order to save money and appease powerful interests beyond a fragmented group of consumers and providers. This thesis research sees a number of the same patterns emerging originally identified in the H&CC legacy of the of the 1980s to early 1990s as researched by Baranek and associates (Baranek et al., 2004). Decades later there remain difficulties in shifting from a fragmented “non-system” of care to a coherent and integrated system. To this point the Walker Report (2011) states that the:

“health care system needs to undergo a broader transformation in order to meet the care needs of an aging population...[For such] system change to occur, many of the institutional and organizational components of our current system will need to re-orient themselves to a priority of caring for seniors in ways not accomplished to date. Without such change, we will experience a wave of frail older Ontarians receiving poor care in the wrong environment amongst those ill equipped to provide it, with resultant disruption of the engines of health care designed for other purposes.” (Walker, 2011, p.3)

Policies that perpetuate continued fragmentation and marginalization of the H&CC sector have a significant impact on the ability of PLWD to age in place and for the province to impose drastic policy reform/retrenchment despite evidence that such services can prevent deterioration and improve health over the long-term (Hollander & Tessaro, 2001). As described in the historical trajectory, even when the government has attempted reform (e.g., Provincial Alzheimer Strategy, Aging at Home Strategy) powerful institutions, interests and ideas have been able to overtake these efforts ensuring that there is no redistribution of finances or priority status from medical and hospital interventions – even when shifts to a more integrated approach to care may help to prevent and reduce issues related to inappropriate use of high cost services like the ER, ALC beds in hospitals, or LTC institutionalization. Compounding the issues of ALC bed use in hospitals, as of 2011 the government has withheld funding of another
“Super Build” of new LTC home beds plus no significant funding increases for community care. The focus thus remains on reacting to complex situations, not preventative functions.

The risk for placement and need for LTC home beds appears to be determined by many factors beyond prevalence rates and need for care including, but not limited to, what is available (options and services for PLWD and caregiver support), cultural appropriateness of services, and affordability of services to name a few. Given that supply determines options for where people go, a lack of adequate, accessible and affordable supports in the community (including supportive housing) and a historical pathway that relies on LTC beds for the care of PLWD the default to LTC placement appears entrenched. While there appears to be continued public interest in improved access to long-term home care, theory leads us to understand that change off of a familiar pathway is difficult and without extraordinary mobilization of political authority and will within the political system to focus more attention and funding on H&CC, change is not likely to occur. Hence, failure to have a targeted, integrated and case managed approach to care for seniors will continue to result in LTC wait-lists (Williams et al, 2010) and premature or inappropriate use of institutional care of PLWD even at relatively low levels of assessed need.
Chapter 7
South West Balance of Care Findings

Historically it has been a complicated road for PLWD to remain safely and cost-effectively in the community despite a strong desire to do so. This chapter further identifies reasons why a system problem – a gap between what people need (demand) and how the system responds to their needs (supply) – exists and how it came to be. Earlier neo-institutional theory was used to look at the historical trajectory and how the problem between demand and supply unfolded. This chapter uses the Balance of Care (BoC) simulation methodology to help qualify and quantify what this problem looks like on the ground in present day. The BoC methodology is a rational starting point to look at what is driving people to LTC placement, and as such, provides an opportunity to look at the costs and consequences of the historical legacy for H&CC, the actual allocation of resources, and give a sense of the present day situation. The BoC is not designed to take people off of the wait-list, but provides a way to look at what vulnerable people look like in a particular region and benchmark to look at where investments can be made (e.g., more LTC beds, more funding for case managers).

Results from the application of the BoC simulation methodology conducted in the South West (SW) region of Ontario shed light on how the health care system responds to the actual needs of people waiting for LTC, with a particular focus on PLWD. Research findings from the literature review and SW BoC research indicate a default to institutional care (placement on a LTC wait-list) continues to be the dominant pathway for PLWD. SW BoC expert panelists were able to craft community care packages (a set of services and programs that would allow a person to remain safe in the community given their degree of need and impairment) for vignettes of PLWD that were safe and appropriate, however were not considered “divertible” off of the LTC placement wait-list when considered from a cost efficiency perspective.

This chapter will discuss why this may have happened and provide observations and insights as to the development of the community care packages by SW BoC expert panelists for the SW BoC vignettes. Specifically it highlights interactions and exchanges between and amongst panelists when asked what services they would give people in the vignettes considering only
safety and appropriateness, not costs. Observations include how panelists decided what care was necessary for each of the vignette sub-groups, and assumptions regarding the construction of care packages. Supportive housing (SH) care packages that were subsequently developed by two SH providers and the rationales behind them are also detailed below.

### 7.1 The South West Local Health Integration Network Region

As described in chapter two: Research Methods, the SW Local Health Integration Network (LHIN) region was chosen as the geographic location of this thesis. This large geographic area has a combination of urban and rural populations, and to a lesser degree, remote pockets/locations. At the time of data collection, the SW LHIN had a higher percentage of seniors, rates of hospitalization, and proportion of people living with chronic health conditions than province-wide averages. Its occupancy rate for LTC beds was also almost at 100%, and the SW Community Care Access Centre (CCAC) was serving nearly one million people (SW CCAC, 2008).

### 7.2 Characteristics of SW CCAC LTC Wait-listed Individuals

The SW CCAC LTC wait-list included 2,876 individuals as of February 24, 2009. All individuals on the wait-list had been administered a RAI-HC assessment (please refer to chapter two for more information on this tool) by a CCAC case manager and had been deemed eligible for a residential LTC placement. Based on stratifications of four key variables: cognition; level of difficulty with activities of daily living (ADLs); level of difficulty with instrumental activities of daily living (IADLs); and presence of an primary (informal/family) caregiver in the home, vignettes were developed based on characteristics of individuals at the 75th percentile within each sub-group. The SW BoC Configuration for all SW CCAC wait-listed individuals (N =2,876) as of February 24, 2009 is presented in the tables below. Each the 14 vignettes provided to the expert panel for review and care package construction are provided in Appendix D. As seen in BoC projects for other regions in Ontario, there was considerable variation in the characteristics and needs of individuals on the wait-list (Kuluski et al., 2012a,b; Williams et al., 2009a; Williams et al., 2010)
Approximately six in ten (64%) were not cognitively intact.

Table 7.1  Cognition

<table>
<thead>
<tr>
<th>Cognition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intact</td>
<td>36%</td>
</tr>
<tr>
<td>Not Intact</td>
<td>64%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>2876</strong></td>
</tr>
</tbody>
</table>

Just under half (43%) experienced little or no difficulty (“none”) with ADL tasks such as eating, personal hygiene, toilet use and locomotion in the home. While not captured in the ADL difficulty score, the majority of individuals indicated up to some limited impairment with bathing.

Table 7.2  Activities of Daily Living

<table>
<thead>
<tr>
<th>Activity of Daily Living Impairment</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Difficulty</td>
<td>43%</td>
</tr>
<tr>
<td>Some Difficulty</td>
<td>30%</td>
</tr>
<tr>
<td>Great Difficulty</td>
<td>27%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>2876</strong></td>
</tr>
</tbody>
</table>

In contrast, more than two thirds (70%) reported “great” difficulty with IADL tasks such as meal preparation, housekeeping, and telephone use and medications management, requiring others to perform these tasks for them.
While 38% of wait-listed individuals had caregivers living with them, a majority (62%) did not.

Table 7.3 Instrumental Activities of Daily Living

<table>
<thead>
<tr>
<th>Instrumental Activity of Daily Living Impairment</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Difficulty</td>
<td>1%</td>
</tr>
<tr>
<td>Some Difficulty</td>
<td>29%</td>
</tr>
<tr>
<td>Great Difficulty</td>
<td>70%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>2876</td>
</tr>
</tbody>
</table>

These patterns are generally consistent with those observed in previous BoC research projects in other regions of Ontario, including urban, rural and remote locations (Kuluski et al., 2012a,b; Williams et al., 2009a,c).

Regarding caregivers – although these data cannot demonstrate a causal connection, expert panel members in these regions pointed to the key role that informal caregivers, both residing with or apart from clients, play in maintaining the well-being and independence of older persons. The SW expert panelists noted that there may be fewer live-in caregivers in the SW region than perhaps in other regions due to an outflow of younger individuals from the region to more urban settings. Where caregivers are absent, or provide less support, the likelihood of a senior’s loss of independence increases. This observation was supported by the literature.
7.3 Distribution by Location of Assessment

The RAI-HC assessments conducted for individuals on the LTC placement wait-list were conducted primarily in the community (61%); however a number of assessments were also conducted in the hospital (9%) suggesting possible ALC status, and others were conducted in LTC homes waiting for a “bed-of-choice”\(^{41}\) (28%) at time of assessment.

<table>
<thead>
<tr>
<th>Low Acuity</th>
<th>High Acuity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1%</td>
<td>5%</td>
</tr>
<tr>
<td>3%</td>
<td>14%</td>
</tr>
<tr>
<td>16%</td>
<td>18%</td>
</tr>
<tr>
<td>0</td>
<td>2%</td>
</tr>
<tr>
<td>*<em>7%</em></td>
<td>*<em>10%</em></td>
</tr>
</tbody>
</table>

Low-acuity (low-needs) BoC sub-groups (those vignettes falling within the first 8 of possible 36 sub-groups) that were assessed in hospitals accounted for 1% of the total LTC wait-list population and 20.6% in general within this low needs stratifications sub-set. High-acuity (high-needs) sub-groups (those vignettes falling within the last eight of 36 possible vignettes and all with dementia) that were assessed in hospitals (indicating they may be waiting in an ALC bed) accounted for 5% of the total wait-list population out of a total 39.5% of the high needs stratifications subset.

\(^{41}\) Some people accept a LTC bed in a location for which may not work well for their circumstances (e.g., out of their own community; far away from family and friends), but may be considered the only option at the time. In this instance they will wait in one LTC home for a bed to become available in another home that feels a better choice.
7.4 Sub-Regions

Wait-listed individuals were also stratified into five SW CCAC sub-regions (please refer to table below). Of the 2,876 wait-listed individuals approximately 44% of the cases were generated by the London Site (urban), 30% by the Stratford Site (rural) and 16% by the Woodstock Site (which is rural yet acts as a hub for other outlying rural communities).

Table 7.6 Wait-listed Individuals by SW LHIN Sub-Regions

<table>
<thead>
<tr>
<th>SW Region</th>
<th>Number of Cases (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>London Site</td>
<td>1251</td>
</tr>
<tr>
<td>Owen Sound Site</td>
<td>223</td>
</tr>
<tr>
<td>Seaforth Site</td>
<td>65</td>
</tr>
<tr>
<td>Stratford Site</td>
<td>875</td>
</tr>
<tr>
<td>Woodstock Site</td>
<td>462</td>
</tr>
<tr>
<td>Total (All SW)</td>
<td>2876</td>
</tr>
</tbody>
</table>

Further stratification by *divertible* sub-group (groups for which the care packages that were developed ended up being both safe and cost efficient for the individuals to live at home in the community or SH) indicates that the first three sub-groups for which vignettes were crafted for (Copper, Davis, and Fanshaw) are generally located in urban centres with the exception that 41% of Coppers are located in the urban location of London region and another 41% in the more rural Stratford region (which is a noted as an Arts community near to London that many retire to). Almost half of the Davis subgroup (46%) is located in the London region with another 29% in the Stratford region. A similar pattern is found with Fanshaw where 34% and 33% were located in London and Stratford respectively (please refer to table below). These are lower acuity sub-groups and this finding seems to indicate lesser need than other sub-groups to be on a LTC wait-list, and therefore less required supports to allow these groups to wait at home.
### Table 7.7 Divertible Sub-Groups by SW LHIN Sub-Regions

<table>
<thead>
<tr>
<th>SW Region</th>
<th>Copper</th>
<th>Davis</th>
<th>Fanshaw</th>
</tr>
</thead>
<tbody>
<tr>
<td>London Site</td>
<td>38</td>
<td>152</td>
<td>39</td>
</tr>
<tr>
<td>Owen Sound Site</td>
<td>0</td>
<td>28</td>
<td>12</td>
</tr>
<tr>
<td>Seaforth Site</td>
<td>2</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Stratford Site</td>
<td>38</td>
<td>97</td>
<td>38</td>
</tr>
<tr>
<td>Woodstock Site</td>
<td>14</td>
<td>52</td>
<td>22</td>
</tr>
<tr>
<td><strong>Total (All SW)</strong></td>
<td><strong>92</strong></td>
<td><strong>331</strong></td>
<td><strong>116</strong></td>
</tr>
</tbody>
</table>

In this study none of those with cognitive impairment were considered a *divertible* sub-group. Possible reasons for this will be explored further in the chapter nine: *Discussion and Conclusions*.

#### 7.5 Observations on Care Package Development

Vignettes as described in the Research Methods chapter were presented to expert panel members who were asked to construct appropriate H&CC care packages considering only safety and appropriateness, not costs. Care packages were designed as generic and not individualized packages and looked at the potential for what could be done for persons in that current situation not wanting to over-serve or under-serve clients within the context of what types of services would be necessary to help vulnerable seniors at risk of LTC placement safely in the community. Additional details from the RAI-HC were provided to expert panel members on request. Typical requests concerned health issues, possible behaviours such as wandering or verbal and physical aggression, and the ability of caregivers to cope and maintain support to the individuals in the vignettes. Each of the 14 vignettes presented to the expert panel and subsequently to SH providers can be found in Appendices D and E.

In order to create a package that was considered both appropriate and safe for each of the vignettes, expert panelists identified a number of important considerations and challenges that
would need to be overcome within the large and diverse SW LHIN region. The following considerations were built into their creation of H&CC care packages based on the fact that many of these practices occurred in some areas of the region and not others, or should be occurring yet were not at the time of care package development:

### 7.5.1 Proactive and Integrated Approaches to Care

The construction of the community care packages to safely address the care needs for wait-listed individuals in the SW region was guided by a proactive and integrated approach to care. While not looking to create an entirely new system, the notion of “Disney” thinking came into play where they were able to craft care packages that they felt would allow the clients in the vignettes to remain safely in the community, yet not be restricted by local constraints with wait-lists, human resource issues, volunteer shortages, or costs. If there was a program working in one region of the SW LHIN it was considered feasible in other area.

Care packages were constructed with start-up and preventative maintenance functions and hospital avoidance in mind. Special consideration was also given to the needs of informal caregivers residing in the home or out of the home (e.g., offering respite care to both caregivers living in the home and out of the home of the client). The rationale provided was to have clients (and the caregivers where relevant), well cared for at the front-end of their condition and maintain them at their current level. They also felt given positive experience with programs like “Wait at Home” offered by the CCAC, such proactive care packages might even be supportive enough to elevate sub-groups to a less intensive care level (e.g., move from an acuity level of Eggerton (5th sub-group) to a Copper (3rd sub-group) or Fanshaw (6th sub-group) to a Davis (4th sub-group). Care packages were also created to address possible “worst case

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42 CCAC Wait at Home programs are available to patients currently in hospital, but who have health care needs that could be met in a long-term care home. Wait at Home programs are designed to meet health care needs at home and in the community for a period of time that will allow individuals to make decisions about their care. There is no age limit but one does need a valid Ontario Health Card (OHIP) and a family physician (Mississauga & Halton CCAC, ND).
These factors combined lead to what panelists recognized as very “rich” care packages with high resource intensity. Given the aim of this simulation exercise was to provide a lower bound estimate for the proportion of potentially divertible patients, this richness ultimately impacted upon overall diversion rates.

7.5.2 Choice of Services Regardless of Location

During the construction of H&CC care packages, panelists noted that the line-by-line approach to services and programs was very provider focused, and that while it may not always happen in real practice, ideally clients would benefit from more individualized choice with services that they themselves feel would meet their needs for safety and independence (e.g., increased Personal Support Worker time if suitable Adult Day Program Services were not available; integrated Adult Day Programs for persons with early stage dementia and specialized day programs when clients would benefit from a more targeted setting). Panelists suggested the notion of a “deck of services” from which wait-listed individuals could pick from to better tailor/individualize necessary care services to remain safely and cost effectively in the community. While panelists noted it was unrealistic to expect all services to be available in rural and remote areas, care packages were still constructed based on services that did exist somewhere in SW LHIN and on what they felt was necessary to ensure the client could remain safely in the community.

7.5.3 Acceptance of Services, Rapport Building, and Consistency of Care Workers

The care packages were constructed under the assumption that if clients would accept the recommended care packages, they should be able to remain safely in the community. Panelists emphasized however while many programs can have extremely beneficial outcomes for clients, seniors can find them invasive and oppose the introduction of any (new) services. Ideally panelists would like to have been able to craft more flexible care packages that would allow time to build rapport/relationships with clients and introduce the services slowly at the pace of each individual client however they felt it important to have all the services in the home to make that person as safe as possible from that point forward. In line with the literature,
panelists also noted that consistency of care workers was seen to be a crucial element towards the acceptance and continuation of care services and thus highly recommended — especially for those with cognitive impairment; however as also noted in the literature, given issues with human resources in the community (high staff turnover due to the part-time nature of the work and issues with travel like who is closest to the client the time they need care) and the fact that not all providers could provide the range of care necessary leading to multiple staff entering the home, this was not always possible in current practice.

7.5.4 User fees/Co-payments

Care package construction assumes that co-payments and fees for community care services will not be a barrier; however, in reality panelists felt that they would likely create potential obstacles to appropriate service use and service coordination. For example, individuals on low, fixed incomes might delay or avoid accessing needed services on the grounds they could not afford them. Others, who could afford to pay fees, may nevertheless put off getting services because they feel they are unnecessary “frills.” Panelists noted that too-often the result is that older persons do not access services until it is too late. To address this they suggested that in real life the SW LHIN might consider providing some free trial H&CC services to introduce clients to the possible benefits of them feeling that it would be a productive way to encourage client safety and uptake of ordinarily non-funded community services. While the affordability of these BoC packages take into consideration the costs to government funded services, co-payments by the persons expected to receive them are not included. Where it may be affordable to deliver some programs like hot or frozen meals through Meals on Wheels, the cost of the actual meals to the clients can be prohibitive in some cases.

7.5.5 Transportation

Panelists highlighted transportation as a key component to H&CC care packages. Many services in the community rely on the availability of volunteer drivers as well as the ability to get around (e.g., weather may be an issue for winter driving in many areas of the SW LHIN). Co-payments for such transportation programs may also have an impact on the potential uptake of recommended care packages.
7.5.6 Adult Day Programs as Hubs of Service

Panelists highlighted a number of different configurations that could be utilized to address the needs of wait-listed individuals. In particular, Adult Day Programs (ADP’s) were incorporated into many of the care packages as a way to concentrate some mix of providers and services at a single location or hub of services. In doing so, it was thought this would improve monitoring, care coordination, and even cost-effectiveness and outcomes. The panel also noted a recent shift towards ADP’s in the SW region now offering on-site bathing/showering for clients. While not offered or accessible across the whole SW LHIN, this option was included in many of the SW H&CC care packages regardless of where the client lived with the assumption that if it did exist it would be integral to keeping the person safely at home in the community.

Care packages were constructed understanding that the abilities of older persons to exit the house to perform everyday tasks such as shopping and banking, to visit the doctor, to attend day programs or possibly attend church are often inhibited by lack of transportation (either unable to drive or access rides). Where frailty and difficulty with ambulation becomes an issue, it was recommended that “accessible” transportation was essential to addressing these physical needs (e.g., para-transit; ramps for wheelchairs or walkers). Although this service was highly valued, the panel acknowledged that in rural and more remote areas, transportation is often problematic, with relatively few providers that can be called on to cover large areas.

Care packages were crafted with the assumption that clients can get around with current transportation programs, but also that support workers and volunteers can also get around and visit their clients. Seasonal issues with travel were not factored into care package development (e.g., winter can prove to be problematic for travel to ADP or services to people’s homes); however, rural areas can be more difficult to access in general – especially during or after a storm.

Panelists also indicated that in rural and remote areas, much time of formal caregivers is spent on the road versus hands on care. This had them favour cluster care and SH types of models for clients living in these regions to limit the amount of travel necessary by care providers, increase consistency of staffing by having reducing the number of providers in caregiving relationships,
and save on costs by having one care provider do more per visit or more local visits at the time. **While the BoC approach taken for SW was to address the region as a whole, it is suspected that there would be different results if panelists were to have constructed care-packages by region (e.g., rural care packages).**

### 7.5.7 Volunteerism

The topic of volunteerism was noted as experiencing many of the current issues faced in the recruitment and retention of health human resources (HHR), and becoming more difficult to recruit and train enough volunteers to support the many volunteer based community support services (e.g., Meals on Wheels, transportation, friendly visiting). Rural and remote areas are even more likely to experience these challenges and/or shortages with the added difficulty associated with geography and volunteer base. Despite these known challenges, care packages incorporated the use of volunteer services where appropriate (e.g., Meals on Wheels, Friendly Visiting). Despite current realities that some areas may not have extensive volunteer programs panelists compensated by dropping off frozen meals instead of hot meals delivery. This was a tradeoff between monitoring the client and limiting the number of people that PLWD had to deal with (or who were available to visit). **As such, there may be further costs that have to be incurred and leading to potential underestimates of cost for those regions that currently do not have an adequate supply of volunteers.**

### 7.5.8 Role of Informal Caregivers in Unit of Care and Caregiver Support

Expert panelists repeatedly emphasized the crucial contribution of informal caregivers who either reside in the home with the client or provide assistance while residing outside of the client’s home, and the need to support that role. They argued that in home and community, the unit of care needs to include family members and friends who provide the bulk of care for older persons and who often themselves require care. Where current rules and restrictions for most panelists inhibited considering the client and caregiver as one unit, they felt that in the development of the care packages doing such would allow the client to remain safely in the community longer and that it was crucial to do so.
As such, care packages were developed to formally address caregiver stress and burnout with such services as in-home respite care, the use of Adult Day Programs and caregiver support groups. When the cognitive abilities were noted as not intact, expert panelists targeted services by suggesting dementia friendly/specific supports (e.g., Adult Day Programs for Dementia, Friendly Visiting by Dementia Trained Volunteers) as close to the point of diagnosis as possible, and by tying both the client and the caregiver into programs provided though the Alzheimer Society such as support groups, the MedicAlert® Safely Home® Program formally known as the Alzheimer Society Wandering Registry (ASC, 2015), and First Link®.

Panelists also noted the influence of changing family dynamics in the SW LHIN as being a factor that can place additional stress on informal caregivers (e.g., rural and remote areas facing challenge where immediate and extended families have members who have moved to urban centres; sandwich generation issues; separation/divorce). In this connection panelists proposed that a soon-to-be-launched program in the SW region called “Share The Care™” would be an appropriate intervention to consider for each of the SW BoC Vignette Care Packages when implemented. Had this volunteer based program been active, it is possible an impact on the final costings and potential diversion rates could have been experienced.

7.5.9 Supportive Housing, Assisted Living, Clustered Care

Expert panelists generally perceived SH and other forms of Assisted Living (AL) or Clustered Care (CC) to be safe and cost-effective options for many of the vignette sub-groups, especially PLWD. Definitions and key assumptions around these care approaches varied amongst panelists, however there was overall agreement that wait-listed seniors could benefit from the

43 First Link® is a program that supports the education and emotional needs of the person with dementia (PLWD) and their caregivers throughout the dementia continuum (ASC, 2014a).

44 The Share The Care™ is a program model aimed at creating and sustaining caregiver groups for individuals who are in need of short-term rehabilitation, suffering from long-term or terminal illness, or just facing the increased difficulties associated with aging.
type of care coordination and the pooling of resources offered by SH, AL buildings, and/or CC models. Although not obligatory, during community care package development the panel indicated vignette sub-groups that they felt would especially benefit from these models of care and that these models were especially appropriate for individuals and caregivers experiencing multiple complex needs requiring multiple services, as well as ongoing coordination and monitoring. They felt SH models would work particularly well for these types of clients and their caregivers due to the 24/7 staffing, access to monitoring and assistance, and the flexibility for more frequent visits of short-term duration basis instead of traditional one hour blocks of time used in community settings. For example, if the main reason for the visit is some simple housekeeping or medication monitoring, a SH model could decrease the number of providers/people making visits in a day. As noted earlier, consistency is especially important for PLWD because as a dementia progresses if a routine has not already been established with regular faces, there is an increased likelihood of rejecting visits.

While SH was considered ideal for many of these clients, panelists also felt the need to move from a home setting into a SH setting could be damaging for people with cognitive impairment as they would need to get familiar with a new environment, and that there would be reluctance by family members to move when a live-in caregiver was present; however when compared to the possible move to institutional LTC, placement was even less desirable.

The expert panel also felt SH, AL and CC models would be particularly responsive to those individuals living in rural and remote areas where accessing services becomes more difficult or less feasible (e.g., reliance on transportation, Meals on Wheels, congregate dining). Additional benefits cited by the panel included, but were not limited to:
• Allowing individuals to remain in familiar communities and not have to relocate to receive services that maintain/improve their ability to remain independent\textsuperscript{45}

• These approaches were thought to require less dedicated staff time for coordination because care staff become familiar with their buildings, their clients and are able to keep an eye out for other residents who may potentially need services. Housing models also allow staff work in close proximity minimizing transportation time, as well as allowing for greater ease in communicating client needs with one another and/or to schedule care on a flexible basis.

• A key assumption shared by panelists around these approaches was a focus on preventative and restorative care which was thought to provide more fitting alternatives to costly/inappropriate care services (e.g., regular onsite monitoring to help circumvent crisis; help with laundry to avoid injury or falls; use of internal emergency response systems instead of defaulting to 911).

• The ability for housing models to monitor changing client needs on a regular basis was also thought to have a positive effect on not only the client, but also the informal caregiver. For example, it was thought that this model of care provision, with its ability for staff to more readily and frequently check in/monitor clients may free up time for informal caregivers weather residing inside or outside of the client home, who would otherwise have to take on this role. It was thought that this flexibility would promote independence for clients and greater peace of mind/relief for the caregiver. It was also noted that while less scheduled caregiver relief may be required in such models, additional Personal Support Worker (PSW) or Attendant Care (AC) services may be needed for everyday activities such as laundry and meal preparation.

\textsuperscript{45}Income (as well as health and social needs) often plays a major role in determining whether or not older persons can age at home or move to a retirement home. The expert panel noted that affordable options to age in place were lacking – especially in rural farming communities.
7.6 Results of Community Care Package Composition

The SW BoC expert panel crafted community care packages for 13 of the 14 vignette sub-groups. An attempt at creating a package for the last sub-group, J. Johns, was made; however, even with a full-time paid caregiver they concluded it would be unsafe for individuals with such high needs (high ADL and IADL needs, cognitive impairment and no informal caregiver living in the home) to remain safely in the community. Accordingly, no cost estimates were generated for the J. Johns sub-group.

7.6.1 Standard Recommendations for Each Vignette

The following tables outline a number of standard recommendations the SW BoC Expert Panel applied to all community care packages and dementia-specific recommendations for those with cognitive impairment.
Table 7.8 Standard Recommendations for Copper to I. Innis Vignettes

- The use of **Blister Packs** (pre-loaded by their local pharmacy) to assist with each sub-groups medication compliance and monitoring
- Enrollment in a **Falls Prevention/Strengthening Program**\(^{46}\) either in a group or in-house to help with maintenance and health prevention (falls are a trigger for placement in a LTC home and increased mortality).
- In-home safety assessments by an **Occupational Therapist** (OT) as a preventative measure to help with safety and ambulation with the intention that the front end costs and reductions in falls related injury and mortality would go a long way to ensure safety in the community and potentially reduce costs in the longer run.\(^{47}\)
- The installation of an **Emergency Home Monitoring System with a built in smoke alarm**.
- **Respite care for caregivers**, both living in the home with the client or those living outside of the home and providing assistance. The panel also recommended that respite hours could be “banked” for later use – as such, all possible respite hours were costed out regardless if the caregiver may or may not have been able to use them.
- Referrals to a **home renovation program** such as the Residential Assistance Program or one offered by the March of Dimes ins cases where the client’s physical limitations left them largely dependent dependent with their mobility (e.g., accessible ramps and other design issues in and around the home to make it safe.
- Possible referral to **SH or CC** to to ensure regular monitoring and assistance were offered and at different points in the day.\(^{48}\)

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\(^{46}\) An example of such an initiative include that they cited is the “SMART” program (a best practice model for PSW or volunteer-led in-home exercise visits).

\(^{47}\) Expert panelists indicated that this is a different approach than current practice due to financial and eligibility restrictions, long wait-lists for this OT service, and/ or reluctance or financial difficulty by these clients to accept such services.

\(^{48}\) Expert panelists noted that there is currently great difficulty with the logistics of timing of a PSW visits in the community (e.g., minimum one hour blocks of time for visits and few visits per week, let alone per day).
Table 7.9  Additional Recommendations for Upperton to I. Innis Vignettes

- The introduction of the Alzheimer Society First Link® program to ensure initial contact is made with the Alzheimer Society for clients and caregivers to access various supports and services (e.g., education, support groups, the wandering registry) and that the PLWD does not fall through the cracks in the system.
- An initial and follow-up visit from the Regional Geriatric Assessment Team to monitor PLWD’s impairment and ability to manage and cope in the community.
- The Adult Day Program (ADP) for those identified as not cognitively intact would be a dementia-specific ADP to ensure staff are knowledgeable about the needs of PLWD.

7.6.2  Key Themes in Community Care Package Construction

The following sections describe key themes for resource allocation and the logic behind care package construction by expert panelists with a primary focus on care packages for those with cognitive impairment.

7.6.2.1  Under-representation of Dementia

Vignette sub-groups with cognitive impairment began with “Upperton.” When the panel read that the first sub-group “Uppertons” accounted for 2.6% of the LTC wait-list they stated that “there’s definitely more than that.” Their experience with this type of client aligns with the research indicating there are many people living in the community with Mild Cognitive Impairment (MCI) or early stage dementia that are performing just well enough on the Cognitive Performance Scale of the RAI to avoid being considered not-intact (please refer to chapter four for more information on MCI).

49 Expert panelists noted the current wait for such an assessment could take up to four months, and may be earlier if the client was deemed urgent.
7.6.2.2 Poor Mobility and the Cognitively Intact

The expert panel expressed great concern for those that were cognitively intact yet had mobility issues where there was potential that people in these sub-groups might not be able to get out of the home if there was an emergency or a need for monitoring (e.g., nutrition, bowel routines). In such cases where there were mobility restrictions and no live-in caregiver, they suggested a high number of days at an Adult Day Program (ADP). At an ADP individuals in these sub-groups can access a variety of services in one location (e.g., nursing offered at ADP’s can have bowel routines taken care of and monitor retention of urine or issues with incontinence; social workers on staff can help with financial counselling and social support while the person adjusts to declining functioning). People in the sub-groups however may not want to be shuffling back and forth many or any days of the week. This is a good example of where there may be a gap between what care recipients and their families feel is important to their own health and well-being and what service providers think is necessary for the these individuals to remain safely in the community. The care providers may privilege safety but care recipients may in addition to safety value their time at home.

7.6.2.3 Poor Mobility and the Cognitively Impaired

Contrary to the concerns about poor locomotion for cognitively intact sub-groups, lack of mobility for PLWD was considered a potentially good condition by panelists as there was less of a chance that the individuals would experience wandering and other “unsafe” behaviours in the community. There was much discussion by panelists the topic of how to manage able bodied PLWD. One panelist stated “this is the kind of client that keeps you up at night.” Another felt that PLWD that “consistently make poor decisions, and are independent with locomotion would not do well in the community or assisted living because he/she could get into a lot of trouble in-between visits and we can’t be in that apartment 24/7.”

There was discussion about possible modifications to the home that can help to mitigate risk (e.g., controls for the stove, audible door alarm to discourage exiting, other safety aides that can be applied when supervision not possible). Another panelist stated “We have to remember their right to live at risk. Just because there is short term memory loss doesn’t mean they are
confused and are not capable in some aspects and not others.” Another panelist stated “We have no idea what these decisions are. With dementia if he has some good established habits, then could likely remain in the home longer.” Although these were points the panel agreed with, they opted to be cautious with sub-groups that indicated decisions were consistently poor and that they would not be capable or have the insight to understand consequences of their choices. Panelists felt these sub-groups would not able to live independently without an intensive resource package with ongoing monitoring.

Further discussion followed that if this individual were to be placed in a LTC home, they would be shocked at how far along others are in the unit when they still have many remaining capabilities, and that a LTC bed would be a poor fit for them. Another panelist pointed out that “LTC homes do not want this type of person ... because they pose a greater risk to other clients when they are still ambulatory and can ‘get at other patients.’ If a PLWD is not mobile any more a LTC home will take them faster.”

7.6.2.4 Adult Day Programs (ADPs) as Hubs of Service

ADPs were considered important for the cognitively intact and the impaired for similar reasons of monitoring overall needs and to offer caregivers respite, especially where a caregiver was in the home and/or needed time to go to work.

Expert panelist stated that there is a general fear associated with clients that have acquired brain injuries (ABI) or dementia attending an ADP as this can potentially increase incidents and displays of aggression. For this reason panelists felt that PLWD would need to attend dementia-specific ADPs or that the ADPs in their area would need increased staffing and specialized training. They stated that “behaviours are a huge component in deciding where the person is going as they can be unpredictable” and that they are “one of the biggest stumbling blocks for getting PLWD into any community programs or even into a LTC home.”

Many of the sub-groups with cognitive impairment were assessed as having few to no “worrisome” behaviours and few caregivers reporting stress with their caregiving role (e.g., 97% of Xaviers displayed no aggressive verbal behaviours, 93% had no wandering behaviours,
and 99.6% had not displayed any physically abusive behaviours and 93% of the primary caregivers of Xavier indicated that they were coping and able to continue to care for this person). Panelists noted however that theoretical behaviours are important barriers to acceptance or continuance in an ADP and felt that while Xaviers may not have behaviours at present, they would likely develop them. The CCAC panelists also clarified that the RAI coding does not pick up the true frequency of behaviours because it is only based on the last three days. Despite a seeming low intensity of need, as part of their preventative focus the panel continued to create high intensity resource packages to keep PLWD safely in their homes. In some cases they relied on six or seven days at an ADP imagining “that it would be meeting most of the persons and their caregiver’s monitoring and respite need.”

This finding demonstrates that service providers are recognizing that for this PLWD, health status is an evolving issue and the services have to anticipate the potential for fluctuations in the capability of clients. The uncertainty associated with the level of care need for subgroups with cognitive impairment means that the costs for them may be higher as a consequence.

7.6.2.5 Care Packages Utilized to Avoid LTC Home Placement

During the development of care packages panelists noted that the high use of ADPs (e.g. five-seven days per week) basically replaced one type of institutional care with another (like a hybrid or lower intensity version). They felt this was the best solution because ADPs were thought to give more hands on direct care and socialization, and also allowed for the person to go to their own home at night – the value of which they felt could not be overstated. Utilizing ADPs extensively therefore was thought preferable to LTC home placement in situations where the PLWD displayed few behaviours, wished to remain at home, and where the caregiver wishes to continue caring at home for as long as possible.

Panelists further noted that PLWD would not receive any better supervision in a LTC home and that offering a strong care package would be in the clients’ best interest. They considered the threshold for placement in a LTC home more about when PLWD become problematic for caregiver stress and become a problem for neighbours and others in their building/community.
A number of panelists brought up the example of the CCAC “Wait at Home Program” designed to get people out of acute care beds and described as a 3 month period where clients are placed on a LTC wait-list, yet are discharged home with increased services (up to 8 hours a day) to help sustain them until placement. Before being discharged from the hospital individuals have to apply to 3 LTC facilities. If they have not been placed by about the 2 month mark, then the CCAC has to revisit the LTC home discussion. If they are coming out of hospital and then get to the stage that it’s working so well then many CCAC managers will take them down from the heightened Wait at Home level to their regular maximum levels. Panelists commented that they have clients that do really well after having had intensive services for 3 months the lower level is adequate. Once on the program clients will often improve enough that they will not go to a LTC home because they are doing better. A suggestion was made that this is the type of program that could benefit clients like Xavier and those before him/her, so that they can live in the community for a longer time – much like the time and resources they are dedicating in PLWD care packages.

7.6.2.6 Behaviours in the Home

While sub-groups with cognitive impairment largely indicated that that there were few to no verbal, physical, or wandering behaviours reported in the prior three days of the RAI assessments, care packages were crafted under the assumption of risk mitigation for possible behaviours and caregiver burnout. Panelists noted the unpredictable nature of dementia and “just because someone is fine today does not mean they will be free of behaviour tomorrow.” Sub-groups if addressed based on their current state may potentially have been crafted a less resource intense care package that would make them divertable off of the wait-list; however, as noted in the literature and here in practice, there is a commonly held belief that a safe community care package would assume and plan for the worst possible case scenario.

To help avoid and better address potential behaviours in the home the panel suggested that care packages offer consistent PSWs and other professional staff in the provision of care or respite as a means to avoid unwanted responsive behaviours (because PLWD do better with a
consistent care team). There was no way to ensure this could or would happen in care package development.

In discussions with SH providers, the vignette sub-group Upperton was considered too low needs to even bring on such individuals on to their program and no SH package was created for them. When SH providers crafted their packages they stopped at D. Davis because they would not take the person into their program due to the possibility of risk to themselves and others (e.g., leaving stove on, forgetting to turn taps off, unattended/smoldering cigarettes if a smoker).

7.6.2.7 Dignity of Risk

An interesting distinction occurred between groups with high-intensity physical care needs and those with cognitive care needs regarding how to balance what panelists referred to as the “Dignity of Risk.” The ability to balance a persons’ desire to age-in-place despite the risk of potentially being trapped in their home with what the panelists considered necessary to remain safe in the community was a great topic of discussion for those with only physical impairments. One panelist noted during care package development that the panel’s responsibility in the BoC exercise was “not about looking at what the client wants – but their best suggestions about what they would need to live safely and independently in the community.”

Interestingly, in the case of sub-groups with cognitive impairment, “Dignity of Risk” was only mentioned in passing and not discussed in near the same fashion. Panelists acknowledged that care packages developed for PLWD were crafted with more resources than were likely needed; however, they felt these resources were important for client and caregiver safety in the community, would help to establish routines and ensure that PLWD were being monitored and receiving the recommended care services (e.g., bath assistance).

An example was provided by one panelist who stated they “had a client like Xavier who developed a bad case of the flu and went into hospital. The hospital would not discharge the person home because it was considered unsafe and instead he went into a LTC home.” Further discussion about hospitals and PLWD resulted. Another panelist stated “Xavier is the
type of person who ends up at the hospital because there are not the community supports in
the home like the type that we are recommending. They are very difficult to get out of the
hospital because considered to be a safety issue if person goes back home.” She went on to
explain “hospitals have difficulty understanding what types of supports are out in the
community. This is the largest group after Davis [in the stratifications] and the type of person
that backs up the hospital ED, and an area that really needs addressing in terms of education
and training.” To this point it is not surprising that hospital based staff do not always know
what community supports are available because there is so much variation by region and even
over time.

7.6.2.8 Caregiver Presence, Stress, and Relief

Caregivers, whether living in the home or not, were considered key to maintaining PLWD in the
community however they could not be expected to be monitoring the client 24/7. One panelist
noted that for those with or without caregivers “it’s the time that this person is alone that we
are particularly worried about.”

Caregivers of PLWD largely indicated that they felt they could continue their caregiving role and
also largely reported little to no distress, anger, or depression; however, there were a minority
who indicated otherwise. Panelists felt that there may be a number of factors contributing to
the low reporting of stress (e.g., stoic personalities, generational perceptions of for better or for
worse). Panelists believed it to be important to keep as many caregiver supports in as possible
to help all caregivers (live-in or otherwise) manage their supportive roles regardless if they
reported (dis)stress. This included the provision of caregiver respite hours that could be banked
(even when some sub-groups like C. Cameron would be out of the house 6 – 8 hours of most
days). It was felt that the person could use that time if they needed to get help or away for the
evening or weekends when they are responsible for care.

Panelists also felt it important that caregivers would be offered a choice of evenings and
extended overnight ADPs in case the caregiver might not be sleeping because of having to
monitor and redirect the PLWD. While extended and overnight ADPs were not a widely
available option in the SW LHIN, because such a program did exist in London, it was considered a viable option for other communities to adopt and include in care packages.

7.6.2.9 Case Management Essential for Dementia

When the expert panelists began constructing care packages for sub-groups with cognitive impairment they noted that the care needs of clients with dementia can be some of the hardest cases to address in the community for a host of reasons detailed in future sections. Panelists stated that case management would be key in handling vignettes with dementia because, although they can suggest all sorts of care services that might be of benefit to PLWD and their caregivers, in their experience the person will likely resist or not accept them. This is another reason they felt that caregiver support would be important. Caregivers, especially those living with the PLWD, have to live with the consequences of doing something the PLWD doesn’t want or think they need. Sometimes it is harder on the caregiver to force services on to PLWD than not have any provided at all. Panelists felt that something as simple as housekeeping can be really helpful to caregiver to take off some of the burden of care, without having to actually care for the PLWD.

7.6.2.10 Flexibility Essential for Dementia

The high resource intensity of each care package for those with cognitive impairment had panelists expressing doubt that PLWD or their informal caregivers would accept all of the services that were included in care packages. By the same token, some people, caregivers included, may not feel that they can manage with the recommended amount of care and would for example need more service to enable them to care for their loved one successfully in the community. So it may be true that the recommended packages would be acceptable to patients and their informal care providers.

For example, when crafting care packages for two low-needs groups with cognitive impairment – Upperton and Vega – panelists stated while they recommend an ADP five days of the week, there is no guarantee the PLWD will accept or attend it. They suggested five days but conceded in all likelihood the PLWD may not go each of the days (e.g., there may be a struggle to get them to get up and to go to such a program in the morning). They also stated they might run
into the opposite problem that if they only planned for one or three days a week at an ADP, that the PLWD may think they actually need to go and get more confused than if it was just kept at five days per week. In general they felt that for PLWD you **need a greater degree of flexibility that is not currently built in to the system**. Currently if you book a day but do not attend, the person or their caregiver will still have to pay which will inhibit uptake, and that spot goes wasted for someone else who may benefit from the program. While panelists thought it might be good to start most people with one day a week and build up to 5 days a week, they strongly felt that for safety reasons that it would take more days a week in each person’s present physical and mental state to keep them living in the community as safely and for as long as possible.

### 7.6.2.11 Diversity

The Wong vignette sub-group prompted discussions by the panel about diversity concerns and the lack of diverse ethno-cultural-linguistic offerings in the SW LHIN. They noted that while this may not be a problem for the majority of clients, for those instances where a cultural or language issue arises there can be complications for matching clients with appropriate services to meet their needs. They did note however that the nature of a changing workforce has also seen more PSWs in the community who are visible minorities. This can be an issue for some PLWD who do not have good judgment or understanding of differences and formal caregivers can encounter discrimination or may be the underlying reason for some clients to not accept service due to prejudice.

They noted in their experience that certain cultural/religious groups (e.g. the large Mennonite population in the SW region) were less likely to seek or accept assistance yet more likely to keep family members at home for longer than others caring for PLWD. Groups such as these have been known to utilize options that may not be as well known about such as parish nursing services from churches or the notion of “fostering” someone’s spouse/parent for the day to help out.
7.6.2.12 Debating the Need for LTC Placement

The last three sub-groups with cognitive impairment comprised approximately 30% of the wait-listed individuals being addressed in the simulation exercise. When the expert panel began to craft a care package for D. Daniels, they felt this client was much like Xavier, but given their increasing difficulty with locomotion (which they noted may just have bad day with their arthritis or something worse), that D. Daniels’ were starting to look like they should be cared for in a LTC home. Some panelists indicated that clients like this at the cusp of LTC placement are often the ones that the caregivers want them to try and make it work just a little longer. The fact that the vignette noted this sub-group was still highly involved in their daily activities and behaviours were not an issue made the panel consider them good candidates for an ADP. As there is no live-in caregiver for this sub-group, there was much discussion about how much time this individual should be spending at an ADP. Panelists went back and forth on thinking if they offered three days per week than the ADP would see the person every other day for monitoring. However for safety they felt that seven days per week would be best. Many panelists still felt uneasy that this might be too much for this person to handle, but the fact that they would have a hot meal every day, ongoing monitoring, and personal hygiene/shower the seven days per week option was decided upon.

The sub-group D. Daniels was the first not-intact vignette where the friendly-visiting program was no longer offered in the care package. This was due to not having a day for a visit given the use of an ADP seven days per week.

The next sub-group I. Innis indicated that they were no longer mobile and became the first sub-group for which the MedicAlert® Safely Home® Program (formerly known as the Safely Home® Alzheimer wandering registry at that time) was not added to care package. At this sub-group ADLs were entering into consideration such that this individual required significant support both physically and cognitively (e.g., assistance required for tasks related to eating; losing ability to make themselves understood). Despite the physical and cognitive issues, 90% indicated no behaviours three days prior to their RAI assessment and therefore panelists felt that I. Innis was still a candidate for and ADP seven days per week.
The last sub-group, J. Johns prompted great discussion about how one might support these individuals safely in the community. Ultimately the panel decided the physical and cognitive needs combined made this sub-group unsafe to remain in the community so no care package was constructed.

### 7.6.2.13 Gratitude for Opportunity to Contribute to Better Care Planning

At the end of the BoC Expert Panel planning session all panelists expressed gratitude for an opportunity to come together and discuss the many issues that affect them and their abilities to help their clients to age at home. Many commented on the learning that they had experienced themselves by being in the room with others who highlighted new programs, services and ways of thinking to address their client’s needs.

Panelists also commented on the difficulty they had “taking off their institutional hats” during the simulation exercise and the freedom to think in terms of an integrated systems perspective. Having done so many were pleased with the set of principles or themes they collectively thought were important to share. One panelist cited feeling “a responsibility to go back to my employer and say this is what we were talking about and these are the things I learned,” and “These principles will be taken back and discussed with my colleagues.” Most panelists indicated feeling similar and were eager to hear the results of the session. A follow-up meeting with participants was scheduled by the SW LHIN and SW CCAC with expert panelists in August of the same year to share preliminary findings and affirmation of findings prior to releasing a preliminary findings report to the SW LHIN in September 2009.

Many expert panelists also expressed their thanks to that the SW LHIN for their active involvement with this research and for the LHIN’s participation at the table to participate and learn from the care package discussions. This was the first BoC research project to have a LHIN member participate in a BoC expert panel.

### 7.6.3 Supportive Housing Care Package Key Observations

Key observations as they pertain to resource allocation and the logic behind care package construction by SH providers are shared below.
For cognitively intact sub-groups SH providers were able to craft a package for all but Copper stating that Coppers would not qualify for their programs. They did mention they would have the ability to informally monitor them and their caregivers in case the need did arise for SH involvement. For sub-groups with cognitive impairment, both SH providers felt that admitting the low-needs sub-groups like Upperton or even Vega onto their program would not happen, especially Upperton as that sub-group have a live in caregiver. The sub-group, Vega, while considered low-needs (more of an “entry level” client in need of monitoring and grooming assistance) was crafted a care package based on the fact that an expert panel had done so and that if experts felt the need to provide proactive care to this sub-group they would too. SH providers modified care packages developed by the SW BoC Expert Panel and offered substitutions from their own or other community services where they felt appropriate.
General Examples of SH substitutions are outlined in the table below.

**Table 7.10 Supportive Housing Substitutions**

- One SH provider was able to substitute for the OT preventative safety review visits because they offered their program in an accessible building with accessible apartments (e.g., grab bars in bathrooms).
- One provider recommended connecting the Lambert sub-group into on-site resident programs in their building (cards, pool, social/spiritual time, gardening, and/or poetry/devotions) thus substituting for the Adult Day Centre in the community care package.
- Both SH providers removed CCAC case management for the lower needs sub-groups as they provided on-site coordination of services for their clients which is built into the unit cost of their program, however did keep CCAC case management in for the Rogers sub-group due to the complexity of care and multiple professional services entering into his/her home.
- Nursing was not offered in many vignettes due to the ability of the program to monitor such issues as medication compliance, incontinence and bowel issues, and skin integrity.

When the SH providers got to the Xavier sub-group they both felt that this individual would not be suitable as new client to their programs, but had Xavier been a client with them prior to his advancing needs, they would aim to maintain them as long as possible. In deciding who can be in the SH programs, providers indicated it was based on possible safety issues (e.g., leaving taps
running, problems or tampering with medications, cooking safety with a stove, wandering without clothes on or appropriate clothing on).

The SH providers stopped crafting care packages at D. Daniels as they felt this sub-group was too high of a care needs group to be in their program and would have to move to a LTC home. Community Care packages for the 14 vignette sub-groups as constructed by the expert panel and care packages crafted by SH providers can be found in Appendices D and E respectively.

7.7 Care Package Cost Estimates and Divert Rates

7.7.1 Phase 1: Home and Community Care Cost Estimates and Divert Rates

Detailed cost estimates based on what was heard from the expert panel, interviews with SH providers, and the best available data provided by the SW LHIN and SW CCAC, were generated for each of the H&CC packages constructed by the expert panel. Diversion rates – the proportion of individuals for which community based care packages were considered both safe and cost effective were then calculated. Individuals in BoC sub-groups were considered to be “diverts”, if the direct cost to the LHIN for their H&CC packages over a 13-week period (excluding user fees and co-payments) was equal to, or less than, the direct cost to the LHIN of a residential LTC bed for the same period (excluding co-payments).

The “overall divert rate” was calculated by dividing the total number of individuals in “divert” sub-groups by the total number of individuals in all 14 sub-groups for which care packages were constructed (N = 2561). The overall divert rate of individuals on the LTC wait-list that could be safely and cost-effectively diverted to home and community was calculated at 20%. The care packages for Copper, Davis and Fanshaw (highlighted in the table below) were the sub-groups considered “divertible” as they were considered both to be safe and cost effective (equal to or less expensive than $7,491.12) alternatives to LTC residential placement for the same 13 week period of time. The overall divert rate for SH was 17% as Copper was not considered eligible for either program given their low needs and presence of a caregiver.

While panelists were advised that in this exercise we don’t want to over-serve or under-serve clients (e.g., Stabilizing or Destabilizing the system), they felt it important to develop care...
packages that were proactive (e.g., the use of emergency response systems with built in smoke detectors for each care package) and preventative (a large focus on social aspects of care such as transportation; strengthening and falls preventions programs; and caregiver respite regardless if living with or away from the client) and based on a worst case scenario to ensure that the client would be able to remain safely in the community. As such, the care packages became very resource rich, and do not reflect many of the current restrictions panelists face in real-practice (e.g., capped budgets, strict eligibility criteria). For this reason the argument could be made that more people could be diverted if more of a maintenance approach had been taken than a more proactive and preventative approach.

This maintenance approach factored into care packages for the not-intact sub-groups such that while very limited to no behaviours were being documented in the RAI assessments, and caregivers rarely to never indicated stress in their roles, expert panelists took an approach that would ensure that should the behaviours occur, they would be addressed given the unpredictable nature of dementia. They covered this by including such care services as visits from regional geriatric programs for each client and extensive use of Adult Day Programs as hubs of service to receive different aspects of care (e.g., personal care, hygiene, monitoring, nutrition, and caregiver respite).

<table>
<thead>
<tr>
<th>Divert: Line by Line</th>
<th>Cost Higher than LTC</th>
<th>LTC Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>South West</td>
<td>20%</td>
<td>70%</td>
</tr>
</tbody>
</table>

### 7.7.1.1 Safety and Cost Efficiency Thresholds

The expert panel felt that most sub-groups could remain safe in the community if accepting of the care packages they crafted, however many of these packages were not considered cost effective (equal or lesser cost than a nursing home). The sub-groups considered safe but not cost effective include Lambert, Quinn, Rogers, Upperton, Vega, Wong, Xavier, C. Cameron, D. Daniels, and I. Innis. Based on the assumption of safe but not cost effective, the divert rate from
LTC wait-list to community calculating for Lambert to I. Innis was 57%. Calculating for all vignette subgroups from Copper to I. Innis the divert rate went up to 78%. A community based option for the J. Johns sub-group was considered unsafe and no care package was generated for this vignette.

**Table 7.12 Safety and Cost Efficiency Thresholds for SW LHIN LTC Wait-list**

<table>
<thead>
<tr>
<th>Safe and Cost Effective</th>
<th>Safe but Not Cost Effective</th>
<th>Not Safe</th>
</tr>
</thead>
<tbody>
<tr>
<td>20%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(calculating for Copper, Davis and Fanshaw)</td>
<td>57% (calculating for Lambert – I.Innis)</td>
<td>12% (calculating for J. Johns)</td>
</tr>
<tr>
<td></td>
<td>78% (calculating for Copper – I. Innis)</td>
<td></td>
</tr>
</tbody>
</table>
Table 7.13 Cost Comparisons for SW LHIN Community and Supportive Housing Care Packages

<table>
<thead>
<tr>
<th>Vignette &amp; Case Number</th>
<th>% of Wait List</th>
<th>Cognition</th>
<th>ADL Difficulty</th>
<th>IADL Difficulty</th>
<th>Live in Caregiver</th>
<th>Cost of Community Care Package</th>
<th>Cost of Supportive Housing 1 Package</th>
<th>Cost of Supportive Housing 2 Package</th>
<th>Safe &amp; Cost Effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>#3 Copper</td>
<td>3.2%</td>
<td>Intact</td>
<td>No</td>
<td>Some</td>
<td>Yes</td>
<td>$3,460.28</td>
<td>N/A</td>
<td>N/A</td>
<td>Yes</td>
</tr>
<tr>
<td>#4 Davis</td>
<td>11.5%</td>
<td>Intact</td>
<td>No</td>
<td>Some</td>
<td>No</td>
<td>$3,313.62</td>
<td>$5,216.11</td>
<td>$4,595.27</td>
<td>Yes</td>
</tr>
<tr>
<td>#6 Fanshaw</td>
<td>4.0%</td>
<td>Intact</td>
<td>No</td>
<td>Great</td>
<td>No</td>
<td>$3,562.84</td>
<td>$7,116.20</td>
<td>$5,982.97</td>
<td>Yes</td>
</tr>
<tr>
<td>#12 Lambert</td>
<td>3.5%</td>
<td>Intact</td>
<td>Some</td>
<td>Great</td>
<td>No</td>
<td>$12,254.77</td>
<td>$9,413.60</td>
<td>$11,797.58</td>
<td>No</td>
</tr>
<tr>
<td>#17 Quinn</td>
<td>2.6%</td>
<td>Intact</td>
<td>Great</td>
<td>Great</td>
<td>Yes</td>
<td>$14,971.09</td>
<td>$12,545.48</td>
<td>$14,281.84</td>
<td>No</td>
</tr>
<tr>
<td>#18 Rogers</td>
<td>3.0%</td>
<td>Intact</td>
<td>Great</td>
<td>Great</td>
<td>No</td>
<td>$21,951.98</td>
<td>$20,504.21</td>
<td>$19,324.10</td>
<td>No</td>
</tr>
<tr>
<td>#21 Upperton</td>
<td>2.6%</td>
<td>Not Intact</td>
<td>No</td>
<td>Some</td>
<td>Yes</td>
<td>$10,015.65</td>
<td>$10,027.24</td>
<td>$11,430.80</td>
<td>No</td>
</tr>
<tr>
<td>#22 Vega</td>
<td>5.6%</td>
<td>Not Intact</td>
<td>No</td>
<td>Some</td>
<td>No</td>
<td>$15,194.43</td>
<td>$15,218.22</td>
<td>$14,763.22</td>
<td>No</td>
</tr>
<tr>
<td>#23 Wong</td>
<td>4.8%</td>
<td>Not Intact</td>
<td>No</td>
<td>Great</td>
<td>Yes</td>
<td>$15,194.43</td>
<td>$11,035.15</td>
<td>$12,833.60</td>
<td>No</td>
</tr>
<tr>
<td>#24 Xavier</td>
<td>8.9%</td>
<td>Not Intact</td>
<td>No</td>
<td>Great</td>
<td>No</td>
<td>$16,726.34</td>
<td>$14,134.45</td>
<td>$14,602.22</td>
<td>No</td>
</tr>
<tr>
<td>#29 C. Cameron</td>
<td>9.2%</td>
<td>Not Intact</td>
<td>Some</td>
<td>Great</td>
<td>Yes</td>
<td>$17,640.71</td>
<td>$15,148.87</td>
<td>$14,393.87</td>
<td>No</td>
</tr>
<tr>
<td>#30 D. Daniels</td>
<td>10.5%</td>
<td>Not Intact</td>
<td>Some</td>
<td>Great</td>
<td>No</td>
<td>$18,995.64</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
</tr>
<tr>
<td>#35 I. Innis</td>
<td>9.0%</td>
<td>Not Intact</td>
<td>Great</td>
<td>Great</td>
<td>Yes</td>
<td>$19,060.64</td>
<td>N/A</td>
<td>N/A</td>
<td>No</td>
</tr>
<tr>
<td>#36 J. Johns</td>
<td>10.4%</td>
<td>Not Intact</td>
<td>Great</td>
<td>Great</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

N/A = a care package was not created because the sub-group was considered unsafe in the community.
7.7.2 Phase 2: Supportive Housing Cost Estimates and Divert Rates

All SH providers noted that because their organizations are located in different regions (e.g., rural and urban), target different populations (e.g., varying degrees of acuity, needs, and eligibility criteria), may offer distinctive services (e.g., affiliations with different community or religious groups), and often rely on multiple funding sources – generating comparable cost estimates to line-by-line approached to services in the community could be challenging. A further challenge in generating comparable cost estimates are differences in provider reporting styles (e.g., reporting on # of clients served or # of service hours; reporting cost per visit or on hourly unit cost.).

The costing process for SH care packages utilized the average unit cost for services funded out of their SH envelope over a 13-week process (also excluding user fees and co-payments), and identified any additional costs for community support services paid for by the LHIN. These costs were also compared against the direct ministry per diem contribution to a residential LTC bed.

Four SW SH providers were interviewed for the development of SH care packages and cost estimates, of which only two were able to provide estimated hourly unit costs. This estimate was averaged at $35.00/hour. The other SH providers felt strongly that their estimated costs would be similar, yet were not able to provide confirmation of unit cost and therefore their packages were not included in the findings.

SH providers reviewed both the vignettes and the care packages crafted by the expert panel to see where they might modify or adapt according to what their program offered. While these providers felt that many of the vignettes they were reviewing would not qualify for SH services or need the high levels of service being offered, services levels were matched. SH providers stated that if an expert panel felt that level was necessary to keep the various sub-groups safe in their home then they too would provide such proactive and preventative care. Had they reconfigured solely on what their programs offered, and the fact that they do not bank respite care hours, the divert rates would likely have been higher.
The diversion rate for SH when compared to the cost of a residential LTC bed for the same 13-week period was calculated at 17%. While there was a strong sense on the part of the expert panel that SH models work well, and may be more cost-effective than care packages received in an individual’s own home in the community, this appeared only to be true with higher needs groups. The data for SH was insufficient to verify greater cost-efficiency. This may be largely due to the fact that SH providers interviewed for this thesis largely built onto the community care packages as opposed to starting from scratch or altering them very much. As such, sub-groups with low intensity care needs that might ordinarily have received less care may have been over serviced than SH programs would generally allow.

Care packages for Copper, Davis, and Fanshaw were determined to be “diverts” for the community care packages and Davis and Fanshaw for the SH care packages. The Copper sub-group, despite being drawn from individuals deemed eligible for LTC placement, was not considered for SH by the two SH providers because in their perspective the needs of Copper coupled with the presence of a live-in caregiver would not meet their program’s eligibility criteria. While a formal SH costing was not conducted for Copper, providers reported that individuals in this sub-group would be informally monitored and offer services if /when the needs increased. (Please see Appendix E for SH Care Package Cost Estimates and Divert Rates).

The two SH providers that were able to provide average unit costs shared many similarities as outlined in the following tables:
### Table 7.14 Eligibility Criteria for Supportive Housing Providers 1 & 2

- Less likely to bring low-needs clients with caregivers onto the program (e.g., Copper or Upperton)
- Attempts to accommodate pre-existing clients in physical and/or cognitive decline when possible (e.g., maintaining pre-established routines with informal caregiver partnering)
- Presence of a live in caregiver, combined with consistency of staff, setting, and previous knowledge of the client, may allow the provider to continue to care for cognitively impaired individuals until such time that physical needs or difficult behaviours increase and perhaps disqualify them from the program
- High needs individuals (e.g., swallowing difficulties putting the client at risk for choking), and cognitive safety issues (e.g., medication safety; forgetting to turn off water) are less likely to be accepted onto the program unless they were pre-existing clients due to finite resources.
### Table 7.15 Services Offered by Supportive Housing (SH)

<table>
<thead>
<tr>
<th>Service</th>
<th>SH Provider 1</th>
<th>SH Provider 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meal Assistance</td>
<td>Offers meal preparation (e.g., slow cooker meals) in addition/in place of MoWs</td>
<td>Offers ‘top-up’ to hot and frozen MoWs</td>
</tr>
<tr>
<td>Accessible Environmental Design</td>
<td>New Building with <em>Senior Friendly Design</em> features</td>
<td>Client responsible for additional modifications as necessary</td>
</tr>
<tr>
<td>Overnight Staff</td>
<td>Operate as a call service during overnight hours</td>
<td></td>
</tr>
<tr>
<td>Personal Care</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>Laundry</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>Grocery Shopping</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>Light Housekeeping</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>Medication Monitoring/Cueing</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>Assistance Arranging Transportation</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>Transportation Accompaniment (e.g., Medical Appointments)</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>In-house Residential Social Programs (e.g., craft groups)</td>
<td>✅</td>
<td>✗</td>
</tr>
<tr>
<td>Access to Local Community Health Centre (e.g., primary care)</td>
<td>✗</td>
<td>✅</td>
</tr>
</tbody>
</table>

Expert panelists and SH providers noted that clients are usually less cognitively impaired when they first enter an SH program, and this may develop an individual’s potential for retained memory/learning even as their impairment advances. A clients’ retained or routine procedural
memory combined with consistency of staff, setting, and previous provider knowledge of the client likes and dislikes, may allow for impaired clients to continue with a SH provider as their condition worsens. As the needs of subgroups with cognitive impairment increased, SH providers highlighted the important balancing act involved in weighing client safety and care needs with program constraints and considerations.

In discussion with SW SH providers, some sub-groups would not qualify for their program because their needs were too light (e.g., Cooper) and they had light needs and a caregiver (Upperton and Vega) or they would not be eligible because of their memory loss (e.g., D. Daniels – J. Johns). Some exceptions would be made if they had been grand-fathered into the program and well established rules overrode the potential issues of concern for wandering, verbal or physical behaviours, fire and water safety in the home, severe incontinence, or becoming non-ambulatory.

7.8 Summary

This chapter has examined what we can expect to see on the ground given the historical legacy of institutional placement of PLWD. Findings demonstrate that the H&CC sector continues to struggle with all sorts of road blocks to integrated care and continues to operate as a patchwork of services. To try and overcome this issue expert panelists suggested that all PLWD would be excellent candidates to programs like SH or cluster care to allow more flexible options for care and service delivery. Working within current system configurations, the expert panel utilized ADPs as “Hubs” to centralize services in one place and limit the number of providers and care staff necessary to assist clients – especially PLWD – to age at home. While it could be argued that the panel in essence traded one form of institution for another (e.g., multiple days of the week at an ADP versus LTC home bed), they felt the benefit of living in one’s own home, sleeping in one’s own bed, and living in one’s own community for individuals and caregivers could not be overstated, and that these delivery forms of care could also potentially reduce their costs in the long run.

In line with the literature review and other BoC projects, this research identified IADLs as key wait-list drivers. Vignette sub-groups were thought to benefit from such general assistance as
transportation (e.g., clients accessing programs or programs accessing clients), nutrition monitoring (e.g., from grocery shopping to ability to cook/meal preparation) or simple housekeeping (e.g., mobility issues and risk of falls).

Again, this and other research reveal a deeply held belief that vulnerable persons’ lives can and should be improved, and using even very “worst case scenario” high intensity care packages, there was a potential 20% divert rate of individuals from the SW CCAC LTC placement wait-list and 17% using SH care packages. This divert rate would likely have been higher and included some low-intensity needs sub-groups with dementia had the panel not also provided for the well-being of informal caregivers both living in the home or out of the home of the various sub-groups. Considering the unit of care as both the individual and the caregiver differs from traditional acute and LTC home models where individuals, diseases, or body parts are the main focus – and because in hospital and LTC home settings the services do not factor in assistance required by or provided from informal caregivers.

Another important distinction in this research is that other BoC projects care packages were created based on the idea that services must be present and that BoC “divert rates” assume sufficient service capacity at the local level. Because of the large geographic region of the SW LHIN and the fact that care packages were not developed based on urban, rural and remote stratifications; if a service existed in one area it was considered viable for all of the region despite the reality that there is definitely a lack of services in rural/remote areas, which would push the LTC “tipping point” downward.

Beyond a lack of services in these areas, the panel also noted issues with access to primary care, specialized geriatric services and mental health services for their clients. They provided insights for future consideration to help improve linkages, access/coordination between providers (e.g., suggested all organizations be familiar with the RAI and talk the same language; consider that every provider they connect with (CCAC or CSA) leads them to an introduction to care services regardless of who originally encounters/intercepts a client; increasing uptake of the First Link® program for PLWD), and methods to reduce the current need for multiple services & providers.
While this research is not an analysis over time, findings from this snap shot in time appear to support the thesis hypothesis that supply determines where people go, and that the gap that occurs between demand and supply appears to largely be related to historical institutions and structures that are inadequate to meet the current or growing needs of PLWD and their caregivers. The next chapter *Discussion and Conclusions* will discuss theoretical and policy implications and conclusions regarding the SW BoC findings combined with the historical trajectory, and using the predictive power of neo-institutional theory, offer predictions on what we might expect to see if we continue down the same pathway.
Chapter 8
Discussion and Conclusions

This thesis has investigated a constellation of factors that influence the ability of PLWD to age at home in the community and avoid or delay placement into a LTC facility. It has looked beyond naturally occurring demand side factors to consider the importance of supply side factors, and the impact of historical legacies in accounting for a seeming gap between the needs of PLWD and what is available to meet those needs. In doing so, this thesis offers an assessment of the different conditions under which the State has had relatively more or less capacity to assert its own internal logic and shape the broader context in which long-term home care is offered in Ontario, and the degree to which and what barriers exist related to the ability of PLWD to age at home.

Neo-institutional theory was used as a framework to help identify and understand broad system-level factors and the role they play in determining individual-level outcomes (in this case, PLWDs). Specifically, Tuohy’s (1999) understanding of neo-institutionalism was used to guide a historical review of broad policy level decisions and milestones affecting H&CC in Ontario focusing between the years 1995 and 2012. This component of my thesis was conducted to explore what has been addressed historically in the health care system; account for the political institutional structures that shape the pace and direction of change in health care; and analyze the current and future ability of health systems to provide for the needs of community dwelling PLWD.

The BoC simulation methodology was then used to examine how these events and legacies continue to shape care options for PLWD at the frontlines (i.e., how demand is currently being met, or could potentially be met from a policy planning perspective at the local level).

While the main focus of this thesis was between the years 1995 and 2012, it did elaborate on the impact of the Canada Health Act of 1984.
Specifically, the methodology looked to determine the proportion of actual individuals waiting for LTC in the SW LHIN region of Ontario at one point in time that could potentially be safely and cost-effectively supported at home if given access to a range of H&CC support services.

The conceptual and applied level questions addressed in this thesis are important because they highlight a persistent set of issues regarding elder care, and identify the systemic features that have led to and sustained them – some of which I consider to be modifiable. While most PLWD desire to age at home in the community and delay or avoid LTC placement; hospitalization and LTC institutionalization have become default options for many PLWD and other vulnerable groups with complex and chronic conditions - even at relatively low levels of need (CIHI, 2010a; Kuluski et al., 2012 a,b; Williams et al., 2009a; Sinha, 2012; Walker, 2011). As indicated in the body of this thesis, this is not ideal for individuals (may not be the most appropriate place to receive care) or for the system (financial and logistical costs to the system).

From the demand side, the literature is clear that there are growing issues with need (more PLWD, living longer with dementia, more complexity of need) that are under-addressed, and as neo-institutional theory would predict, on the supply side I find that the H&CC policy response has been very limited; as such, the “rising tide” of dementia combined with supply stasis is contributing to a growing gap between the needs of PLWD and the supply side solutions made available.

On a conceptual level, the findings of my research indicate that institutions, historical events and legacies play a large part in shaping current policies, patterns, and policy outcomes affecting the ability of the system to support the H&CC needs of PLWD – particularly those in the early stages of the progression where the needs are mostly daily instrumental activities of daily living than medical/clinical care needs. Findings from the historical review suggest that while there have been attempts at change in the H&CC sector that might benefit populations with chronic and complex health issues like PLWD, momentum has often been stalled or redirected by the entrenched “logic” of the Medicare Mainstream of “medically necessary” hospital and doctor services.
Neo-institutional theory predicts that big change is not the rule but the exception, and as my analysis of SW LHIN BoC simulation clearly demonstrated – not much was available for PLWD from a system/cost effectiveness point of view to allow for diversion from the LTC wait-list. Results from the SW BoC simulation documented the costs and consequences of a lack of integration or targeted system response to the needs of chronic complex populations, and how, in the face of sparse community options, placement on a LTC home wait-list often becomes the default option for PLWD. Where the literature notes that dementia and difficulties with basic activities of living (ADLs) are common triggers for LTC placement, instrumental activities of living (IADLs) were a key driver for PLWD on to the SW LTC wait-list.

While the simulation did not end up diverting any PLWD off of the LTC wait-list due largely to current constraints within the system, SW BoC Expert Panelists and the literature review did highlight a number of localized opportunities for change, albeit at the margins, through dementia-friendly interventions and structural “fixes” described in the body of this thesis (e.g., early and ongoing case management, supportive housing, cluster care, expanding First Link®). The promise afforded by these opportunities, and how they might meet change criteria on more organizational and local levels, are discussed later in this chapter.

The remainder of this chapter discusses implications and conclusions from the theoretical and applied findings of my thesis, explores prospects for change, and describes limitations of this research as well as potential areas for further investigation.

8.1 Theoretical Implications and Conclusions

The conceptual research questions pursued in this thesis sought to explore where: what is the historical legacy of policy decisions around H&CC for PLWD in Ontario? What are the political and institutional factors that have shaped this legacy? How does this legacy continue to shape care options for PLWD? Implications for the conceptual findings are discussed below.
8.1.1 PLWD are not always institutionalized because they need to be, but rather are a consequence of policy dynamics and historical legacies in health care that lead to LTC placement, even at relatively low levels of assessed need.

The era between 1984 (when the CHA was proclaimed) and 2012 crystalized dominant political relationships, and perpetuated the historical emphasis on curative hospital and physician care and chronic care in institutional LTC settings. This has reinforced the Medicare Mainstreams’ influence and biomedical focus over the pace and direction of change in other policy subfields and subsequent development of policy for the H&CC sector and dementia care. Neo-institutional theory suggests that this legacy is a result of the institutions of health care and their vested interests becoming rigidified/inflexible over time making them very difficult to change.

As a consequence, PLWD are defaulting to some of the most expensive places in the system (ED, ALC and LTC home beds) because alternative places or supports are limited or non-existent. Part of the default to LTC placement or a LTC home wait-list is institutionally-based and shows up in how home care is set up and funded compared with protected “medically necessary” entitlements under CHA; and part relates to ideas and interests that have built buildings, beds, bureaucracies and jobs around biomedical responses to health concerns (e.g., caring for PLWD with hospital and LTC facility supports but limited non-clinical and social care supports).

As noted in the body of this thesis, the legacy of premature and/or inappropriate placement of frail and impaired seniors is not a new phenomenon; it has been highlighted as an area in need of addressing for decades in numerous Ministry directed reports and others\(^\text{51}\) (Ministry of Senior Citizens Affairs, 1986; HayGroup, 1997; Drummond, 2012; Walker, 2011; Sinha, 2012).

\[^{51}\text{These have called for reductions to inappropriate LTC institutionalization in Ontario, improved access to long-term homecare services, and coordination of a more integrated approach to community-based care for seniors.}\]
Yet corrective action has been slow and sometimes contradictory. For example, the 1998 Long-Term Care Redevelopment project (*Super Build*) “funded the development of 20,000 new LTC beds and refurbishing of additional outdated beds to address LTC wait-lists; however, the initiative and its targets were not informed by a rigorous process” (MoHLTC, 2002, p. 117), nor accompanied by policy reform to address the concurrent supply issues of long-term home care.

While neo-institutional theory indicates that transformational change to the Mainstream pathway is unlikely, is does not limit the ability for other types of change. Tuohy (1999) and other neo-institutional theorists note that most change that occurs in health care is incremental, and not radical, because major change is not just a clinical or technical issue, but a very political one. Radical, substantive change largely has to do with the ability of the State to make such change, and the ability of vested interests to push back, resist, or modify these attempts. While there have been some attempts at change to the system, it has been at the margins, mostly incremental or incomplete, and slowed or impeded by institutional and structural barriers that keep any major reform from happening; this is very consistent with the predictions offered by neo-institutional theory.

Long-term home care has been presented as a way to shift some care out of hospitals and/or delay LTC placement. However, as demonstrated in this thesis, when change has occurred its focus largely remains on Mainstream issues such as earlier discharge from hospitals, or - more recently - the relief of ALC and ER pressures (e.g., topped up home care until a LTC bed becomes available). The dominance of the Mainstream was also seen in the 2004 Health Accord funding arrangements where the focus remained on more medical based needs (funding for specific medical procedures to deal with wait times and short-term home care) and not towards integration efforts or those with more complex and chronic care needs.

While the government of Ontario has a great deal of latitude to make changes to health care policy as seen with the sweeping policy reforms in the late 1990’s (Baranek et al., 2004; Armstrong & Armstrong, 2006), there has not been any major structural change constituting sufficient reinvestment in long-term home care to address the growing complexity of needs of frail and cognitively impaired seniors. Ontario’s provincial *Aging at Home Strategy (2007 –*
2011) attempted to depart from the dominant pathway with its original focus to “enable people to continue leading healthy and independent lives in their own homes” through the provision of such supports as meals, transportation, shopping, friendly visiting, snow shoveling, adult day programs and caregiver relief/support (MoHLTC, 2007a) – all of which are important to community dwelling PLWD. This attempt to address supply issues however was redirected less than half-way through to address Mainstream ALC and ER pressures (MoHLTC, 2009). The logic of ER/ALC issues thus hijacked the preventative focus of picking people up earlier (delaying illness, dependency and the need for costly institutional care through the use of lower cost H&CC) for a reactive one, picking them up after they arrived in hospital (addressing the discharge planning needs of hospitals and their struggles with ER bottlenecks and ALC beds). In part, this change in direction has to do with a legacy which funds and protects “medically necessary” hospital and doctor care while not providing equal funding or protection for H&CC alternatives that could substitute for higher cost clinical services. It also has to do with historical ideas and framing around the value and perceived need of government funded H&CC.

In the case of the Ontario’s Alzheimer Strategy (1999 – 2004), whose original premise was access to system navigators for every PLWD to help navigate and coordinate care in the community, the direction changed to largely education-focused initiatives. While these strategies resulted in some positive incremental change to care offerings for community dwelling PLWD (funding for Public Education Coordinators at Alzheimer Societies, U-First training for community care providers, investments in adult day programs, and dementia-focused mentor and preceptor opportunities and education with family physicians) they had little impact on the structural relationships of the Mainstream; hence the system structure remained “protected” and the vested powers and interests were preserved.

Another factor contributing to the policy legacy for PLWD is the way in which dementia is framed. Through a medical lens, dementia is viewed as a progressive and incurable organic brain disease yet from a holistic care perspective dementia can be viewed as a complex chronic health condition with physical, psychological and social needs and possible interventions to address health and well-being at all stages of the progression. When PLWD are discussed in the media, it is often in a manner that highlights people at the end stages of the condition, as “bed
“blockers” in the hospital disrupting patient flow, or the potential risk they pose to themselves (e.g., wandering behaviours in the community) and to others (e.g., dangerous behaviours in LTC home settings). As indicated in the body of this thesis, this contributes to stigma felt by PLWD and their caregivers which can affect their seeking or revealing a diagnosis of dementia, and/or reaching out for help early in the progression of the disorder. This negative portrayal also further entrenches a “locked in” mindset by policy makers and health care providers on how to deal with the real and perceived health and safety concerns of PLWD and their possible risk to others. This advantages historical structures and a default to hospitals and LTC placement partially based in reality that dementia-specific resources are lacking in the community to consider otherwise. It may also be based in a lack of imagination, insight, or political will to include long-term community care as a possible solution to health care sustainability.

My analysis of the historical legacy therefore concludes that in the absence of proactive and preventative policy in the H&CC sector, the default to high intensity hospital care and placement in residential long-term care appears entrenched. Where demand side factors play an important role in service utilization and policy planning, supply side factors and the system’s capacity to support PLWD in the community are crucial in determining where they end up.

8.1.2 The proximate policy sub-field of long-term home care is constrained by the dominant Mainstream of the system, which limits their ability to open a window for transformative change.

Findings from the historical review indicate that Ontario’s historical power imbalances, sustained over time, have privileged some organizations, interests and ideas at the expense of others (Tuohy, 1999; Baranek et al., 2004; Pierson & Skocpol, 2000; Immergut, 1998). Using Baranek and associates (2004) understanding of neo-institutionalism, this thesis research has revealed that the institutions, interests and ideas in the H&CC sector are more unstable and susceptible to pressure and power than the prevailing Medicare Mainstream (Baranek et al., 2004). Where the State is largely restricted as to how it provides “medically necessary” services as described in the CHA, H&CC and institutional LTC are not protected in the same way. While not protected under the CHA, the LTC home sector is more coherent, very active and powerful
(strong LTC home associations with a majority of their members being for-profit corporations).
It is also a long-established pathway to care for PLWD when their needs are considered too
great to manage in the community. Long wait-lists also offer a great deal of protection to the
sustainability and value of this sector despite evidence that home care may be more suitable
for PLWD with lower intensity needs.

By comparison, the community care sector does not have the same power, structures,
organization, funding, visibility, or voice as the Mainstream and LTC home sectors. This has
limited its ability to influence policy change. Furthermore, the mix of market forces, range of
services, providers, settings, unpredictable/part-time nature of employment, needs, and
populations within the community sector have made it difficult to mobilize H&CC in an
organized fashion; harder still to mobilize vulnerable consumers like PLWD and their informal
caregivers. This gives the State a large measure of freedom both in making and avoiding
decisions when it comes to H&CC service provision.

Mobilization did occur in the community sector during the early 1990’s when H&CC sector not-
for-profit and commercial providers rose against the NDP’s attempts to create a Multi Service
Agency and offer provincially funded in-home services, case management and placement
coordination through a single NFP agency (Baranek et al., 2004). However, with the election of
the PC government, a new window of opportunity opened that allowed the PC’s to act on the
NDP’s passing of Bill 173 and enact policy that greatly changed the dynamics of the H&CC
sector. The structures for government funded H&CC changed (new CCAC model introduced),
services were opened up to market forces (moved to favour commercial over not-for-profit
providers), the focus was redirected back to Mainstream issues (acute homecare to
accommodate earlier discharge of patients from hospital), and the scope of conflict was
affected making an already divided policy community even more so, and the health care system
even more fragmented than before. This had many implications for care. Where community
care organizations had worked to fill gaps with one another for the good of their clients, the
new system replaced a cooperative model with a competitive model which had organizations
now competing with one another for contracts (Baranek et al., 2004). Evidence of this
continued legacy was observed during the SW BoC simulation when SH providers were
reluctant to estimate unit cost for their programs and be identified in this research due to the competitive bidding process and not wanting others to know what these figures were.

In 2007, Local Health Integration Networks (LHINs) were introduced as a means to help deal with system fragmentation, silos, and disjointed service. They were intended to realign politics and ensure that money/resources flowed with patients and that one sector would not be privileged over another one. One could argue that they have not existed long enough to make a difference; however, it could also be argued that they have simply fit within the existing structure, and may have reinforced it.

Addressing the needs of PLWD in the community to avoid unnecessary or premature use of higher intensity care in any major way would involve veering off a long-established legacy for care, and rebalancing or redirecting resources/funding from the hospital and LTC home sectors to more sufficiently address H&CC solutions. Theory would predict resistance because when Mainstream and institutional LTC policy communities become concerned that portions of their budgets may get redirected/ redistributed to other areas of care, they hold considerable power and influence to dominate the scope of conflict and maintenance of status quo. Even if the government were to announce new money (albeit this is rare), funding generally comes from one source so if one area or sector gets more funding then another, by definition others get less. This further contributes to some of the earlier mentioned volatility in the system. While there is growing evidence towards the need for more integrated and holistic approaches to health care to avoid unnecessary or premature use of institutional based care, the H&CC sector continues to be marginalized. Even so, there has been change moving incrementally the right direction on some fronts that can have a cumulative effect to help hold off and avoid the default to ALC or placement (e.g., early diagnosis and First Link® programs to support primary care; dementia specific SH as mechanisms for integrated care; adult day programs as hubs of service).

While it is hard to see how to manage any truly transformative change toward a fully integrated health care system, my analysis of the historical trajectory demonstrates that the present and future challenge in addressing the needs of community dwelling PLWD wishing
to age-in-place may not lie with radical change as much as exploiting a number of positive incremental changes that have been shown to be of benefit to PLWD particularly in the early to moderate stages, their caregivers, and the system when accessed.

8.2 Policy Implications and Conclusions

The applied level research questions this thesis sought to explore were: what proportion of individuals on a LTC placement wait-list in one region of Ontario that could potentially be safely and cost-effectively supported at home if given access to needed H&CC resources; and how might this change for PLWD? Implications for the applied level findings are discussed below.

8.2.1 The “rising tide” of dementia holds the potential for increased strain on a system that is already having difficulty responding to vulnerable populations with multiple, chronic and complex needs.

The current and future impact of dementia on the health care system is great given the growing needs of PLWD and others with multiple chronic needs are not being matched by system change. The projections of those currently living with or expected to experience a dementia are increasing and people are living longer with the condition (WHO & ADI, 2012; ASC, 2010). These projections do not include a growing number of people diagnosed with MCI which can be a precursor to Alzheimer’s disease. As described in the body of this thesis, PLWD account for two to five times higher rates of health service utilization across the spectrum (Aminzadeh et al., 2012); have a significantly higher burden of chronic diseases often experiencing multiple morbidities that can become even more difficult to manage with the symptoms of dementia; account for one third to one half of ALC beds (CIHI, 2011); experience more negative clinical outcomes compared to older adults without dementia (Gill et al., 2011; Ho et al., 2011; CIHI, 2011a); and often only come to the attention of the system at a point when they are experiencing a crisis resulting in the use of high cost hospital care (Goodwin et al., 2014; Phelan et al., 2012; Samaras et al., 2010; McAiney et al., 2008). Furthermore, concurrent with the literature, SW BoC expert panelists noted that CCAC case managers often do not interact with PLWD in the early stages of their progression unless the individuals are already connected to the system when the dementia developed.
Supply determines where people end up in the system, and while demographics are changing, supply - and the way dementia is addressed in the community largely - is not. This has people with dementia ending up in very expensive places in the system. Reports by Drummond (2012), Sinha (2012), and Walker (2011), while not specifically addressing dementia, highlight concerns about health care system sustainability (e.g., rising residential and hospital care costs which erode system sustainability), and identify a consumer health cost piece regarding those with multiple chronic and complex care needs. This sub-population, while only representing about five percent of Ontario’s population, accounts for approximately two-thirds of Ontario’s health care budget (Health Links, 2014). Dementia is a complex and progressive chronic condition within this sub-population of high intensity resource use. This thesis has argued that where lower intensity care in the community is available in a timely, flexible, coordinated and integrated fashion, there is the possibility to decrease or delay in the use of high-cost and intensity services.

Supply of informal caregivers also influences the ability of PLWD to age at home and all indications from the SW BoC expert panelists and the literature are that the supply of informal caregivers is also in decline, with rural and remote areas especially facing a challenge where immediate and extended families have members who have moved to urban centres; sandwich generation issues; separation/divorce. Given a reliance on informal caregivers, and that they largely emerge from families and PLWD’s own social network, changing family dynamics in the SW LHIN are affecting the ability of informal caregivers to provide care to PLWD.

Failure of the health care system to respond in a meaningful way to the increasing demand and supply factors of community dwelling PLWD will be costly to individuals (e.g., once in hospital, dementia often becomes more complicated by mental trauma, delirium, hospital-borne diseases, physical decline, and restraints all of which can further entrench the path to LTC placement) and to the system (e.g., financial and administrative costs).
8.2.2 The tipping point for placement of PLWD from the community into institutional LTC is predicated on more than need (demand), in that it is also affected by the availability, accessibility, and awareness of H&CC options (supply) on the part of PLWD, their informal caregivers, and primary care and H&CC providers alike.

Findings from the SW BoC simulation and previous BoC research demonstrate that volumes of individuals in LTC homes or wait-lists (PLWD aside) who could potentially be diverted to community are falling through the cracks in the current fragmented system. These individuals, then, “get what they get”, depending on the various institutional and structural factors affecting supply (Williams et al., 2009a,b; Kuluski, 2012a,b; Challis & Hughes, 2002; Hughes & Challis, 2004). Working within current system configurations and costs of providing care in the community, the SW BoC simulation 20% diversion rate did not include any of the sub-groups classified as cognitively not-intact/having dementia. This is not because expert panelists could not figure out a better way of offering services to PLWD (given that seven of the eight sub-groups with dementia were crafted care packages that would allow them to remain in the community), but rather because the feasibility of options was influenced or constrained by resources (e.g., regional availability, eligibility criteria, risk mitigation/prevention, line by line service provision) or economics.  

The literature and SW BoC findings indicate that PLWD rely on informal caregivers to help support and maintain independence in the community for as long as possible in addition to

52 Where the SW LHIN expert panel determined that seven of the eight SW BoC sub-groups with cognitive impairment/dementia could conceivably age safely at home with a range of HCC services and supports including being ideal for SH programs, care packages were so in such a conservative manner (planning for worst case scenarios, proactive and preventative in nature, treating caregiver and PLWD as a unit of care) that none were considered divertible due to costs. This speaks to the notion of risk mitigation. Even when these vignettes indicated the PLWD had no recorded behaviours or difficulties with certain tasks – panelists landed on the side of caution and anticipated for them due to the unpredictability of dementia. Expert panelists noted that while the care packages they created would likely permit PLWD to remain safely in the community, they exceeded what is currently available in practicality (e.g., rural communities may not have access to some services; current budgets and mandates would not permit for the resource intensity) and that there might even be resistance from PLWD and their caregivers at such rich (and possibly invasive) care packages.
accessible, and available, appropriate and accessible H&CC services. In many jurisdictions across Ontario often-needed programs and supports in the community – both general and dementia specific – are either non-existent, not-integrated, hard to negotiate, or not flexible enough to accommodate for the progressive and chronic needs of PLWD and their caregivers (ASUK, 2011; ASC, 2012; ASO, 2010; Morton, 2010; BSO, 2010). Even when services are present, they are not enough and access can be difficult due to wait-lists, geographic disparities, restrictive eligibility criteria or fees, cultural inappropriateness (ASUK, 2011; ASC, 2012; ASO, 2010; Morton, 2010). System fragmentation, silos between and within health and social care sectors, insufficient information about services, and lack knowledge of and collaboration between health professionals all contribute to ongoing barriers for effective care and support of seniors in general (Lee et al., 2010; Morton, 2010; McAiney et al., 2008; Cantegreil-Kallen, et al., 2006); however, they can pose additional barriers for PLWD given their issues with progressive memory loss, confusion, lack of sound judgment, reasoning and declining ability to communicate and function. “When they cannot navigate the system, hospitalization or institutionalization become the default option” (Williams & Lum, 2011, p. 55).

The patchwork system of care also poses challenges to informal caregivers in trying to access, qualify for, and in many cases, afford services that meet the changing needs of PLWD. Implications of fragmented and siloed system are that care is often more provider focused than person-focused including many different people coming in to the homes of PLWD to perform assessments, cover off care that is not offered by any one single agency (e.g., case management from one organization, personal support worker from another organization, RN from yet another, Meals on Wheels from another). This has PLWD and their caregivers reluctant to accept care even when they qualify for services as the current system can be intrusive, inflexible and inconsistent.

The lack of coordinated and integrated care often leads PLWD, their informal caregivers and even case managers to avail themselves to ‘upward substitutions’ of higher intensity and cost services (ER, ALC beds, and early LTC institutionalization of PLWD) (Williams et al., 2009a,c). Results from the SW BoC simulation echoes those from previous BoC research where “many experienced front-line care managers across the province stressed that while in some cases the
needs of older persons were so high that institutionalization or hospitalization was the only viable option, in many cases, both might be avoided, or at least considerably delayed if older persons had early access to a coordinated mix of ‘lower-level’ but essential, community based supports and primary health care” (Williams & Lum, 2011, p. 55). A growing body of evidence suggests that lower intensity H&CC supports that are targeted, offered in an integrated manner, and coordinated by case managers/system navigators knowledgeable about the needs of frail and vulnerable seniors and their caregivers are considered to hold the potential for diversion away from inappropriate ER or ALC usage, provide options for a safe return to home if they do visit hospital, and delay placement in a LTC home (de Witt & Ploeg, 2014; Williams et al., 2009a,c; Billings & Leichsenring 2004; Chappell et al. 2004; Hollander & Prince 2008; Leichsenring & Alaszewski 2004; MacAdam, 2008; Onder et al., 2007; Challis & Hughes, 2002).

While LHINs have been introduced to address health system fragmentation and silos of care, and the Health Links initiative represents a further attempt to fix structural issues related to the problem of chronic complex care cases, barriers remain. There remains no one point of access or pathway to care for PLWD and their caregivers, their ongoing IADL needs remain largely unmet, and there are multiple issues with coordinating and sharing of information amongst and between providers. Primary care is one potential point of coordination, however many physicians can feel unfamiliar, inadequately informed, or disinterested in diagnosing and treating dementia (Aminzadeh et al., 2012; Lee et al., 2014; Lee et al., 2010; McAiney et al., 2008; Chertkow, 2008; Boustani, 2005). Furthermore, proper diagnosis and follow-up visits for PLWD is very time intensive for which the system is not designed. While efforts with First Link® have been successful at working with many family physicians and primary care teams to better link PLWD and their caregivers to education, care supports, and system navigation – awareness to the program and uptake by physicians remain a problem. Programs such as First Link® can be life changing for those pockets of PLWD and caregivers who get connected. Possible ways to expand its reach may involve targeting more money to physicians specifically for this population and program, and a greater use of interdisciplinary teams. In the community CCAC case managers are considered a common point of access to care; however, while able to help fund and oversee a limited selection of services, they are relatively powerless to coordinate any
additional or top-up services that PLWD would need beyond recommendations and referrals to these supports.

The lack of a single point of entry for PLWD and their caregivers to turn to for help navigating and coordinating care early in the progression of the disorder often leaves PLWD and their caregiver without H&CC services and resorting to more traditional/familiar pathways to care (hospitals or LTC placement) in times of crisis. If timely, integrated and coordinated dementia-friendly resources offered through dementia-trained\(^{53}\) providers are not made available and accessible in the community, demand for and use of costly higher intensity services will likely continue to occur, and with greater frequency given the increasing numbers of PLWD.

8.2.3 Instrumental Activities of Daily Living (IADLs) drive placement on a LTC home wait-list for PLWD and others at the margins of care. When compared to care offered in a hospital or LTC home, these basic H&CC options would be considered lower intensity and therefore lower cost services.

The extent to which H&CC services can impact favourable outcomes for PLWD appears largely dependent upon the ability to access a mix of flexible dementia-friendly IADL and ADL supports and services from early to late stages in the progression. However, the ability of the current system to meet the growing and evolving needs of PLWD for funded H&CC services is limited. The literature and SW BoC results demonstrate that IADLs are an important trigger for placement to institutional LTC. While often assumed that ADLs are the key driver for placement, findings from the literature and the SW BoC simulation indicate that IADLs are at least as troublesome for PLWD and their caregivers. Every SW BoC sub-group with dementia reported having some or great difficulty with their IADLs (100% combined), yet 35% of PLWD

\(^{53}\) Despite past efforts of the Alzheimer Strategy and the current Behavioural Support Program, there exists a shortage of dementia trained providers and dementia specific services.
reported having no difficulty with basic ADLs. If left unaddressed, challenges with IADLs can lead to further withdrawal and decline in physical and mental health (Crampton & Eley, 2013).

This has important implications for PLWD because requiring help with IADLs does not match up with the more medically based eligibility criteria for many government-funded care services (e.g., medical professional and personal supports). While a mix of both are important, without assistance with simple yet crucial IADL supports like grocery shopping, meal preparation, or transportation, PLWD can land in a hospital ERs due to complications from trying to manage without them (e.g., malnutrition resulting in delirium). Limitations on eligibility criteria and funding for low level care IADL supports (e.g., homemaking, meal preparation, medication monitoring/assistance) will likely result in a continued default to higher level supports. Incremental improvements to funding and expanded eligibility criteria would seem a proactive measure to help substitute in lower cost care to prevent unnecessary or premature use of higher cost hospital and institutional LTC.

8.2.4 Current system configurations do not fully address the needs of PLWD and their caregivers as a unit of care often only stepping in when crisis or caregiver stress or burnout occurs.

Informal caregivers (both living in the home and out) provide crucial support and linkages to care for older adults in the community, while often themselves requiring care and support. As indicated in the literature and the SW BoC findings, H&CC to help support them in their efforts is often not provided from one source (most often provided through multiple services offered by multiple and changing providers), the time available for help and number of hours of service offered are not adequate for their need, and the care is often provided by staff with limited to no dementia specific training; all of which can be stressful for PLWD and their informal caregivers. While the need for support for PLWD and their caregivers is important, current configurations of service are often declined until a point of crisis because it can contribute to more confusion in the home than help. As such, there appears a need for a rebalancing of care offerings and the timing of these supports to meet somewhere in-between the perceived needs of providers with practical needs of PLWD and their caregivers. Co-ordination and introduction of services for PLWD and their caregivers appear to work best when offered as a unit of care
early and gradually to avoid the possibility of rejecting services altogether (both by PLWD and/or caregivers).

While my thesis findings suggest it is both proactive and preventative practice to coordinate the care of PLWD and their caregivers as a unit, from a policy point of view it is important to also consider the needs of these caregivers as distinct but critical to the success of home care. Additional or separate funding to ensure both parties care needs are addressed would help to better access the appropriate type and amount of services best suited to support the unit of care in the community and avoid premature or inappropriate use of high cost upward substitutions (Medicare and LTC home beds).

8.2.5 Supportive Housing can act as an integrating mechanism for PLWD to age at home in the community.

Despite few options by which to overcome system fragmentation and manage dementia care in a coordinated and streamlined way, findings from the literature and SW BoC expert panelists (which included a representative from Supportive Housing) did perceive supportive housing (SH) and other forms of Assisted Living (AL) or Clustered Care (CC) to be the safest and most cost-effective community based service configurations for managing and integrating care across the continuum for PLWD. These models were considered especially beneficial for having the potential to address multiple complex needs and multiple services at one site with regular consistent staff. While definitions and key assumptions around these care approaches varied amongst panelists and in the literature, the general features of access to 24/7 staffing and the flexibility for more frequent visits of short-term duration basis instead of traditional one-hour blocks of time used in community settings appeared to be an optimal mechanism to meet the needs of PLWD, while also moderating demand for hospital and institutional care, and achieving cost-efficiencies. This was especially germane for PLWD living in rural and remote areas where transportation and access to services becomes more difficult or less feasible (e.g., relatively few providers that can be called on to cover large areas, getting care to people’s homes, getting people to programs congregate dining, or delivery of Meals on Wheels).
While SH providers agreed in theory and practice with the SW BoC expert panelists that the ongoing coordination of care and monitoring to be beneficial to PLWD, they indicated that this group would be problematic given their current resources. They expressed reluctance to take on clients with low intensity needs (too light needs to qualify), and even less so if the PLWD had low needs and a caregiver present. When needs of PLWD were higher, SH providers cited they were less likely to accept these clients into their programs because their models were not dementia-specific and as a dementia progressed they could not guarantee the safety of PLWD and other residents in the building (e.g., PLWD risk for wandering, leaving water running, medication tampering, bothering other residents). They did note that for clients already in the program that developed dementia while in their care, they would do their best to “grandfather” the client along as the rapport and routines to help maintain them would already be in place.

The extent to which SH impacts favourable outcomes for PLWD to avoid premature or inappropriate use of high end institutionally based care appears largely contingent on: the degree of support that can be offered (available time, dementia-training, consistency of staff); the target population of the program and stage of the dementia (eligibility criteria, impairment level; populations served – mixed populations and “grandfathered” or coming in with a dementia); goals of the SH program (do they transfer out when behaviours or mobility issues arise or are they cared for through to palliation); regional availability (need a critical mass); and presence of a caregiver (proximity to SH and expectations of caregivers).

SW BoC expert panelists further noted that if PLWD and/or their caregivers are not already in a SH setting, the need to move from a home setting into SH could be distressing if not orchestrated early enough to get familiar with a new environment, and there would be reluctance by both PLWD and family caregivers to move when a live-in caregiver was present. When the relevant comparator is institutional LTC, the ability to age at home in SH generally appears a more desirable option from the perspective of PLWD and their caregivers. A possible way to address transitions may be through focusing on naturally occurring sites of care. Many older adults have aged in place in apartment buildings around the province that are becoming “de facto nursing homes.” Targeting care in these settings – regardless if privately or publically
owned buildings – would serve a number of seniors with, or at risk of developing dementia in the community.

8.3 Prospects for Change

If the plethora of warnings about the current state of health systems in Ontario and the “rising tide” of PLWD do not have an effect, it is hard to say what type of “crises” would be necessary to catalyze transformative change. As neo-institutional theory points out, people and systems do not experience major change or have an interest in thinking about what can be done differently until there is enough incentive to spark major policy reform and move off of a familiar path (Pierson, 2000; Tuohy, 1999; Levi, 1997; Sewell, 1996). As long as resources continue to support the dominant Medicare Mainstream and LTC home interests, ideas and institutions, there remains little incentive for transformative change.

One outcome of change occurring from no change may be a “collapse” of the publicly-funded system and the rise of market solutions to address the care issues of frail and vulnerable populations like PLWD. If the government continues to rely on a declining supply of informal caregivers to take on more of the existing burden of care for community-dwelling PLWD while the CCAC draws back services, caregivers are likely to become overburdened and PLWD will have to go somewhere (e.g., continuing to default to high end institutional beds). If PLWD want to remain in the community and have the means to do so, they will turn to the private sector (e.g., retirement homes; live in caregivers), which is already happening to some extent. This collapse of the system where the CCAC’s are still active, but retreating such that the system further restricts/ withdraws government funded H&CC to a point that is almost passive privatization poses new problems of access and equity particularly for persons with fewer
resources. Those who cannot afford private care would continue along the same pathway to hospital and institutional LTC beds.

While there has been historical resistance to significant change in familiar pathways of care in Ontario, it is likely that there would be also be resistance to moving to a private insurance system by doctors, hospitals, their respective associations and others like the RNAO. Other stakeholders like the Ontario Association of CCACs would see a reduction in their role in a private market, and union employees would not enjoy the same freedom and opportunities experienced in a publicly funded health care system.

While neo-institutional theory suggests that the likelihood of radical system change is low, it does not say that change will not happen, but that when it does, it will generally be marginal or incremental (Tuohy, 1999). As noted in the discussion of the historical trajectory, there have been a number of positive incremental changes happening at points along history, including the development of many dementia-specific and dementia-friendly initiatives across Ontario (e.g., Memory Clinics, Support Groups, Public Education, and First Link® Programs), and a number of mechanisms that can improve access to integrated care (e.g., Supportive Housing, Cluster Care and Adult Day Programs acting as hubs of service in the community). While these have been minimally resourced and offered in a patchwork fashion, this thesis argues that they may be enough to build upon to see more incremental positive change for PLWD wishing to age at home for as long as possible.

Prospects for what it might take to push the issues of PLWD ahead and the likelihood of politics changing will be considered at a System, Organizational and Ground/Client-Level noting that while discussed at three separate levels, these levels can and do interact.

54 Much like the market based system in the United States – which can have negative consequences for vulnerable populations like PLWD and for the vested interests in the current system.
8.3.1 System-Level Change

Theory and history also tell us that the prospects for a national or provincial dementia strategy in which PLWD have all their needs met are low. While transformative change could technically come from a strong central government that is willing to take the necessary steps to make dementia a priority issue with a comprehensive dementia strategy like what is happening in Brittan, Canada has a different institutional mix and structural balance than Brittan.\(^5\) Thus making sweeping changes to the CHA, protecting funding of chronic long-term home care, or moving towards a fully integrated system of care unlikely.

While transformative policy change at the larger system level seems unlikely, some change is not impossible (Tuohy, 1999). For example, a window of opportunity toward policy change in Canada may open based on external pressures in the form of national Alzheimer strategies in other countries, and growing international agreement that such strategies are crucial. In December 2013 health ministers from G8 (now G7) countries met at an inaugural dementia summit to discuss global approaches to fighting dementia. The overarching aim of this summit was to work as a collective to find a treatment or cure for those with and at risk of dementia by 2025. This was largely motivated in the interests of preventing the potential bankrupting of health care systems if no action is taken. Other topics discussed included improving life and care for PLWD and their caregivers, preventing and delaying dementia, and social adaptation to global ageing and dementia (Department of Health, 2013). The summit also led to the creation of a World Dementia Council aimed at stimulating innovation, development and commercialization of life enhancing drugs, treatments and care for PLWD with through providing independent, non-governmental advocacy and global leadership in these matters.

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\(^5\) Tuohy describes Brittan’s health system as hierarchical (dominated by state actors and stable over time making change easier to implement) and conceptualizes Canada as being collegial (change occurs at a slow pace because consensus among peers is required) and health care professions dominated, attributing to Canada’s relatively static Medicare sector (Tuohy, 1999). As described in the body of this thesis, one weakness of Tuohy’s analysis is her failure to emphasize the institutional mix and structure balance of sectors outside of Medicare (Baranek et al., 2004).
(Department of Health, 2014). The views expressed by the council will be independent of any
government and not representative of government policy limiting its reach for actual change
(Ibid) and representation on this council appears to be well aligned with Mainstream. This
thesis has noted even when well-intentioned, Mainstream stakeholders are not neutral. They
will be influenced in some way by their work with the Mainstream and deeply embedded ideas
within about where any new money should go likely perpetuating the historical pathway of care
for PLWD (e.g., medical interventions, research into a cure for dementia, and pharmaceutical
interventions – not frontline long-term home care). While the scope and power of this council
may be limited to affect big system, it does bring attention to the growing impact of dementia
and may raise this as a valance issue for people with the power and authority to actually take
action.

In Canada, a meeting of federal, provincial and territorial health ministers was held in October
2014 where forging a national plan to help reduce the personal, societal and economic impact
of dementia was discussed. The federal Minister of Health announced that she and her
counterparts were at the “early stages” of an agreement to bring research and best practices
together to create such a plan (Canadian News Wire, 2014). The Alzheimer Society of Canada is
eager to partner with the federal government to help achieve a national dementia plan for
Canada and submitted a proposal to the Government of Canada in August 2014 requesting $30
million per year over five years, for a total of $150 million, to create and fund a Canadian
Alzheimer’s disease and Dementia Partnership (CADDP) to spearhead a national dementia plan
(ASC, 2014). The partnership would include researchers, health professionals, provincial
governments, industry, people with dementia and their families, as well as Alzheimer Societies
across Canada to help develop and implement an integrated, comprehensive national dementia
plan in Canada (Ibid). Time will tell if this comes to fruition.

While the 2013 summit and 2014 meeting of the health ministers aspire to generate a window
of opportunity for change, the historical institutions, interests and ideas that have created the
system that exists remain largely the same, and these efforts have no institutional basis to
effect transformative change on their own. Nevertheless, the possibility for incremental change
exists as the federal government appears to be working towards some kind of arrangement
with the provinces. There may be great interest and traction for a strategy that is aimed at addressing Mainstream ALC issues by framing the benefits of dealing with the issue at the front-end (prevention, hospital admission avoidance) using earlier and more appropriate H&CC than the current pathway leading to premature or inappropriate use of higher intensity/cost care (ER, ALC beds).

In the case of the Ontario, the introduction of LHINs in 2007 was an attempt at integration at a regional level. Findings of this thesis indicate that LHINs appear to have been only marginally successful to date because of structural limitations with their authority to change the system players. This seems to have allowed institutions and vested interests to continue to reproduce themselves. Prospects of increasing Ontario LHINs’ chances at changing the politics that continue to block substantive change would appear to involve providing them with the necessary tools/authority to effect such change.

The current mantra of Ontario’s MoHLTC is “better health, better care, better value” highlighting that demographic and fiscal challenges have required action to improve health care and ensure health care dollars are allocated better (Government of Ontario, 2012). While the action plan targets the need for better support in the community through such mechanisms as community health centres and the CCAC, historical pathways tend to influence interpretations of quality and value measured in strategically managing immediate costs to the Medicare Mainstream (e.g., ALC usage) more than long-term investments to health and social interventions or alleviating suffering. Because people with complex and chronic illnesses are thought to be the major contributors to health care costs (Health Links, 2014), the issue of ALC beds could be leveraged with a provincial strategy to address complex needs with affiliated cognitive difficulties. While it can sometimes be easier to mobilize when targeting an illness which in the case of dementia, it lacks visibility and palatability because of cognitive versus physical manifestations and historical perceptions regarding safety and risk mitigation), a broader “populations with complex needs” initiative may get more traction from a wider array of stakeholders.
A broad initiative may also address to some extent the issue of stigma involved with dementia (e.g. PLWD will still deny or withhold a diagnosis and resist using dementia specific services for fear of being “found out”). The framing of a strategy that addresses the physical and cognitive issues of individuals with “complex conditions” and helps them in the community to avoid inappropriate or unnecessary visits to the ER, use of ALC beds or delay placement in a LTC home may in fact be a positive direction to mobilize a coalition of disease based organizations and affiliates to move their collective concerns forward.

In 2014 the Liberal government was re-elected and went from a minority government to a majority government with greater power to make change. Their 2014 election platform indicated they would increase supports for dementia care and the government has since announced in a November 2014 Mandate Letter to a parliamentary assistant with the MoHLTC plans to develop more evidence regarding supports for persons with dementia and work towards a comprehensive strategy to care for patients with dementia (MoHLTC, 2014d). The wording reference to “patients” indicates a mindset, as theory would predict, largely along the familiar pathway of medically based interventions. While consultations towards the development of another dementia strategy, expanding access points to care and the implementation of 25 new Memory Clinics across Ontario are all helpful steps to improve care for PLWD and their caregivers, time will tell if these will veer off of the current pathway and lead to more integrated care or effect any fundamental change to the structures of the system. Something will need to change somewhere though because where LTC beds have been the government’s historic solution (regardless of political stripe) to address the needs of frail and vulnerable populations on LTC home wait-lists, recent freezes to the development of any new LTC beds with no new H&CC funding make the future of PLWD uncertain, and may lead to an even greater reliance on costly ALC beds.

8.3.2 Organization-Level Change

While there may be institutional road blocks to transformative system change, theory suggests that if everybody agrees on a problem, but action is not forthcoming, maybe it is a political issue (Kingdon, 1984). As discussed earlier in this thesis, there are windows of opportunity
which open under certain conditions, one of which is political mobilization. The way the current system is structured in Ontario, however, limits the ability of H&CC to mobilize as they are less powerful and less organized as the policy communities of the Mainstream and LTC home sectors, and in competition with one another for funding and visibility (Baranek et al., 2004).

**Disease-based organizations like the Alzheimer Society while not as powerful as Mainstream policy communities in Ontario, hold a great deal of moral authority and rapport with government and health care sectors especially following their close work together during the provincial Alzheimer’s Strategy and Transition Period.** While the government does not want to appear to be favouring one disease based group over another, there may be prospects for the Society to leverage their existing relationships with current projects to advocate for expansion on successful initiatives already in place (e.g., First Link®, Behavioural Support Program) in addition to their push for another dementia specific strategy. Enduring legacy projects of the Alzheimer Strategy and current BSO initiatives – while largely education related and education is not policy per se – have been examples where these types of strategies can lead to change at an organizational level and may be expanded upon to incorporate a greater community-based focus.

A successful example of education leading to change at an organizational level to be learned from may be the Registered Nurses Association of Ontario’s (RNAO’s) Best Practices Guidelines. Many hospitals, LTC homes, and H&CC providers have adopted and endorse these evidence based tools. What this may further indicate is that to get dementia on the policy agenda it may be worth approaching nursing associations to get on side and mobilize somehow, making this more of a political issue and not an institutional one.

**Informal caregivers may be another potential (and historical) place of change as demographics shift and baby boomers are concerned about the lack of system to care for their parents and eventually themselves.** A window for change may be opened by them with the help of interest groups like the Alzheimer Society or broader scope groups like the Canadian Association for Retired Persons (CARP), to mobilize in an attempt to have State reform to address the poor system response to PLWD. This recently occurred in Holland (Alzheimer Europe, 2013) however, they have a very different government system there, and as described
by Tuohy, mobilizing in this instance will be from the fringes and therefore tough without extraordinary mobilization of political authority and will within the political system (Tuohy, 1999). Where this type of mobilization may not effect transformative change to the system, it can magnify the voice of caregivers and lead towards possible incremental change in the way of more tangible supports (e.g., enhanced and expanded respite offerings, expansions to compassionate care leaves to reflect the unpredictability and long-term nature of dementia).

There may also be prospects of mobilizing some change at the LHIN level by using the reputation and power of a few established organizations to champion more systems-level change (e.g., having local Alzheimer Societies at the tables and leveraging their relationships with the Ontario College of Family Physicians (OCFP), and Regional Geriatric Programs (RGPs) across Ontario to help influence change in primary care, LTC home, or hospital approaches and care pathways for PLWD through their alliances with providers).

The government’s introduction of Health Links is another initiative which sees communities starting to mobilize. This initiative has both medical and social needs based providers come together to think about how to work together to fix problems and mobilize delivery of coordinated care across the continuum of care for those with chronic complex conditions (MoHLTC, 2012). It attempts to change the scope of conflict by moving from a broader base to a smaller community base, and trying to realign the politics by changing the unit of analysis and so altering the dynamic. This is an interesting attempt at change from the ground up yet, while it would be nice to consider that those at these tables (e.g., doctors, hospital representatives and other professionals) are global thinkers grounded in person-centred philosophies, they are not neutral parties; and there appears to be no counterweight in these discussions. For more balanced discussions it may be beneficial to have representation on Health Links tables by First Link® affiliated primary care as a means to develop more targeted and integrated pathways of care for PLWD and those with MCI. Representation by groups like local Alzheimer Societies and providers of Supportive Housing, who well understand the complex and chronic needs of PLWD at the ground-level, would also be valuable. So too would having a person in the early stages of dementia and or an informal caregiver to help keep the discussions focused more on the needs
of the client/family than the providers. If the Alzheimer Society or people with “lived-experience” cannot be at these tables, they may need to empower others to do it.

The logic of Health Links is also consistent with the latest directive from the Premier of Ontario mandating “change from within” and tasked with the responsibility to develop policies to use public assets effectively and to build stronger relationships among different sectors through community hubs (Lum & Ying, 2014). As it pertains to this thesis research, community hubs which co-locate health (physician or primary care) and community and social care centralizing services and care has been described by panel members of the SW BoC and the literature as a way to optimize the health and well-being of all seniors (both well and functionally compromised) in a natural and cost effective way (Ibid).

While any these types of organizational change alone are not likely enough to radically move the system – together or in some combination, there is much that could be done incrementally to have a cumulative effect in holding off and ideally avoiding premature or inappropriate default to hospital and LTC beds by PLWD.

8.3.3 Ground/Client-Level Change

Findings of this thesis have pointed to a number of integrating mechanisms that could be addressed at a local level. One such mechanism is enhanced case management to assist PLWD with improved system navigation and access to care in the current fragmented system (as was the original intent behind the Alzheimer Strategy in Ontario before being redirected). The issue of system navigation remains relevant today with the Alzheimer Society of Canada, amongst other reports, again highlighting the need for system navigators in its 2010 Rising Tide report (ASC, 2010). Local Alzheimer Societies can and do provide some assistance with navigation through such programs as First Link®, however not everyone with dementia or their caregivers know about the Alzheimer Society or programs like First Link®. As a means to work within the existing structure, SW BoC panellists indicated that it would be beneficial to enhance the role of CCAC case managers to offer more assistance with system navigation and care coordination of these services from first point of contact. Broadening the scope of care for CCAC managers can offer more flexible community care options – IADL or ADL needs – and
eligibility criteria to optimize physical health, cognition and well-being were described as a means of offering one point of care coordination and system navigation promoting greater safety and independence in the community for PLWD. Even if PLWD or their caregivers do not currently have need for, or qualify for CCAC services at that time case managers could help with a base line assessment and keeping the file open to pick a client up at the earliest point of indicated need for services. Panelists also thought PLWD could be considered an exception to regular eligibility criteria of CCAC programs due to the nature of dementia being mental health and not physical health and in terms of the sharing of files and information about the client with different sectors for more integrated care. Furthermore, expanding the basket of services CCAC managers can offer (e.g., transportation), while not health care per se, can mean the difference between making it to doctor appointments and other important destinations like grocery shopping. As described by Williams and Lum (2011), the lack of transportation service for PLWDs can translate into poor nutrition, poor medication and primary care management, premature functional decline and preventable illness, resulting in hospitalization or institutionalization with considerable personal and system costs (Williams & Lum, 2011).

Integrating mechanisms such as SH (particularly dementia-specific models), Assisted Living and Cluster Care programs have been identified as beneficial to PLWD wishing to age at home in the community largely due to their ability to provide improved coordination/navigation, ongoing monitoring, assistance with IADLs and more chronic care needs, smoother transitions to and from hospital, and crisis avoidance. From a system perspective these options have the ability to concentrate resources in a single location and increased flexibility in the use of available resources including staff (Lum et al., 2005; Lum et al., 2007; Williams et al., 2009b). Dementia-friendly and dementia-specific SH however are not widely available or accessible across the province. Where SH is available, eligibility criteria will vary (e.g., some SH will not take PLWD, some will grandfather them out of the program, while others are dementia specific), and in Ontario, often offered in social housing locations run by municipalities with their own eligibility criteria and long wait-lists (Morton, 2010; Lum et al., 2007; Lum et al., 2005). Possible options to improve SH offerings across the province would be expansion and increased funding by the province for existing programs currently demonstrating value to PLWD
(quality of life, increased independence, the importance of place and the familiar in their own community) and the system (reduced incidents leading to hospital admission or LTC placement). The development of more dementia-specific SH programs for PLWD would also go a long way to meet the needs of those requiring more supervision nearing the middle and later stages of dementia. As a means to increase the number of SH locations the government might capitalize on existing housing stock and naturally occurring settings (private apartment buildings and more municipal housing buildings) to improve offerings in the system for PLWD and their caregivers and avoid capital costs and construction delays. Cultural and ethnic groups may enter into any mobilization by the H&CC sector to advocate for a wider range of culturally and linguistically appropriate SH for PLWD.

**Environmental design adaptations in the community for both private and congregate dwellings have also been described in the literature as ways to support PLWD and their caregivers longer and more safely in the community** (CMHC, 2009; CMHC, 1999; Calkins, 2001). These adaptations are often assumed as private expenses to the family of PLWD; however, government funding and expanded tax credits for physical modifications (e.g., improved lighting, grab bars, walk in showers, ramps) and helpful technology (e.g., call response units, door chimes, and in some cases global positioning technology) may improve safety and independence of PLWD and help to mitigate issues related to the use of higher intensity sites of care (e.g., falls, wandering). Funding for Occupational or Physical Therapists to help review and decide best approaches for the implementation of design modifications is another intervention SW BoC Expert Panelists felt would enhance the safety, monitoring of, and uptake of dementia-friendly design interventions.

**Expanding the use of Adult Day Programs (ADPs) for both dementia-specific and mixed populations is another possible way to integrate care in the community by concentrating resources in a single location (hub of services) and providing a large degree of monitoring for health and wellness** (e.g., monitoring of nutrition, medication compliance, continence and hygiene). ADPs might also be levered to establish a service hub for the broader community for preventative maintenance of populations with multiple chronic and complex conditions.
Capitalizing on programs and services already benefiting PLWD and their caregivers may have a greater likelihood for positive albeit incremental change at the margins. Initiatives such as First Link® have already spread across the province and nation (e.g., in British Columbia and Nova Scotia), received greater recognition and funding during the A@H Strategy and more recently through Ontario Seniors Strategy (which is now partially funded in 12 of 14 LHINs). While the First Link® program can be life-changing for PLWD and caregivers who have a knowledgeable physician/primary care team, there is no overarching directive, or specific plan for buy-in from physicians, nor special funding for long-term home care services for PLWD. This might be an area of development as First Link® is largely reliant on primary care physicians to opt in and connect PLWD to programs and services at their local Alzheimer Society. In addition, expansion of this program may help to improve and increase diagnosis rates and enhance the competencies of more family physicians in dementia care and/or making such connections mandatory. Better uptake by physicians who might otherwise not know to refer PLWD to their local Alzheimer Society or CCAC is one mechanism to improve coordination and integration of care.

Related to this initiative would be leveraging some of the previous attempts of the Alzheimer Strategy to incorporate more dementia-specific education and training into college and university curriculum (e.g., physicians, registered nurses, allied health, para-professional, health administration) as a possible method to help providers of care better understand and address the needs and concerns of community dwelling PLWD. Building on existing dementia-training programs and community offerings for PLWD and all those caring for them (e.g., formal and informal caregivers) can also help to empower better decision-making from all partners in care.

The Behaviour Support Ontario (BSO) project is another area for possible expansion from a largely LTC home focused initiative to more H&CC offerings. As described in the body of this thesis, BSO works mostly within the current pathway of institutional care for PLWD – not veering from it – which may be why it still has traction when other attempts at change do not. Although limited, the BSO community offerings together with their LTC offerings have received positive evaluations (Dudgeon & Reed 2010; Ontario Behavioural Support System Project
Team, 2010). Although such limited community outreach may not be a coherent policy for H&CC needs of PLWD, BSO is a funded program from which it may be possible to build upon to potentially avert or support the ALC problem. Theory suggests that not everything happens at once, and while such a proposal may be reactive not proactive – it may be a starting place to focus on even more H&CC offerings even within a fractured system.

While more of the services could be implemented at the local/client level (e.g., retrofitting houses, supporting caregivers), the real question becomes “can these ground-level interventions open a window of opportunity to be scaled up/moved up from the margins?” Here again the answer may be a need to work within the current fractured system and tie in community based dementia care offerings as one of the Mainstreams’ key considerations to avoid premature or inappropriate use of high-intensity, high-cost resources in the first place.

### 8.4 Summary

Findings of this thesis indicate that while demand side factors are changing and people’s needs are more chronic and complex in nature, there is difficulty at the local level in supporting PLWD in the community. The policy dynamics and historical legacies of health care in Ontario have marginalized PLWD leaving them vulnerable to institutionalization as a default, even at relatively low levels of assessed need. Findings also suggest that when lower-intensity H&CC support services are more readily accessible (e.g., eligibility for IADL and ADL needs, ethnoculturally and linguistically appropriate), available (e.g., timeliness, frequency, location), integrated (e.g., case management, communication and coordination amongst and between sectors) and dementia-specific (e.g., proactive, flexible, chronic care focused supports and services, dementia trained staff, PLWD and their caregivers treated as a unit of care) the need for and use of higher-intensity resources (hospital ER/ALC beds, LTC home placement) can be decreased or delayed.
In Ontario there exists a considerable degree of freedom for policy-makers in deciding how to use scarce resources in response to the changing needs of the population; however, this lack of constraint over policy-makers can work both for the good and to the detriment of policy-making in the community. Unconstrained policy-making can provide opportunities for ramping up H&CC services and for innovation by using new approaches to LTC with new interests and partnerships represented at planning tables. In contrast, it can also go in the reverse direction with resource investments in H&CC getting scaled back, stalled or even redirected to address constraints in the Mainstream. As this thesis reveals, if and to what extent change happens is likely to be a function of politics, not evidence. The costs and consequences of inaction to health care systems if they do not adapt to the burgeoning needs of the growing population of seniors with more complex and chronic health needs like PLWD have been highlighted by numerous provincial, national and international reports (MoHLTC, 1999; NACA, 2004; MAS, 2008; ASC, 2010; Walker, 2011; WHO & ADI, 2012; Drummond, 2012; Sinha, 2012). Despite these repeated warnings, change is difficult and we continue to see only incremental change around the margins, and in a patchwork approach.

Understanding the political dynamics of policy, the prospects for transformative change to the health care system are low because it would involve changing the way that people think and the related institutional structures; however, this does not mean that there are no prospects for other types of change. Some type of change is inevitable if the current fragmented non-system is not addressed. As described in the body of this thesis, as the need for change grows,

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56 Lack of legislation has allowed provinces to introduce of user fees, eligibility requirements and decreases in service volumes at their own discretion.

57 For example, the expert panel convened by the HSRC advised a critical component of LTC should be an integrated system of care focusing on maximizing (restoring, maintaining or decelerating the decline in) the social, psychological and physical functioning and the health status of each individual. Furthermore, LTC should be provided in different settings including private homes, SH and care facilities depending on the desires, level of dependence and care requirements of the individual and the availability of compensating informal and formal systems of support (HayGroup for HSRC, 1997).
any change that does occur will likely be incremental and originate at an organization or client/ground level.

To this point, there are a number of policies that seem to be recognizing the growing needs of populations with complex and chronic health needs such as Health Links which are looking to work at change from the “ground up” in an attempt to avoid more historical solutions to care — yet with an absence of the dementia constituency in this work. Widening the representation of the groups to also reflect the H&CC interests of PLWD into this local approach may hold some potential to change the dynamics of the system at a larger level. Findings also suggest that there are many integrating mechanisms and dementia-friendly interventions that currently exist in the community that if, enhanced or expanded upon, even incrementally could have a positive cumulative effect and help to improve the system of care for many PLWD while also helping the system by preventing or delaying their use of higher intensity resources. It would appear the key to sustainability of services and programs for community dwelling PLWD is to build on existing or proven interventions or work within/align with the current Medicare Mainstream pathway – not veering to far from it. If the logic of change from the community-based ground/client-level holds true, many of the possible interventions and structural fixes to improve the ability of PLWD to age in place might be achieved, albeit incremental change.

8.5 Data Limitations

8.5.1 Assumptions for Care Package Construction

Care packages were constructed using a number of assumptions aspiring to the ideal package for each sub-group in order to remain home safely in the community. Construction was based on a worst case scenario basis and the assumption that people would accept the services; however, the assumption of acceptance of service was noted as questionable. While the care packages developed for the community and SH were very rich when compared with current practice and restrictions, there was recognition that PLWD and their caregivers would likely not accept the amount of care being recommended for reasons including but not limited to:

- too many different people coming in and out of their home due with multiple providers of service
• reluctance to attend a program outside of their home (e.g., ADP)
• a lack of ethnically or culturally appropriate service providers and staff or
• service providers that did not fit with what PLWD were used to (e.g., racism, ageism, gender) on the part of the PLWD

Despite reservations about the amount of care being suggested, no reductions were made in the final review of the packages.

Care packages were also constructed to address the SW LHIN region as a whole, although expert panellists suspected that there would be different results if they were to have constructed care-packages by sub-region (e.g., urban care packages and rural/remote care packages). The SW BoC care packages were based on that ability of PLWD to access the recommended services – even when the type of service may only be present in a few regions (e.g. Regional Geriatric Teams), have long wait-lists (e.g., wait time for OT or PT), or reliant on unpredictable factors like volunteer availability (e.g., Meals on Wheels, congregate dining) and “accessible” transportation (e.g., para-transit; ramps for wheelchairs or walkers. All of these services were highly valued and included in the care packages; however, the panel acknowledged that in practice accessing these services is often problematic, and with relatively few providers that can be called on to cover larger rural and remote areas.

8.5.2 Provider Focus of Methodology

The BoC methodology is viewed through the lens of the provider and not from the perspective of PLWD or their caregivers (although a number of expert panelists had both personal and professional experience with dementia). If one were to convene panels with PLWD and/or their caregivers, a comparison could be made of the impressions as to what is necessary to include in care packages for PLWD to remain independent in the community as safely and cost effectively as possible and for informal caregivers to feel they can manage in supporting them to do so. This is a recommendation for future study.
8.5.3 Unit Costs Difficult to Assess

There was difficulty assessing the unit cost for integrated care offered in SH and as such only two of the four SH providers interviewed were able to provide an estimate based on staff time and overhead costs – not actual services. In addition, it was difficult for SH providers to share this information due to the competitive nature of the H&CC sector. As such, SH programs asked not to be identified so as not to share that information openly with competitors.

8.6 Recommendations for Future Research

The issue of how best to rebalance the system to address the growing needs of PLWD will only become more pressing. Future research to help prioritize dementia care policy might look at conducting BoC simulations with PLWD, persons with mild cognitive impairment (MCI), and informal caregivers to address possible limitations with the provider focus in previous BoC research.

Priority areas for funding related to dementia research often focus on biomarkers and seeking a cure, however a vast number of PLWD in the present and near future would benefit from a comparable focus on psycho-social qualitative research that addresses their present day needs. Another growing area of investigation is prevention of dementia (e.g., vascular health, diet, brain exercises) and ways to address the needs of those with a diagnosis of MCI in an effort to delay the onset of a full dementia, thus reducing the impact of dementia on individuals and the system. Research targeting the H&CC needs of those with pre-dementia and early health and social supports that would benefit them is recommended. To this point, if policy were to build on successful programs such as, but not limited to, First Link®, SH, or interdisciplinary memory clinics; conducting longitudinal research on the impact of these initiatives would provide valuable insight on different components of care (e.g., early diagnosis, improved system navigation, support groups and education) and which elements best address the health and social care needs of community dwelling PLWD until a point of transition to institutional care.

A final suggestion relates to synthesizing the extensive amount of data already available from various sources (e.g., CCAC, hospital, physicians, CSS providers). It would be valuable to have it
captured at a centralized level and offer the ability to communicate and address “adverse events” related to how the health system is not meeting the needs of PLWD (e.g., learn from medical and community support data what would have prevented admission to LTC home or hospital) and visa versa.
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Appendix A
South West Balance of Care
Best Level of Care and Quality Steering Committee

In the South West Balance of Care project’s first stage, the researcher was able to leverage an existing “Best Level of Care and Quality” Steering Committee comprised of senior leaders of organizations providing a range of health and social services to older persons in the. This Steering Committee performed a dual role in that it also assumed the role of the South West Balance of Care Steering Committee (SW BoC Steering Committee). The leaders on this Steering Committee represent a care continuum that includes hospitals, social services, long-term residential care, community supports, the South West (SW) Community Care Access Centre (CCAC), housing, mental health and addictions, primary care, and the South West (SW) Local Health Integration Network (LHIN).

Steering Committee members were:

- Mark Brinntell, Co-chair, SW LHIN
- Renate Cowan, Lee Manor Home for the Aged
- Mary Cardinal, Huron Perth Healthcare Alliance
- Margret Comack, Listowel Memorial Hospital/Wingham & District Hospital
- Mary Jane Dandeno, Grey Bruce Health Services
- Heather DeBruyn, Canadian Mental Health Association (Elgin Branch)
- Judi Fisher, Cheshire Homes of London, Inc.
- Elaine Gibson, London Health Sciences Centre/St. Joseph’s Health
- Kelly Gillis, SW LHIN
- Julie Girard, SW LHIN
- Lynn Hinds, VON Perth-Huron Branch
- Donna Ladouceur, SW CCAC
- Gordon Milak, SW CCAC (invited guest)
The Steering Committee provided advice and guidance to the project, nominated individuals for the expert panel (please see Appendix 2), reviewed and validated the project findings, and assisted with knowledge transfer. The BoC project was specifically discussed at three meetings:

**February 28, 2009:** BoC overview presented at this first meeting including BoC approach, key findings from previous BoC studies in Ontario, and preliminary results from the SW CCAC LTC wait-list data analysis.

**April 28, 2009:** second meeting of the Committee with presentation of preliminary findings from the expert panel.

**June 23, 2009:** presentation of sample care packages, cost estimates, and estimates for divert rates for community and supportive housing.

While questions were raised by Steering Committee members about the implications of the findings, there was general agreement that they accurately reflected reality “on the ground” in the SW region. The Steering Committee decided at the June meeting to organize an opportunity to share results with members of the expert panel, which took place on August 11, 2009.
Appendix B
South West Balance of Care Expert Panel

In the project’s fifth stage, an expert panel was convened including experienced front-line case managers from organizations across the health and social care continuum (including hospitals, community support services, supportive housing, the South West Community Care Access Centre, community mental health, and attendant care).

South West Balance of Care (SW BoC) Expert Panel members were:

- Anna Ackland, Care Connector Case Manager – SW CCAC
- Maeve Armstrong-Harris, London Health Sciences Centre Hospital Supervisor – SW CCAC
- Carol Weigel, Home and Community Support Services Program Director – Grey Bruce
- Lesley Brown, Home At Last Manager – Town and Country Support Services
- Elaine Burns, Program Director – Grey Bruce Health Services
- Joanne De Brabandere, Parkwood Hospital Case Manager – SW CCAC
- June Dudgeon, Southampton Hospital Integrated Discharge Planner – SW CCAC
- Julie Girard, Planning and Integration Team Lead – SW LHIN
- Laura Hare, Public Education Coordinator – Alzheimer Society of Stratford
- Leah Hood - Program Manager, Mental Health – Grey Bruce Health Services
- Angela McMillan, Manager, Community Support – VON, Middlesex/Elgin Branch
- Sallie Morrison, Attendant Services Manager – Cheshire London
- Judi Restemeyer, Education & Family Support Worker – Alzheimer Society of Oxford
- Bonnie Rowe, Community Health Services Manager – West Elgin Community Health Centre
- Karen Peat, Woodstock Community Case Manager – SW CCAC

The SW BoC Expert Panel met in Stratford for approximately three working days (March 3—5, 2009) and a follow-up teleconference in April. The panel reviewed each of the 14 SW vignettes and constructed H&CC care packages needed to support typical individuals in each vignette.
safely and appropriately in the community. Panelists were asked to consider only the needs of individuals (and caregivers), not costs (which would be estimated later). While there was lengthy discussion and debate about the mix and intensity of services required for individuals in each vignette, consensus was achieved in every case.
Appendix C
Distribution of All South West Community Care Access Centre
Wait-listed Individuals as of February 24, 2009*

<table>
<thead>
<tr>
<th>Sub-group</th>
<th>Cognition</th>
<th>ADL Difficulty</th>
<th>IADL Difficulty</th>
<th>Live in Caregiver</th>
<th>Frequency and Percent</th>
</tr>
</thead>
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<tr>
<td>#1 Appleton</td>
<td>Intact</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>4 0.1%</td>
</tr>
<tr>
<td>#2 Bruni</td>
<td>Intact</td>
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<td>No</td>
<td>No</td>
<td>11 0.4%</td>
</tr>
<tr>
<td>#3 Copper</td>
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<td>No</td>
<td>Some</td>
<td>Yes</td>
<td>92 3.2%</td>
</tr>
<tr>
<td>#4 Davis</td>
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<td>Some</td>
<td>No</td>
<td>331 11.5%</td>
</tr>
<tr>
<td>#5 Eggerton</td>
<td>Intact</td>
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<td>Yes</td>
<td>41 1.4%</td>
</tr>
<tr>
<td>#6 Fanshaw</td>
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<td>No</td>
<td>Great</td>
<td>No</td>
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</tr>
<tr>
<td>#7 Grimsby</td>
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</tr>
<tr>
<td>#8 Hamilton</td>
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<td>None</td>
<td>No</td>
<td>11 0.4%</td>
</tr>
<tr>
<td>#9 Islington</td>
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<td>Some</td>
<td>Some</td>
<td>Yes</td>
<td>39 1.4%</td>
</tr>
<tr>
<td>#10 Jones</td>
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<td>Some</td>
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<tr>
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<td>Yes</td>
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</tr>
<tr>
<td>#12 Lambert</td>
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<td>No</td>
<td>102 3.5%</td>
</tr>
<tr>
<td>#13 Moore</td>
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<td>Yes</td>
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</tr>
<tr>
<td>#14 Nickerson</td>
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<td>No</td>
<td>0 0.0%</td>
</tr>
<tr>
<td>#15 Opus</td>
<td>Intact</td>
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<td>Some</td>
<td>Yes</td>
<td>15 0.5%</td>
</tr>
<tr>
<td>#16 Pringle</td>
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<td>13 0.5%</td>
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<tr>
<td>#17 Quinn</td>
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<td>Yes</td>
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<tr>
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<tr>
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<tr>
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<tr>
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<td>No</td>
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<tr>
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<tr>
<td>#29 C. Cameron</td>
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<td>Yes</td>
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<tr>
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<td>Great</td>
<td>No</td>
<td>303 10.5%</td>
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<tr>
<td>#34 H. Hogan</td>
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<td>No</td>
<td>5 0.2%</td>
</tr>
<tr>
<td>#35 I. Innis</td>
<td>Not Intact</td>
<td>Great</td>
<td>Great</td>
<td>Yes</td>
<td>260 9.0%</td>
</tr>
<tr>
<td>#36 J. Johns</td>
<td>Not Intact</td>
<td>Great</td>
<td>Great</td>
<td>No</td>
<td>300 10.4%</td>
</tr>
</tbody>
</table>

* Total Number Wait-listed = 2,876
Including in Analysis = 2,541 (88%)
Number of Vignettes = 14

Note: Highlighted Bars are those sub-groups with 2.5% of the population or greater from which vignettes were created.
D.1  Vignette #3: Copper

Copper is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Copper has no difficulty using the phone, some difficulty with transportation managing medications, meal preparation, and great difficulty with housekeeping. Copper has a live-in caregiver (adult-child or spouse). This live-in caregiver provides advice/emotional support and assistance with IADLs.

1) Cognition- Intact (short-term memory recall is good; makes consistent/reasonable/safe decisions and can express ideas without difficulty)

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- No difficulty using the phone, some difficulty with transportation and managing medications (needs some help, is very slow/fatigues), meal preparation, and great difficulty with housekeeping (little or no involvement in the activity is possible).

4) Caregiver (in home?)- Yes. (49% = adult-child, 44% = spouse) Caregiver providing advice/emotional support and assistance with IADLs.
<table>
<thead>
<tr>
<th>Vignette: Copper 3.2%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Units of Service for 1 week</th>
<th>Units for 13 weeks</th>
<th>Units for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professional</strong></td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$146.66</td>
<td>1</td>
<td></td>
<td>$146.66</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>2</td>
<td></td>
<td>$230.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support)</td>
<td>10A</td>
<td>Hour</td>
<td>$29.90</td>
<td>2</td>
<td>26</td>
<td></td>
<td>$777.40</td>
</tr>
<tr>
<td><strong>CSS</strong></td>
<td>Congregate Dining</td>
<td>03A</td>
<td>Attendance</td>
<td>$11.16</td>
<td>6</td>
<td></td>
<td></td>
<td>$66.96</td>
</tr>
<tr>
<td></td>
<td>Elder Person's Centre</td>
<td>09J</td>
<td>Attendance</td>
<td>$6.40</td>
<td>1</td>
<td>13</td>
<td></td>
<td>$83.20</td>
</tr>
<tr>
<td></td>
<td>Strengthening/falls prevention</td>
<td></td>
<td>Visit</td>
<td>$31.00</td>
<td>1</td>
<td>13</td>
<td></td>
<td>$403.00</td>
</tr>
<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$33.45</td>
<td>1</td>
<td>13</td>
<td></td>
<td>$434.85</td>
</tr>
<tr>
<td></td>
<td>Meals on Wheels</td>
<td>02A</td>
<td>Meal</td>
<td>$8.79</td>
<td>3</td>
<td>39</td>
<td></td>
<td>$342.81</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$42.16</td>
<td>15</td>
<td></td>
<td></td>
<td>$632.40</td>
</tr>
<tr>
<td><strong>One Time</strong></td>
<td>Connect Care Emergency Response System</td>
<td>09F</td>
<td></td>
<td>$343.00</td>
<td></td>
<td></td>
<td></td>
<td>$343.00</td>
</tr>
<tr>
<td></td>
<td>Pharmacy (blist packs)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Community Care Package</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$3,460.28</td>
</tr>
</tbody>
</table>
D.2  Vignette #4: Davis

Davis is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Davis has no difficulty using the phone, some difficulty with managing medications, meal preparation, and transportation, and great difficulty with housekeeping. Davis does not have a live-in caregiver. Davis has a caregiver outside of the home (an adult-child) who provides advice/emotional support and assistance with IADLs.

1) Cognition- Intact- good short-term memory; makes consistent/reasonable/safe decisions and can express ideas without difficulty

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- No difficulty using the phone, some difficulty with managing medications, meal preparation (needs some help, is very slow/fatigues), and transportation, and great difficulty with housekeeping and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?)- No. (75% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
<table>
<thead>
<tr>
<th>Vignette: Davis 11.5%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit =</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professional</strong></td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td>1</td>
<td></td>
<td>$ 146.66</td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy (falls assess)</td>
<td>17A</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>2</td>
<td></td>
<td>$ 230.00</td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support)</td>
<td>10A</td>
<td>Hour</td>
<td>$ 29.90</td>
<td>2</td>
<td>26</td>
<td>$ 777.40</td>
</tr>
<tr>
<td><strong>CSS</strong></td>
<td>Congregate Dining</td>
<td>03A</td>
<td>Attendance</td>
<td>$ 11.16</td>
<td>6</td>
<td></td>
<td>$ 66.96</td>
</tr>
<tr>
<td></td>
<td>Elder Person's Centre</td>
<td>01B?</td>
<td>full day</td>
<td>$ 6.40</td>
<td>1</td>
<td>13</td>
<td>$ 83.20</td>
</tr>
<tr>
<td></td>
<td>Strengthening/falls prevention</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>1</td>
<td>13</td>
<td>$ 434.85</td>
</tr>
<tr>
<td></td>
<td>Meals on Wheels (3 hot/wk; 4 frozen drop off of 16)</td>
<td>02A</td>
<td>Meal</td>
<td>$ 8.79</td>
<td>3</td>
<td>39</td>
<td>$ 342.85</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$ 42.16</td>
<td>15</td>
<td></td>
<td>$ 632.40</td>
</tr>
<tr>
<td><strong>One Time</strong></td>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$ 343.00</td>
<td></td>
<td></td>
<td>$ 343.00</td>
</tr>
<tr>
<td></td>
<td>Pharmacy (Blister Pack &amp; meds check)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Community Care Package</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$ 3,313.62</td>
</tr>
</tbody>
</table>
D.3 Vignette #6: Fanshaw

Fanshaw is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Fanshaw has some difficulty using the phone and great difficulty with transportation, managing medications, preparing meals and housekeeping. Fanshaw has a caregiver outside the home (an adult-child who provides advice/emotional support and assistance with IADLs).

1) Cognition- Borderline Intact (short-term memory recall problem; has some difficulty making decisions in new situations only but can express ideas without difficulty.

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- Some difficulty using the phone (needs some help, is very slow/fatigues); great difficulty managing medications, preparing meals, housekeeping and with transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - No (72% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs).
<table>
<thead>
<tr>
<th>Vignette: Fanshaw 4%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit =</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professional</strong></td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td>1</td>
<td></td>
<td>$ 146.66</td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy (falls assess)</td>
<td>17A</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>3</td>
<td></td>
<td>$ 345.00</td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support)</td>
<td>10A</td>
<td>Hour</td>
<td>$ 29.90</td>
<td>2</td>
<td>26</td>
<td>$ 777.40</td>
</tr>
<tr>
<td></td>
<td>Nursing (CCAC - med management)</td>
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<td>Visit</td>
<td>$ 57.47</td>
<td>4</td>
<td></td>
<td>$ 229.88</td>
</tr>
<tr>
<td><strong>CSS</strong></td>
<td>Adult Day Service (Frail Elderly)</td>
<td>01B</td>
<td>full day</td>
<td>$ 86.71</td>
<td>1</td>
<td>13</td>
<td>$ 1,127.23</td>
</tr>
<tr>
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<td>Home Help/Homemaking/Housekeeping</td>
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<td>Hour</td>
<td>$ 25.14</td>
<td>2</td>
<td>26</td>
<td>$ 653.64</td>
</tr>
<tr>
<td></td>
<td>Meals on Wheels (3 hot/wk; 4 frozen dropoff of 16)</td>
<td>02A</td>
<td>Meal</td>
<td>$ 8.79</td>
<td>3</td>
<td>39</td>
<td>$ 342.81</td>
</tr>
<tr>
<td></td>
<td>Strengthening/falls program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$ 42.16</td>
<td>2</td>
<td>26</td>
<td>$ 1,096.16</td>
</tr>
<tr>
<td><strong>One Time</strong></td>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$ 343.00</td>
<td></td>
<td></td>
<td>$ 343.00</td>
</tr>
<tr>
<td></td>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Community Care Package</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$ 3,562.84</td>
</tr>
</tbody>
</table>
D.4 Vignette #12: Lambert

Lambert is cognitively intact and requires assistance with some ADLs (supervision with locomotion; set-up help with eating; limited assistance with personal hygiene and toilet use; extensive assistance with bathing activities and extensive assistance with bathing (client can perform 50% on their own and requires full help for part of the task). Lambert has some difficulty using the phone and great difficulty with all other IADLs (meal preparation, housework, medication management, and transportation). Lambert has an adult-child caregiver outside the home who provides advice/emotional support and assistance with IADLs.

1) Cognition- Intact (short-term memory recall is good; some difficulty making decisions in new situations only. Can express ideas without difficulty).

2) ADL- Supervision required with locomotion (oversight, encouragement or cuing needed); set-up help only with eating (article or device provided within reach); limited assistance with toilet use and personal hygiene; and extensive assistance required with bathing activities (client can perform 50% of activity on own and requires full help for part of this task).

3) IADL- Some difficulty using the phone (needs some help, is very slow/fatigues); great difficulty with housekeeping, meal preparation, managing medications, and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - No. (71% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
<table>
<thead>
<tr>
<th>Vignette:</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit =</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lambert</td>
<td>Professional</td>
<td>Case Management</td>
<td>Visit</td>
<td>$146.66</td>
<td>1</td>
<td>$146.66</td>
<td></td>
</tr>
<tr>
<td>3.5%</td>
<td></td>
<td>Nursing (CCAC - incontinence &amp; med management)</td>
<td>Visit</td>
<td>$57.47</td>
<td>6</td>
<td>$344.82</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>3</td>
<td>$345.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physio Assessment (&amp; strengthening program)</td>
<td>Visit</td>
<td>$100.00</td>
<td>3</td>
<td>$300.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>PSW (CCAC In-Home Support &amp; exercise)</td>
<td>10A</td>
<td>Hour</td>
<td>$29.90</td>
<td>17</td>
<td>$345.00</td>
</tr>
<tr>
<td></td>
<td>CSS</td>
<td>Adult Day Service (Frail Elderly-include bath &amp; exercise)</td>
<td>01B</td>
<td>Full Day w Bath</td>
<td>$86.71</td>
<td>2</td>
<td>26</td>
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<tr>
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<td></td>
<td>Home Help/Homemaking/Housekeeping</td>
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<td>26</td>
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</tr>
<tr>
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<td></td>
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<td>meal</td>
<td>$8.79</td>
<td>3</td>
<td>$26.37</td>
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<td></td>
<td>Strengthening/falls prevention – PSW</td>
<td>Hours</td>
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<td>1</td>
<td>13</td>
<td>$403.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$42.16</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>One Time</td>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$343.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>TOTAL</td>
<td>Community Care Package</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
D.5  **Vignette #17: Quinn**

Quinn is cognitively intact and requires assistance with all ADLs (extensive assistance with eating; maximal assistance with personal hygiene activities, and is totally dependent with locomotion in the home, toileting, and bathing (full activity is performed by another person). Quinn has some difficulty using the phone and **great** difficulty with all other IADLs (meal preparation, housework, medication management, and transportation). Quinn has a live-in caregiver. **The caregiver is a spouse** who provides advice/emotional support, assistance with ADLs and IADLs.

1) **Cognition- Intact** (short-term memory recall is good; makes good or consistent decisions and can express ideas without difficulty).

2) **ADL- Extensive assistance required with eating** (client can perform 50% of activity on own and requires full help for part of this task); **maximal assistance with personal hygiene activities** (client involved and completed less than 50% of activity on own); and **totally dependent with locomotion in the home, bathing and toileting** (full performance of these tasks done by someone else).

3) **IADL- Some difficulty using the phone** (needs some help, is very slow/fatigues); **great difficulty with housekeeping, meal preparation, managing medications, and transportation** (little or no involvement in the activity is possible).

4) **Caregiver (in home?) - Yes. (70% = spouse)** Caregiver providing advice/emotional support and assistance with ADLs and IADLs.
<table>
<thead>
<tr>
<th>Vignette: Quinn 2.6%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professional</strong></td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td>1</td>
<td></td>
<td>$ 146.66</td>
</tr>
<tr>
<td></td>
<td>Nursing (CCAC - incontinence &amp; med management)</td>
<td>15A</td>
<td>Visit</td>
<td>$ 57.47</td>
<td>6</td>
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<td>$ 344.82</td>
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<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>3</td>
<td></td>
<td>$ 345.00</td>
</tr>
<tr>
<td></td>
<td>Physio Assessment (&amp; strengthening program)</td>
<td></td>
<td>Visit</td>
<td>$ 100.00</td>
<td>3</td>
<td></td>
<td>$ 300.00</td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support &amp; strengthening exercise)</td>
<td>10A</td>
<td>Hour</td>
<td>$ 29.90</td>
<td>18</td>
<td>234</td>
<td>$ 6,996.60</td>
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<td>Full Day w bath</td>
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<td>39</td>
<td>$ 3,381.69</td>
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<td>Caregiver Support Group</td>
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<td>65</td>
<td>$ 2,065.05</td>
</tr>
<tr>
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<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>2</td>
<td>26</td>
<td>$ 869.70</td>
</tr>
<tr>
<td></td>
<td>Meals on Wheels</td>
<td>72 5 82 10 - CSS IH COM - Meals Delivery</td>
<td>meals</td>
<td>$ 8.79</td>
<td>5</td>
<td>65</td>
<td>$ 571.35</td>
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<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2 Way Trip</td>
<td>$ 42.16</td>
<td>1</td>
<td>13</td>
<td>$ 548.08</td>
</tr>
<tr>
<td><strong>One time</strong></td>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$ 343.00</td>
<td></td>
<td></td>
<td>$ 343.00</td>
</tr>
<tr>
<td></td>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Community Care Package</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$14,971.09</td>
</tr>
</tbody>
</table>
D.6 Vignette #18: Rogers

Rogers is cognitively intact and requires assistance with all ADLs (supervision when eating, maximal assistance with personal hygiene activities and is totally dependent with locomotion in the home, bathing and toileting). Rogers also requires assistance with all IADLs (some difficulty using the phone; great difficulty with meal preparation, housework, managing medications and transportation). Rogers does not have a live-in caregiver. Rogers does have an adult-child caregiver who lives outside the home who provides advice/emotional support and assistance with IADLs.

1) Cognition- Intact (memory recall is good, can make safe and reasonable decisions and express ideas without difficulty).

2) ADL- Supervision required when eating (oversight, encouragement or cuing needed); maximal assistance required with personal hygiene activities (client involved and completed less than 50% of activity on own); totally dependent with locomotion in the home, toileting and bathing (entire task performed by others).

3) IADL- Some difficulty using the phone (needs some help, is very slow/fatigues); great difficulty with meal preparation, managing medications housekeeping and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - No. (62% = adult-child, 17% = other relative who lives outside the home) Caregiver providing advice/emotional support and assistance with IADLs).
<table>
<thead>
<tr>
<th>Vignette: Rogers 3%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td>1</td>
<td>$ 146.66</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing (CCAC - incontinence &amp; med management)</td>
<td>15A</td>
<td>Visit</td>
<td>$ 57.47</td>
<td>6</td>
<td>$ 344.82</td>
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</tr>
<tr>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>3</td>
<td>$ 345.00</td>
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</tr>
<tr>
<td></td>
<td>Physio Assessment (&amp; strengthening program)</td>
<td></td>
<td>Visit</td>
<td>$ 100.00</td>
<td>3</td>
<td>$ 300.00</td>
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</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support &amp; exercise)</td>
<td>10A</td>
<td>Hour</td>
<td>$ 29.90</td>
<td>29</td>
<td>377</td>
<td>$11,272.30</td>
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<td></td>
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<td>Visit</td>
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<td></td>
<td>Speech Language Pathologist</td>
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<td>Visit</td>
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<td>$ 268.00</td>
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</tr>
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<td>CSS</td>
<td>Adult Day Service for Dementia (with exercise)</td>
<td>01B</td>
<td>Full Day w bath</td>
<td>$ 86.71</td>
<td>5</td>
<td>65</td>
<td>$ 5,636.15</td>
</tr>
<tr>
<td></td>
<td>Caregiver Support Group</td>
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<td>$ 195.62</td>
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<td>Hour</td>
<td>$ 31.77</td>
<td>5</td>
<td>65</td>
<td>$ 2,065.05</td>
</tr>
<tr>
<td></td>
<td>Friendly Visiting</td>
<td></td>
<td>Hour</td>
<td>$ 2.53</td>
<td>2</td>
<td>26</td>
<td>$ 65.78</td>
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<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>1</td>
<td>13</td>
<td>$ 434.85</td>
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<tr>
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<td>Meals on Wheels</td>
<td>72 5 82 10 - CSS IH COM - Meals Delivery</td>
<td>Meals</td>
<td>$ 8.79</td>
<td>1</td>
<td>13</td>
<td>$ 114.27</td>
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<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2 Way Trip</td>
<td>$ 42.16</td>
<td>1</td>
<td>13</td>
<td>$ 548.08</td>
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<tr>
<td>One Time</td>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$ 343.00</td>
<td></td>
<td></td>
<td>$ 343.00</td>
</tr>
<tr>
<td></td>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>Community Care Package</td>
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<td></td>
<td></td>
<td>$22,373.58</td>
</tr>
</tbody>
</table>
D.7 Vignette #21: Upperton

Upperton is not cognitively intact but functionally independent in all ADLs with the exception of bathing (limited assistance is required). Upperton has some difficulty using the phone, managing medications and preparing meals and great difficulty with transportation and housekeeping. Upperton has a live-in caregiver. This live-in caregiver provides advice/emotional support and assistance with IADLs. (*note: more than half provide assistance with ADLs).

1) Cognition- not intact (short term memory problem; in specific situations, decisions consistently poor or unsafe and cues/supervision necessary at all times; has difficulty finding words or finishing thoughts but if given enough time little or no prompting is required).

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene); client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- Some difficulty using the phone, managing medications; housekeeping and preparing meals and transportation (needs some help, is very slow/fatigues).

4) Caregiver (in home?) - Yes, (53 % = spouse, 42 % = adult-child) Caregiver providing advice/emotional support, [61% provide assistance with ADLs] and almost all provide assistance with IADLs).
<table>
<thead>
<tr>
<th>Vignette: Upperton 2.6%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit =</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professional</strong></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$146.66</td>
<td>1</td>
<td>$146.66</td>
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<td></td>
</tr>
<tr>
<td>Geriatric Assessment Team</td>
<td></td>
<td>Visit</td>
<td>$161.68</td>
<td>2</td>
<td>$323.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>2</td>
<td>$230.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td>08B</td>
<td>Visit</td>
<td>$147.00</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(replaced with First Link)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CSS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Day Service for Dementia (support group, bath &amp; exercise)</td>
<td>01C</td>
<td>Full Day w bath</td>
<td>$86.71</td>
<td>5</td>
<td>65</td>
<td>$5,636.15</td>
<td></td>
</tr>
<tr>
<td>Caregiver Support Group /First Link counselling</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$60.19</td>
<td>5</td>
<td></td>
<td>$300.95</td>
<td></td>
</tr>
<tr>
<td>Caregiver Support Respite (Paid) Bank of 5 hrs/wk (can be used or banked) same as Lambert but Lambert is per month</td>
<td>08C</td>
<td>Hour</td>
<td>$31.77</td>
<td>5</td>
<td>65</td>
<td>$2,065.05</td>
<td></td>
</tr>
<tr>
<td>Friendly Visiting (dementia trained)</td>
<td></td>
<td>Hour</td>
<td>$2.53</td>
<td>2</td>
<td>26</td>
<td>$65.78</td>
<td></td>
</tr>
<tr>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$33.45</td>
<td>2</td>
<td>26</td>
<td>$869.70</td>
<td></td>
</tr>
<tr>
<td><strong>One Time</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Response System W smoke alarm</td>
<td>09F</td>
<td>Client</td>
<td>$343.00</td>
<td></td>
<td></td>
<td>$343.00</td>
<td></td>
</tr>
<tr>
<td>Safely Home (Alz Wander Registry)</td>
<td></td>
<td></td>
<td>$35.00</td>
<td></td>
<td></td>
<td>$35.00</td>
<td></td>
</tr>
<tr>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Community Care Package</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$10,015.65</td>
</tr>
</tbody>
</table>
Vignette #22: Vega

Vega is not cognitively intact but is functionally independent in all ADLs with the exception of bathing (limited assistance is required). Vega has no difficulty using the phone, some difficulty with meal preparation, and managing medications and great difficulty with transportation and housekeeping. Vega does not have a live-in caregiver. The caregiver is an adult-child who lives outside of the home who provides advice/emotional support and assistance with IADLs.

1) Cognition- Not Intact (short term memory problem; in specific situations, decisions become poor or unsafe and cues/supervision necessary at those times; has difficulty finding words or finishing thoughts but if given enough time little or no prompting is required)

2) ADL- independent in eating, locomotion in the home, toilet use and personal hygiene). Limited assistance required when bathing (highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- No difficulty using the phone; some difficulty with meal preparation, and managing medications (needs some help, is very slow/fatigues); great difficulty with housekeeping and transportation (little or no involvement in activity is possible).

4) Caregiver (in home?) - No. (75% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
<table>
<thead>
<tr>
<th>Vignette: Vega 5.6%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
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<tr>
<td>Professional</td>
<td>Case Management</td>
<td>Visit</td>
<td>$146.66</td>
<td>1</td>
<td>$146.66</td>
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</tr>
<tr>
<td></td>
<td>Geriatric Assessment Team</td>
<td>Visit</td>
<td>$161.68</td>
<td>2</td>
<td>$323.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy</td>
<td>Visit</td>
<td>$115.00</td>
<td>2</td>
<td>$230.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support monitoring meds, evening meals)</td>
<td>Hour</td>
<td>$29.90</td>
<td>16</td>
<td>208</td>
<td>$6,219.20</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social Worker (replaced with First Link)</td>
<td>Visit</td>
<td>$147.00</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSS</td>
<td>Adult Day Service for Dementia (with exercise)</td>
<td>01C</td>
<td>Full Day with bath</td>
<td>$86.71</td>
<td>5</td>
<td>65</td>
<td>$5,636.15</td>
</tr>
<tr>
<td></td>
<td>Caregiver Support Group / First Link counselling</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$60.19</td>
<td>5</td>
<td></td>
<td>$300.95</td>
</tr>
<tr>
<td></td>
<td>Caregiver Support Respite (Paid)</td>
<td>08C</td>
<td>Hour</td>
<td>$31.77</td>
<td>15</td>
<td></td>
<td>$476.55</td>
</tr>
<tr>
<td></td>
<td>Friendly Visiting (dementia trained)</td>
<td>Hour</td>
<td>$2.53</td>
<td>2</td>
<td>26</td>
<td></td>
<td>$65.78</td>
</tr>
<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$33.45</td>
<td>2</td>
<td>26</td>
<td>$869.70</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$42.16</td>
<td>1</td>
<td>13</td>
<td>$548.08</td>
</tr>
<tr>
<td>One Time</td>
<td>Emergency Response System W smoke alarm &amp; reminders</td>
<td>09F</td>
<td>Client</td>
<td>$343.00</td>
<td></td>
<td></td>
<td>$343.00</td>
</tr>
<tr>
<td></td>
<td>Safely Home (Alz Wander Registry)</td>
<td></td>
<td></td>
<td>$35.00</td>
<td></td>
<td></td>
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<tr>
<td>TOTAL</td>
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<td>$15,194.43</td>
</tr>
</tbody>
</table>
D.9 Vignette #23: Wong

Wong is not cognitively intact. Wong is independent with locomotion in the home, eating, and toileting but requires set-up help when engaging in personal hygiene activities and requires limited assistance when bathing. Wong experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). Wong has a live-in caregiver (usually a spouse) who provides advice/emotional support and assistance with IADLs.

1) Cognition- Not Intact (short term memory problem; in specific situations, decisions become poor or unsafe and cues/supervision necessary at those times; has difficulty finding words and finishing thoughts. However, if given enough time little or no prompting is required).

2) ADL- Independent in locomotion inside the home, eating, and toileting; set-up help required when engaging in personal hygiene activities (article or device needs to be provided within reach); limited assistance required when bathing (highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- Great difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) – Yes. (58% = spouse, 37% = adult-child) Caregiver providing advice/emotional support, assistance and assistance with IADLs.
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<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>Case Management</td>
<td>Visit</td>
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<td>1</td>
<td>$ 146.66</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Geriatric Assessment Team</td>
<td>Visit</td>
<td>$ 161.68</td>
<td>2</td>
<td>$ 323.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>2</td>
<td>$ 230.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support monitoring meds, evening meals)</td>
<td>Hour</td>
<td>$ 29.90</td>
<td>16</td>
<td>208</td>
<td>$ 6,219.20</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social Worker (replaced with First Link)</td>
<td>Visit</td>
<td>$ 147.00</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSS</td>
<td>Adult Day Service for Dementia (with exercise &amp; Bath)</td>
<td>01C</td>
<td>Full Day w bath</td>
<td>$ 86.71</td>
<td>5</td>
<td>65</td>
<td>$ 5,636.15</td>
</tr>
<tr>
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<td>Caregiver Support Group /First Link counselling</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$ 60.19</td>
<td>5</td>
<td></td>
<td>$ 300.95</td>
</tr>
<tr>
<td></td>
<td>Caregiver Support Respite (Paid)</td>
<td>08C</td>
<td>Hour</td>
<td>$ 31.77</td>
<td>15</td>
<td></td>
<td>$ 476.55</td>
</tr>
<tr>
<td></td>
<td>Friendly Visiting (dementia trained)</td>
<td>Hour</td>
<td>$ 2.53</td>
<td>2</td>
<td>26</td>
<td>$ 65.78</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>2</td>
<td>26</td>
<td>$ 869.70</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$ 42.16</td>
<td>1</td>
<td>13</td>
<td>$ 548.08</td>
</tr>
<tr>
<td>One Time</td>
<td>Emergency Response System W smoke alarm</td>
<td>09F</td>
<td>Client</td>
<td>$ 343.00</td>
<td></td>
<td></td>
<td>$ 343.00</td>
</tr>
<tr>
<td></td>
<td>Safely Home (Alz Wander Registry)</td>
<td>Case</td>
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<td></td>
<td></td>
<td></td>
<td>$ 35.00</td>
</tr>
<tr>
<td>TOTAL</td>
<td>Community Care Package</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$15,194.43</td>
</tr>
</tbody>
</table>
D.10 Vignette #24: Xavier

Xavier is not cognitively intact. Xavier requires some assistance with ADLs (independent in locomotion in the home, personal hygiene and toileting; some assistance required with eating; and limited assistance with bathing). Xavier experiences some difficulty using the phone and great difficulty with housekeeping, meal preparation, managing medications, and transportation. Xavier does not have a live-in caregiver. Xavier’s caregiver is an adult child who lives outside the home. The adult-child caregiver provides advice/emotional support and assistance with IADLs.

1) Cognition- Not Intact (short term memory problem; decisions are consistently poor or unsafe and cues/supervision are necessary at those times; Has difficulty finding words or finishing thoughts, prompting usually required).

2) ADL- Independent in eating, locomotion inside the home, personal hygiene and toileting. Set-up help required for only for eating (article or device needs to be provided within reach); Limited assistance required when bathing (client is highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- Some difficulty in using phone (needs some help, is very slow/fatigues); great difficulty with housekeeping, meal preparation, managing medications and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - No. (77% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
<table>
<thead>
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<th>Vignette: Xavier 8.9%</th>
<th>Service</th>
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<th>Unit =</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td>1 week</td>
<td>1 + additional hr ($48.88)</td>
<td>$ 195.54</td>
</tr>
<tr>
<td></td>
<td>Geriatric Assessment Team</td>
<td></td>
<td>Visit</td>
<td>$ 161.68</td>
<td>2</td>
<td></td>
<td>$ 323.36</td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>2</td>
<td></td>
<td>$ 230.00</td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support</td>
<td>10A</td>
<td>Hour</td>
<td>$ 29.90</td>
<td>18</td>
<td>234</td>
<td>$ 6,996.60</td>
</tr>
<tr>
<td></td>
<td>Social Worker (replaced with First Link)</td>
<td></td>
<td>Visit</td>
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<td>2</td>
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<td></td>
</tr>
<tr>
<td>CSS</td>
<td>Adult Day Service for Dementia (w exercise,</td>
<td>01C</td>
<td></td>
<td>$ 86.71</td>
<td>6</td>
<td>78</td>
<td>$ 6,763.38</td>
</tr>
<tr>
<td></td>
<td>support grp &amp; Bath)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Live-Out Caregiver</td>
<td>Caregiver Support Group / First Link</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$ 60.19</td>
<td>5</td>
<td></td>
<td>$ 300.95</td>
</tr>
<tr>
<td></td>
<td>counselling</td>
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</tr>
<tr>
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<td>Caregiver Support Respite (Paid)</td>
<td>08C</td>
<td>Hour</td>
<td>$ 31.77</td>
<td>15</td>
<td></td>
<td>$ 476.55</td>
</tr>
<tr>
<td>Still Needs Help</td>
<td>Friendly Visiting (dementia trained)</td>
<td></td>
<td>Hour</td>
<td>$ 2.53</td>
<td>2</td>
<td>26</td>
<td>$ 65.78</td>
</tr>
<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>2</td>
<td>26</td>
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<tr>
<td></td>
<td>Transportation</td>
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<td>$ 42.16</td>
<td>3</td>
<td></td>
<td>$ 126.48</td>
</tr>
<tr>
<td>One Time</td>
<td>Emergency Response System W smoke alarm &amp;</td>
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<td>Client</td>
<td>$ 343.00</td>
<td></td>
<td></td>
<td>$ 343.00</td>
</tr>
<tr>
<td></td>
<td>reminders</td>
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<td></td>
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<tr>
<td></td>
<td>Safely Home (Alz Wander Registry)</td>
<td></td>
<td></td>
<td>$ 35.00</td>
<td></td>
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<td>$ 35.00</td>
</tr>
<tr>
<td></td>
<td>Pharmacy/Blister pack</td>
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<td></td>
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<tr>
<td>TOTAL</td>
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<td></td>
<td></td>
<td></td>
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<td>$16,726.34</td>
</tr>
</tbody>
</table>
D.11 Vignette #29: C. Cameron

C. Cameron is not cognitively intact. C. Cameron requires some assistance with all ADLs (supervision with locomotion and eating; limited assistance with personal hygiene activities and toileting; extensive assistance with bathing). C. Cameron experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, transportation and phone use). C. Cameron has a live-in caregiver (a spouse or adult-child who provides advice/emotional support, assistance with IADLs and ADLs).

1) Cognition- Not Intact (short term memory problem; decisions consistently poor or unsafe, cues/supervision required at all times. Has difficulty finding words or finishing thoughts, prompting usually required).

2) ADL- Supervision/oversight, encouragement and cuing required with locomotion in the home and when eating; limited assistance with toileting and personal hygiene activities (client is highly involved in activity but requires some assistance/guided maneuvering); extensive assistance required when bathing (full performance of part of these activities performed by others).

3) IADL- Great difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - Yes. (68% = Spouse, 24% = adult-child) Caregiver providing advice/emotional support and assistance with both IADLs and ADLs.
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<th>Vignette: C Cameron 9.2%</th>
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<th>Cost/Unit for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
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<td><strong>Professional</strong></td>
<td>Case Management</td>
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<td>$146.66</td>
<td>1</td>
<td>$195.54</td>
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</tr>
<tr>
<td></td>
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<td></td>
<td>Visit</td>
<td>$161.68</td>
<td>2</td>
<td>$323.36</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>2</td>
<td>$230.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physio Assessment (restorative/strengthening program to ADP/PSW)</td>
<td></td>
<td>Visit</td>
<td>$100.00</td>
<td>3</td>
<td>$300.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support monitoring meds, evening meals)</td>
<td>10A</td>
<td>Hour</td>
<td>$29.90</td>
<td>18</td>
<td>$6,996.60</td>
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<tr>
<td></td>
<td>Social Worker client &amp; caregiver (enhance w First Link)</td>
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<td>Visit</td>
<td>$147.00</td>
<td>4</td>
<td>$588.00</td>
<td></td>
</tr>
<tr>
<td><strong>CSS</strong></td>
<td>Adult Day Service for Dementia (w exercise &amp; Bath)</td>
<td>01C</td>
<td>Full Day w bath</td>
<td>$86.71</td>
<td>6</td>
<td>$6,763.38</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caregiver Support Group / First Link counselling</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$60.19</td>
<td>5</td>
<td>$300.95</td>
<td></td>
</tr>
<tr>
<td></td>
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<td>Hour</td>
<td>$31.77</td>
<td>15</td>
<td>$476.55</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Friendly Visiting (dementia trained)</td>
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<td>Hour</td>
<td>$2.53</td>
<td>2</td>
<td>$65.78</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$33.45</td>
<td>2</td>
<td>$869.70</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Meals on Wheels</td>
<td>02A</td>
<td>Meal</td>
<td>$8.79</td>
<td>26</td>
<td>$26.37</td>
<td></td>
</tr>
<tr>
<td></td>
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<td>04A</td>
<td>2-Way Trip</td>
<td>$42.16</td>
<td>3</td>
<td>$126.48</td>
<td></td>
</tr>
<tr>
<td><strong>One Time</strong></td>
<td>Emergency Response System W smoke alarm</td>
<td>09F</td>
<td>Client</td>
<td>$343.00</td>
<td>1</td>
<td>$343.00</td>
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<tr>
<td></td>
<td>Safely Home (Alz Wander Registry)</td>
<td></td>
<td>Case</td>
<td>$35.00</td>
<td>1</td>
<td>$35.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Community Care Package</td>
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<td></td>
<td></td>
<td></td>
<td>$17,640.71</td>
<td></td>
</tr>
</tbody>
</table>
D. Daniels is not cognitively intact. D. Daniels requires assistance with all ADLs (setup help required when eating; supervision required with locomotion in the home; limited assistance with toileting, personal hygiene activities, and extensive assistance required when bathing). D. Daniels experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). D. Daniels does not have a live-in caregiver. D. Daniels has an adult child caregiver who lives outside the home who provides advice/emotional support and support with IADLs.

1) Cognition- Not Intact (short term memory problem; decisions consistently poor or unsafe, cues/supervision required at all times. Has difficulty finding words or finishing thoughts, prompting usually required).

2) ADL- Set-up help required when eating (article/device provided within reach); oversight, encouragement and cuing required with locomotion in the home; limited assistance required with toileting and personal hygiene activities (client is still highly involved in activity but requires some assistance/guided maneuvering); extensive assistance with bathing (client perform only 50% of tasks on own, full performance required by others for part of tasks).

3) IADL- Great Difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or involvement in the activity is possible).

4) Caregiver (in home?) - No. (72% = adult-child) Caregiver provides advice/emotional support and assistance with IADLs.
<table>
<thead>
<tr>
<th>Vignette: D. Daniels 10.5%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Min</th>
<th>Unit of Service for 1 week</th>
<th>Units for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td>1 + additional hr ($48.88)</td>
<td>1</td>
<td>$ 195.54</td>
</tr>
<tr>
<td></td>
<td>Geriatric Assessment Team</td>
<td></td>
<td>Visit</td>
<td>$ 161.68</td>
<td>2</td>
<td></td>
<td>$ 323.36</td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>2</td>
<td></td>
<td>$ 230.00</td>
</tr>
<tr>
<td></td>
<td>Physio Assessment (restorative/strengthening program)</td>
<td></td>
<td>Visit</td>
<td>$ 100.00</td>
<td>2</td>
<td></td>
<td>$ 200.00</td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support monitoring meds, evening meals)</td>
<td>10A</td>
<td>Hour</td>
<td>$ 29.90</td>
<td>14</td>
<td>182</td>
<td>$ 5,441.80</td>
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<td></td>
<td>Social Worker for client &amp; caregiver (enhance w First Link)</td>
<td></td>
<td>Visit</td>
<td>$ 147.00</td>
<td>6</td>
<td></td>
<td>$ 882.00</td>
</tr>
<tr>
<td>CSS</td>
<td>Adult Day Service for Dementia (w exercise &amp; Bath)</td>
<td>01C</td>
<td>Full Day w bath</td>
<td>$ 86.71</td>
<td>7</td>
<td>91</td>
<td>$ 7,890.61</td>
</tr>
<tr>
<td>Live-Out Caregiver</td>
<td>Caregiver Support Group/First Link counselling</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$ 60.19</td>
<td>5</td>
<td></td>
<td>$ 300.95</td>
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<tr>
<td>Determined Still Needs Help</td>
<td>Caregiver Support Respite (Paid)</td>
<td>08C</td>
<td>Hour</td>
<td>$ 31.77</td>
<td>5</td>
<td>65</td>
<td>$ 2,065.05</td>
</tr>
<tr>
<td></td>
<td>Friendly Visiting (dementia trained)</td>
<td></td>
<td>Hour</td>
<td>$ 2.53</td>
<td>2</td>
<td>26</td>
<td>$ 65.78</td>
</tr>
<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>2</td>
<td>26</td>
<td>$ 869.70</td>
</tr>
<tr>
<td></td>
<td>Meals on Wheels</td>
<td>02A</td>
<td>Meal</td>
<td>$ 8.79 (26 frozen/mth)</td>
<td>3</td>
<td></td>
<td>$ 26.37</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$ 42.16</td>
<td>3</td>
<td></td>
<td>$ 126.48</td>
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</table>
## Vignette: D. Daniels 10.5%

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<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Min</th>
<th>Unit of Service for 1 week</th>
<th>Units for 13 weeks</th>
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</tr>
</thead>
<tbody>
<tr>
<td>One Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Response System W smoke alarm &amp;&amp; reminders</td>
<td>09F</td>
<td>Client</td>
<td>$343.00</td>
<td></td>
<td></td>
<td>$343.00</td>
</tr>
<tr>
<td>Safely Home (Alz Wander Registry)</td>
<td></td>
<td>Case</td>
<td>$35.00</td>
<td></td>
<td></td>
<td>$35.00</td>
</tr>
<tr>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>Community Care Package</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$18,995.64</td>
</tr>
</tbody>
</table>
D.13 Vignette #35: I. Innis

I.Innis is not cognitively intact. I.Innis requires assistance with all ADLs (extensive assistance required when eating and is totally dependent with locomotion in the home, toileting, personal hygiene and bathing). I. Innis also experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). I.Innis has a live-in caregiver who is a spouse or adult-child. This caregiver provides advice/emotional support and assistance with IADLs and ADLs.

1) Cognition- Not Intact (short term memory problem; decisions consistently poor or unsafe, cues/supervision required at all times. Ability to make self understood is limited to making concrete requests).

2) ADL- Extensive assistance required when eating (client perform only 50% of tasks on own, full performance required by others for part of tasks); totally dependent on others to complete all other ADLs: locomotion in the home, toilet use, bathing and personal hygiene (full performance of activities performed by others).

3) IADL- Great Difficulty with all IADLs: housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in activity is possible).

4) Caregiver (in home?)- Yes. (69% = Spouse and 25% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs and 72% with ADLs.
<table>
<thead>
<tr>
<th>Vignette: I. Innis 9%</th>
<th>Service</th>
<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professional</strong></td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$146.66</td>
<td>1 week</td>
<td>1 + additional hr ($48.88)</td>
<td>$195.54</td>
</tr>
<tr>
<td>Geriatric Assessment Team</td>
<td></td>
<td></td>
<td>Visit</td>
<td>$161.68</td>
<td>2 weeks</td>
<td>2</td>
<td>$323.36</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>2 weeks</td>
<td>2</td>
<td>$230.00</td>
<td></td>
</tr>
<tr>
<td>Physio Assessment (resorative/strengthening program passed to ADP)</td>
<td></td>
<td>Visit</td>
<td>$100.00</td>
<td>3 weeks</td>
<td>3</td>
<td>$300.00</td>
<td></td>
</tr>
<tr>
<td>PSW (CCAC In-Home Support monitoring meds, evening meals)</td>
<td>10A</td>
<td>Hour</td>
<td>$29.90</td>
<td>14 weeks</td>
<td>14</td>
<td>$5,441.80</td>
<td></td>
</tr>
<tr>
<td>Social Worker for client &amp; caregiver (enhance w First Link®)</td>
<td></td>
<td>Visit</td>
<td>$147.00</td>
<td>6 weeks</td>
<td>6</td>
<td>$882.00</td>
<td></td>
</tr>
<tr>
<td><strong>CSS</strong></td>
<td>Adult Day Service for Dementia (w exercise, bath &amp; barber)</td>
<td>01C</td>
<td>Full Day w bath</td>
<td>$86.71</td>
<td>7 weeks</td>
<td>91</td>
<td>$7,890.61</td>
</tr>
<tr>
<td>Caregiver Support Group/ First Link® counselling</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$60.19</td>
<td>5 weeks</td>
<td>5</td>
<td>$300.95</td>
<td></td>
</tr>
<tr>
<td>Caregiver Support Respite (Paid)</td>
<td>08C</td>
<td>Hour</td>
<td>$31.77</td>
<td>5 weeks</td>
<td>5</td>
<td>$2,065.05</td>
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</tr>
<tr>
<td>Friendly Visiting (dementia trained)</td>
<td></td>
<td>Hour</td>
<td>$2.53</td>
<td>2 weeks</td>
<td>2</td>
<td>$65.78</td>
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<tr>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$33.45</td>
<td>3 weeks</td>
<td>3</td>
<td>$869.70</td>
<td></td>
</tr>
<tr>
<td>Meals on Wheels</td>
<td>02A</td>
<td>Meal</td>
<td>$8.79</td>
<td>26 frozen/mth</td>
<td>26</td>
<td>$26.37</td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$42.16</td>
<td>3 weeks</td>
<td>3</td>
<td>$126.48</td>
<td></td>
</tr>
<tr>
<td><strong>One Time</strong></td>
<td>Emergency Response System W smoke alarm &amp; &amp; reminders</td>
<td>09F</td>
<td>Client</td>
<td>$343.00</td>
<td></td>
<td></td>
<td>$343.00</td>
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<tr>
<td>Safely Home (Alz Wander Registry)</td>
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<td></td>
<td>no longer mobile</td>
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</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Community Care Package</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$19,060.64</td>
</tr>
</tbody>
</table>
D.14 Vignette #36: J. Johns

J. Johns is not cognitively intact. J. Johns requires assistance with all ADLs (limited assistance when eating, maximal assistance with personal hygiene, and is totally dependent with locomotion inside the home, toilet use and bathing). J. Johns has great difficulty in all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). J. Johns does not have a live-in caregiver.” J. Johns has an adult-child caregiver outside of the home who provides advice/emotional support and assistance with IADLs.

1) Cognition- Not Intact (short-term memory problem; never/rarely makes decisions; difficulty finding words or finishing thoughts, promoting usually required).

2) ADL- Limited assistance required when eating (client is still highly involved in activity but requires some assistance/guided maneuvering); Maximal assistance with personal hygiene (client involved and completed less than 50% of activity on own); Totally dependent in locomotion in the home, toileting, and bathing (full performance of activities by others).

3) IADL- Great Difficulty with all IADLs: housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in activity is possible).

4) Caregiver (in home?)- No (63% = adult-child, 19% = other relative living outside the home) Caregiver providing advice/emotional support and assistance with IADLs.

No care package was crafted for J. Johns as the SW BoC Expert Panel deemed this sub-group to be unsafe to remain in the community with supports.
Appendix E
South West Balance of Care Supportive Housing Care Packages and Costings

Care packages below with strike through formatting indicate services that were removed from the original community care packages entirely created by the SW BoC Expert Panel, or replaced with in-house programs.
E.1  Vignette #3: Copper

Copper is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Copper has no difficulty using the phone, some difficulty with transportation managing medications, meal preparation, and great difficulty with housekeeping. Copper has a live-in caregiver (adult-child or spouse). This live-in caregiver provides advice/emotional support and assistance with IADLs.

1) Cognition- Intact (short-term memory recall is good; makes consistent/reasonable/safe decisions and can express ideas without difficulty)

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- No difficulty using the phone, some difficulty with transportation and managing medications (needs some help, is very slow/fatigues), meal preparation, and great difficulty with housekeeping (little or no involvement in the activity is possible).

4) Caregiver (in home?)- Yes. (49% = adult-child, 44% = spouse) Caregiver providing advice/emotional support and assistance with IADLs.

No care package was developed for Copper by Supportive Housing providers as they felt the care needs of this sub-group were too light and they had support by a live in caregiver.
E.2 Vignette #4: Davis

Davis is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Davis has no difficulty using the phone, some difficulty with managing medications, meal preparation, and transportation, and great difficulty with housekeeping. Davis does not have a live-in caregiver. Davis has a caregiver outside of the home (an adult-child) who provides advice/emotional support and assistance with IADLs.

1) Cognition- Intact- good short-term memory; makes consistent/reasonable/safe decisions and can express ideas without difficulty

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- No difficulty using the phone, some difficulty with managing medications, meal preparation (needs some help, is very slow/fatigues), and transportation, and great difficulty with housekeeping and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?)- No. (75% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
<table>
<thead>
<tr>
<th>Vignette: Davis 11.5%</th>
<th>SH 1 + Services</th>
<th>Ministry Code</th>
<th>Unit =</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$146.66</td>
<td>On-site coordination</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy (falls assess)</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>Accessible Design &amp; Monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>PSW (CCAC In-Home Support)</td>
<td>10A</td>
<td>Hour</td>
<td>$35.00</td>
<td></td>
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<tr>
<td></td>
<td>Elder Person's Centre</td>
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<td>$6.40</td>
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<td>In-House Seniors' Program (wkly)</td>
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<td>Free</td>
<td>cards, pool, social, spiritual</td>
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<td></td>
<td>SMART-Strengthening/falls prevention</td>
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<td>1</td>
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<td></td>
<td>Homemaking</td>
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<td>Hour</td>
<td>$33.45</td>
<td>incorporated in PSW</td>
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<tr>
<td></td>
<td>Meals on Wheels (3hot/wk;4 frozen drop-off of 16)</td>
<td>02A</td>
<td>Meal</td>
<td>$8.79</td>
<td></td>
<td>3</td>
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<td>04A</td>
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<td>Price by that organization</td>
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<tr>
<td>One Time</td>
<td>Emergency Response-System</td>
<td>09F</td>
<td>Client</td>
<td>$34.12</td>
<td>Would inform that call centre may use SH office -not pay for unit service</td>
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<td></td>
<td>Pharmacy (Blister Pack &amp; med check)</td>
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<tr>
<td>TOTAL</td>
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<td>Unit =</td>
<td>Cost/Unit of Service for Ministry</td>
<td>Unit of Service for 1 week</td>
<td>Units of Service for 13 weeks</td>
<td>Total Ministry Cost</td>
</tr>
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<td>Case Management</td>
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<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapy (falls assess)</td>
<td>17A</td>
<td>Visit</td>
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<td>84.5</td>
<td>$ 2,957.50</td>
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<td>13</td>
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<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>incorporated in PSW</td>
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<td>Meals on Wheels (3hot/wk;4 frozen dropoff of 16)</td>
<td>02A</td>
<td>Meal</td>
<td>$ 8.79</td>
<td>39</td>
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<td>2-Way Trip</td>
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<td>Price by that organization</td>
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<td>One Time</td>
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<td></td>
</tr>
<tr>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$ 343.00</td>
<td>PART OF UNIT COST</td>
<td></td>
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</tr>
<tr>
<td>Pharmacy (Blister Pack &amp; meds check)</td>
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<td></td>
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E.3  Vignette #6: Fanshaw

Fanshaw is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Fanshaw has some difficulty using the phone and great difficulty with transportation, managing medications, preparing meals and housekeeping. Fanshaw has a caregiver outside the home (an adult-child who provides advice/emotional support and assistance with IADLs).

1) Cognition- Borderline Intact (short-term memory recall problem; has some difficulty making decisions in new situations only but can express ideas without difficulty.

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- Some difficulty using the phone (needs some help, is very slow/fatigues); great difficulty managing medications, preparing meals, housekeeping and with transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - No (72% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs).
<table>
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<th>Vignette: Fanshaw 4%</th>
<th>1 SH &amp; Services</th>
<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>Case Management</td>
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<td>Visit</td>
<td>On-site coordination</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occupational therapy (falls assess)</td>
<td>17A</td>
<td>Visit</td>
<td>Accessible Design/ongoing monitoring</td>
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</tr>
<tr>
<td>PSW (In-Home Support - includes bath, meds, housework, exercise, support)</td>
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<td>Hour</td>
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<td>10</td>
<td>130</td>
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<td>Visit</td>
<td>SH Staff to check blister pack daily</td>
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</tr>
<tr>
<td>CSS</td>
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<td>full day</td>
<td>$86.71</td>
<td>1</td>
<td>13</td>
<td>$ 1,127.23</td>
</tr>
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<td>Home Help/Homemaking/ Housekeeping</td>
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<td>Hour</td>
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<td></td>
<td></td>
<td></td>
<td>$ 0.00</td>
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<tr>
<td>Meals on Wheels (3hot/wk;4 frozen drop off of 16)</td>
<td>02A</td>
<td>Meal</td>
<td>$8.79</td>
<td>3</td>
<td>39</td>
<td>$ 342.81</td>
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</tr>
<tr>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$42.16</td>
<td>2</td>
<td>26</td>
<td>$ 1,096.16</td>
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</tr>
<tr>
<td>One Time</td>
<td>Emergency Response System with additional gadgets to be encouraged</td>
<td>09F</td>
<td>Client</td>
<td>Would inform that call centre may use SH office -not pay for unit service</td>
<td></td>
<td></td>
<td>$ 0.00</td>
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<tr>
<td>Pharmacy/Blister pack</td>
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</tr>
<tr>
<td>TOTAL</td>
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<td>$ 7,116.20</td>
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<td>Vignette: Fanshaw 4%</td>
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<td>Units of Service for 13 weeks</td>
<td>Total Ministry Cost</td>
</tr>
<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Case Management</td>
<td></td>
<td></td>
<td>Visit</td>
<td>$115.00</td>
<td>3</td>
<td></td>
<td>$345.00</td>
</tr>
<tr>
<td>Occupational Therapy (falls assess)</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>3</td>
<td>$345.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSW (CCAC In-Home Support)</td>
<td>10A</td>
<td>Hour</td>
<td>$35.00</td>
<td>6.5</td>
<td>84.5</td>
<td>$2,957.50</td>
<td></td>
</tr>
<tr>
<td>Nursing (CCAC - med management)</td>
<td></td>
<td>Visit</td>
<td>$35.00</td>
<td>SH Staff to check blister pack daily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CSS</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Day Service (Frail Elderly)</td>
<td>01B</td>
<td>full day</td>
<td>$86.71</td>
<td>1</td>
<td>13</td>
<td>$1,127.23</td>
<td></td>
</tr>
<tr>
<td>Home Help/Homemaking/Housekeeping</td>
<td>09B</td>
<td>Hour</td>
<td>$343.00</td>
<td>PART OF UNIT COST</td>
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<td></td>
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</tr>
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<td><strong>One Time</strong></td>
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<td></td>
</tr>
<tr>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$343.00</td>
<td>PART OF UNIT COST</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacy/Blister pack</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
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<td></td>
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<td>$5,982.97</td>
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</tbody>
</table>
E.4  Vignette #12: Lambert

Lambert is cognitively intact and requires assistance with some ADLs (supervision with locomotion; set-up help with eating; limited assistance with personal hygiene and toilet use; extensive assistance with bathing activities and extensive assistance with bathing (client can perform 50% on their own and requires full help for part of the task). Lambert has some difficulty using the phone and great difficulty with all other IADLs (meal preparation, housework, medication management, and transportation). Lambert has an adult-child caregiver outside the home who provides advice/emotional support and assistance with IADLs.

1) Cognition- Intact (short-term memory recall is good; some difficulty making decisions in new situations only. Can express ideas without difficulty).

2) ADL- Supervision required with locomotion (oversight, encouragement or cuing needed); set-up help only with eating (article or device provided within reach); limited assistance with toilet use and personal hygiene; and extensive assistance required with bathing activities (client can perform 50% of activity on own and requires full help for part of this task).

3) IADL- Some difficulty using the phone (needs some help, is very slow/fatigues); great difficulty with housekeeping, meal preparation, managing medications, and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - No. (71% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
<table>
<thead>
<tr>
<th>Vignette: Lambert 3.5%</th>
<th>1 SH &amp; Services</th>
<th>Ministry Code</th>
<th>Unit =</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional</td>
<td>Case Management</td>
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<td>Visit</td>
<td>$ 146.66</td>
<td>on-site coordination</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing (CCAC – incontinence &amp; med management)</td>
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<td>Visit</td>
<td>$ 115.00</td>
<td>Accessible</td>
<td>3</td>
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<tr>
<td></td>
<td>Physio Assessment (strengthening program)</td>
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<td>26</td>
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<tr>
<td></td>
<td>In-House Seniors’ Programs</td>
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<td>26</td>
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<td></td>
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<td>Hour</td>
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<td>2</td>
<td>26</td>
<td>$ 65.78</td>
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<tr>
<td></td>
<td>Homemaking/Housekeeping</td>
<td></td>
<td>Hour</td>
<td>$ 33.45</td>
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<td>26</td>
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<td>Meals on Wheels (frozen/month)</td>
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<td></td>
<td>Strengthening/falls prevention - Trained volunteer</td>
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<td>Hours</td>
<td>$ 2.53</td>
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<td>13</td>
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<td>04A</td>
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<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
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<td>PART OF UNIT COST</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Pharmacy/Blister pack</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>TOTAL</td>
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<td>Ministry Code</td>
<td>Unit =</td>
<td>Cost/Unit of Service for Ministry</td>
<td>Unit of Service for 1 week</td>
<td>Units of Service for 13 weeks</td>
<td>Total Ministry Cost</td>
</tr>
<tr>
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<td>-----------------</td>
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<td>-------------------</td>
</tr>
<tr>
<td>Professional</td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$146.66</td>
<td>on-site coordination</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing (CCAC - incontinence &amp; med management)</td>
<td></td>
<td>Visit</td>
<td>$57.47</td>
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<td>3</td>
<td>$172.41</td>
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<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td></td>
<td>3</td>
<td>$345.00</td>
</tr>
<tr>
<td></td>
<td>Physio Assessment (&amp; strengthening program)</td>
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<td>Visit</td>
<td>$100.00</td>
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<td>3</td>
<td>$300.00</td>
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<td>10A</td>
<td>Hour</td>
<td>$35.00</td>
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<td>Price by that organization</td>
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<td>09F</td>
<td>Client</td>
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<td></td>
<td>PART OF UNIT COST</td>
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<tr>
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<td>Pharmacy/Blister pack</td>
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E.5  Vignette #17: Quinn

Quinn is cognitively intact and requires assistance with all ADLs (extensive assistance with eating; maximal assistance with personal hygiene activities, and is totally dependent with locomotion in the home, toileting, and bathing (full activity is performed by another person). Quinn has some difficulty using the phone and great difficulty with all other IADLs (meal preparation, housework, medication management, and transportation). Quinn has a live-in caregiver. The caregiver is a spouse who provides advice/emotional support, assistance with ADLs and IADLs.

1) Cognition- Intact (short-term memory recall is good; makes good or consistent decisions and can express ideas without difficulty).

2) ADL- Extensive assistance required with eating (client can perform 50% of activity on own and requires full help for part of this task); maximal assistance with personal hygiene activities (client involved and completed less than 50% of activity on own); and totally dependent with locomotion in the home, bathing and toileting (full performance of these tasks done by someone else).

3) IADL- Some difficulty using the phone (needs some help, is very slow/fatigues); great difficulty with housekeeping, meal preparation, managing medications, and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - Yes. (70% = spouse) Caregiver providing advice/emotional support and assistance with ADLs and IADLs.
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<th>Unit</th>
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<th>Unit of Service for 13 weeks</th>
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<td>$146.66</td>
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<tr>
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<td>15A</td>
<td>Visit</td>
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<td>Visit</td>
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<td>2</td>
<td>200.00</td>
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<td>Hour</td>
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<td>2-Way Trip</td>
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<td>Price by that organization</td>
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<td>Unit =</td>
<td>Cost/Unit of Service for Ministry</td>
<td>Unit of Service for 1 week</td>
<td>Units of Service for 13 weeks</td>
<td>Total Ministry Cost</td>
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<tr>
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<td>Units of Service for 13 weeks</td>
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</tr>
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<td>Nursing (CCAC - incontinence &amp; med management)</td>
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<td>Visit</td>
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<td>3</td>
<td>$ 345.00</td>
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<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>2</td>
<td>26</td>
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<td>SH PSW</td>
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E.6  Vignette #18: Rogers

Rogers is cognitively intact and requires assistance with all ADLs (supervision when eating, maximal assistance with personal hygiene activities and is totally dependent with locomotion in the home, bathing and toileting). Rogers also requires assistance with all IADLs (some difficulty using the phone; great difficulty with meal preparation, housework, managing medications and transportation). Rogers does not have a live-in caregiver. Rogers does have an adult-child caregiver who lives outside the home who provides advice/emotional support and assistance with IADLs.

1)  Cognition - Intact (memory recall is good, can make safe and reasonable decisions and express ideas without difficulty).

2)  ADL - Supervision required when eating (oversight, encouragement or cuing needed); maximal assistance required with personal hygiene activities (client involved and completed less than 50% of activity on own); totally dependent with locomotion in the home, toileting and bathing (entire task performed by others).

3)  IADL - Some difficulty using the phone (needs some help, is very slow/fatigues); great difficulty with meal preparation, managing medications housekeeping and transportation (little or no involvement in the activity is possible).

4)  Caregiver (in home?) - No. (62% = adult-child, 17% = other relative who lives outside the home) Caregiver providing advice/emotional support and assistance with IADLs).
<table>
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<th>Unit</th>
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<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
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<td><strong>Professional</strong></td>
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<td></td>
<td>3</td>
<td>$ 345.00</td>
</tr>
<tr>
<td></td>
<td>Physio Assessment (&amp; strengthening program)</td>
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<td>Visit</td>
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<td>3</td>
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<td>Visit</td>
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<td>2</td>
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<tr>
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</tr>
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</tr>
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<td>Units for 13 weeks</td>
<td>Total Ministry Cost</td>
</tr>
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</tr>
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<td>Case Management</td>
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<td>Speech Language Pathologist</td>
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<td>2</td>
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<td>$ 33.45</td>
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<td>Part of SH Unit Cost</td>
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<tr>
<td></td>
<td>Pharmacy/Blister pack</td>
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<td>TOTAL</td>
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<td>$19,324.10</td>
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E.7 Vignette #21: Upperton

Upperton is not cognitively intact but functionally independent in all ADLs with the exception of bathing (limited assistance is required). Upperton has some difficulty using the phone, managing medications and preparing meals and great difficulty with transportation and housekeeping. Upperton has a live-in caregiver. This live-in caregiver provides advice/emotional support and assistance with IADLs. (*note: more than half provide assistance with ADLs).

1) Cognition- not intact (short term memory problem; in specific situations, decisions consistently poor or unsafe and cues/supervision necessary at all times; has difficulty finding words or finishing thoughts but if given enough time little or no prompting is required).

2) ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene); client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- Some difficulty using the phone, managing medications; housekeeping and preparing meals and transportation (needs some help, is very slow/fatigues).

4) Caregiver (in home?) - Yes, (53 % = spouse, 42 % = adult-child) Caregiver providing advice/emotional support, [61% provide assistance with ADLs] and almost all provide assistance with IADLs).
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<thead>
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<th>Vignette: Upperton 2.6%</th>
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<th>Ministry Code</th>
<th>Unit</th>
<th>Cost/Unit of Service for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
</tr>
</thead>
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<td>Case Management</td>
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<td></td>
<td>Entry-level monitoring and grooming assist using CCAC PSW</td>
<td>1 week</td>
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<tr>
<td>Entry Level</td>
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<td>Visit</td>
<td>$ 161.68</td>
<td></td>
<td>2 week</td>
<td></td>
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</tr>
<tr>
<td>Occupational Therapy</td>
<td>17A Visit</td>
<td>$ 115.00</td>
<td></td>
<td>Accessible design/monitoring</td>
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<tr>
<td>Social Worker</td>
<td>08B Visit</td>
<td>$ 147.00</td>
<td></td>
<td></td>
<td>2 week</td>
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<td>01C Full Day w bath</td>
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<td>5</td>
<td>65</td>
<td>$ 5,636.15</td>
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<td>Caregiver Support Group (First Link® counselling)</td>
<td>08A &amp; 08B Hour</td>
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<tr>
<td>Friendly Visiting (dementia trained)</td>
<td>Hour</td>
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<td>2</td>
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<td>Will explain to client and caregiver</td>
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<td>Caregiver to monitor</td>
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<td>Pharmacy/Blister pack</td>
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<td>Cost/Unit of Service for Ministry</td>
<td>Unit of Service for 1 week</td>
<td>Units of Service for 13 weeks</td>
<td>Total Ministry Cost</td>
</tr>
<tr>
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<td></td>
<td>Visit</td>
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<td>Onsite coordination</td>
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<td>Visit</td>
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<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td></td>
<td>2</td>
<td>$230.00</td>
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<tr>
<td></td>
<td>First Link®</td>
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<td>2</td>
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<td>$31.77</td>
<td>5</td>
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<tr>
<td></td>
<td>Friendly Visiting (dementia trained)</td>
<td></td>
<td>Hour</td>
<td>$2.53</td>
<td>2</td>
<td>26</td>
<td>$65.78</td>
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<tr>
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<td>Price by that organization</td>
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E.8 Vignette #22: Vega

Vega is not cognitively intact but is functionally independent in all ADLs with the exception of bathing (limited assistance is required). Vega has no difficulty using the phone, some difficulty with meal preparation, and managing medications and great difficulty with transportation and housekeeping. Vega does not have a live-in caregiver. The caregiver is an adult-child who lives outside of the home who provides advice/emotional support and assistance with IADLs.

1) Cognition- Not Intact (short term memory problem; in specific situations, decisions become poor or unsafe and cues/supervision necessary at those times; has difficulty finding words or finishing thoughts but if given enough time little or no prompting is required)

2) ADL- independent in eating, locomotion in the home, toilet use and personal hygiene). Limited assistance required when bathing (highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- No difficulty using the phone; some difficulty with meal preparation, and managing medications (needs some help, is very slow/fatigues); great difficulty with housekeeping and transportation (little or no involvement in activity is possible).

4) Caregiver (in home?) - No. (75% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
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<th>Ministry Code</th>
<th>Unit =</th>
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<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
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<td>$ 323.36</td>
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<td>Visit</td>
<td>$ 161.68</td>
<td>2</td>
<td>$ 323.36</td>
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<tr>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
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<td>2</td>
<td>$ 230.00</td>
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</tr>
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<td>Visit</td>
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<td>2</td>
<td></td>
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<tr>
<td><strong>CSS</strong></td>
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<td>01C</td>
<td>Full Day w bath</td>
<td>$ 86.71</td>
<td>5</td>
<td>65</td>
<td>$ 5,636.15</td>
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<td>Hour</td>
<td>$ 2.53</td>
<td>2</td>
<td>26</td>
<td>$ 65.78</td>
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<tr>
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<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>2</td>
<td>26</td>
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<tr>
<td></td>
<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$ 34.12</td>
<td>Price by that organization</td>
<td>3</td>
<td>$ 102.36</td>
</tr>
<tr>
<td><strong>One Time</strong></td>
<td>Emergency Response System W smoke alarm &amp; reminders</td>
<td>09F</td>
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<td>$ 343.00</td>
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<td>$ 343.00</td>
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</tr>
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<td>Pharmacy/Blister pack</td>
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<tr>
<td><strong>TOTAL</strong></td>
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<td>Units of Service for 13 weeks</td>
<td>Total Ministry Cost</td>
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<tr>
<td>Professional</td>
<td>Case Management</td>
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<td>Visit</td>
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<td>on-site coordination</td>
<td>1</td>
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</tr>
<tr>
<td>Geriatric Assessment Team</td>
<td></td>
<td>Visit</td>
<td>$161.68</td>
<td>2</td>
<td>$323.36</td>
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</tr>
<tr>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$115.00</td>
<td>2</td>
<td>$230.00</td>
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<tr>
<td>CSS</td>
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<td>01C</td>
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<td>$86.71</td>
<td>5</td>
<td>65</td>
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<td>2</td>
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<td>2-Way Trip</td>
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<td>Price by that organization</td>
<td>3</td>
<td>$102.36</td>
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<td>$35.00</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
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<td><strong>$14,763.22</strong></td>
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E.9  Vignette #23: Wong

Wong is not cognitively intact. Wong is independent with locomotion in the home, eating, and toileting but requires set-up help when engaging in personal hygiene activities and requires limited assistance when bathing. Wong experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). Wong has a live-in caregiver (usually a spouse) who provides advice/emotional support and assistance with IADLs.

1) Cognition- Not Intact (short term memory problem; in specific situations, decisions become poor or unsafe and cues/supervision necessary at those times; has difficulty finding words and finishing thoughts. However, if given enough time little or no prompting is required).

2) ADL- Independent in locomotion inside the home, eating, and toileting; set-up help required when engaging in personal hygiene activities (article or device needs to be provided within reach); limited assistance required when bathing (highly involved in activity but requires some assistanceguided maneuvering).

3) IADL- Great difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) – Yes. (58% = spouse, 37% = adult-child) Caregiver providing advice/emotional support, assistance and assistance with IADLs.
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<th>Units for 13 weeks</th>
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<td></td>
<td>Visit</td>
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<td>Visit</td>
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</tr>
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<td>9</td>
<td>117</td>
<td>$4,095.00</td>
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<td>$147.00</td>
<td></td>
<td></td>
<td>2</td>
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<td>Full Day w bath</td>
<td>$86.71</td>
<td>5</td>
<td>65</td>
<td>$5,636.15</td>
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<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$60.19</td>
<td>5</td>
<td>$300.95</td>
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<td>Caregiver Support Respite (Paid)</td>
<td>08C</td>
<td>Hour</td>
<td>$31.77</td>
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<td>$476.55</td>
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<td></td>
<td>Hour</td>
<td>$2.53</td>
<td>2</td>
<td>26</td>
<td>$65.78</td>
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<td>Home Help/Homemaking</td>
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<td>Price by that organization</td>
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<td>$102.36</td>
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<td><strong>One Time</strong></td>
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<tr>
<td>Emergency Response System W smoke alarm</td>
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<td>$343.00</td>
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<td>$35.00</td>
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<tr>
<td>Pharmacy/Blister pack</td>
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<td>Units for 13 weeks</td>
<td>Total Ministry Cost</td>
</tr>
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<td>PSW (SH respite, meds monitor, bath, clean, meals)</td>
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<td>$35.00</td>
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<td>65</td>
<td>$5,636.15</td>
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<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$60.19</td>
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<td>Hour</td>
<td>$31.77</td>
<td>15</td>
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<tr>
<td></td>
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<td>$2.53</td>
<td>2</td>
<td>26</td>
<td>$65.78</td>
</tr>
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<td>$102.36</td>
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<td>Emergency Response System W smoke alarm</td>
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<td>Client</td>
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<td>PART OF UNIT COST</td>
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<td>Safely Home (Alz Wander Registry)</td>
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E.10 Vignette #24: Xavier

Xavier is not cognitively intact. Xavier requires some assistance with ADLs (independent in locomotion in the home, personal hygiene and toileting; some assistance required with eating; and limited assistance with bathing). Xavier experiences some difficulty using the phone and great difficulty with housekeeping, meal preparation, managing medications, and transportation. Xavier does not have a live-in caregiver. Xavier’s caregiver is an adult child who lives outside the home. The adult-child caregiver provides advice/emotional support and assistance with IADLs.

1) Cognition- Not Intact (short term memory problem; decisions are consistently poor or unsafe and cues/supervision are necessary at those times; Has difficulty finding words or finishing thoughts, prompting usually required).

2) ADL- Independent in eating, locomotion inside the home, personal hygiene and toileting. Set-up help required for only for eating (article or device needs to be provided within reach); Limited assistance required when bathing (client is highly involved in activity but requires some assistance/guided maneuvering).

3) IADL- Some difficulty in using phone (needs some help, is very slow/fatigues); great difficulty with housekeeping, meal preparation, managing medications and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - No. (77% = adult-child) Caregiver providing advice/emotional support and assistance with IADLs.
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<th>Vignette: Xavier 8.9%</th>
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<th>Unit</th>
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<th>Unit of Service for 1 week</th>
<th>Units for 13 weeks</th>
<th>Total Ministry Cost</th>
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<tr>
<td>Occupational Therapy</td>
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<td>Accessible Design/monitoring</td>
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<td>10A Hour</td>
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<td>14</td>
<td>182</td>
<td>$6,370.00</td>
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<tr>
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<td>$294.00</td>
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<td>Full Day w bath $86.71</td>
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<td>78</td>
<td>$6,763.38</td>
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<td>Caregiver Support Group (First Link® counselling/education)</td>
<td>Hour</td>
<td>$60.19</td>
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<td><strong>Determined still needs help &amp; education</strong></td>
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<tr>
<td>Friendly Visiting (dementia trained)</td>
<td>Hour</td>
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<td>2</td>
<td>26</td>
<td>$65.78</td>
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<tr>
<td>Home Help/Homemaking</td>
<td>09B Hour</td>
<td>$33.45</td>
<td>2</td>
<td>26</td>
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<td></td>
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<tr>
<td>Transportation</td>
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<td>$34.12</td>
<td>Price by that organization</td>
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<td>$102.36</td>
<td></td>
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<tr>
<td><strong>One Time</strong></td>
<td>Emergency Response System W smoke alarm &amp; reminders</td>
<td>Client</td>
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<tr>
<td>Safely Home (Alz Wander Registry)</td>
<td>Case</td>
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<tr>
<td>Pharmacy/Blister pack</td>
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<td>Unit =</td>
<td>Cost/Unit of Service for Ministry</td>
<td>Unit of Service for 1 week</td>
<td>Units of Services for 13 weeks</td>
<td>Total Ministry Cost</td>
</tr>
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<tr>
<td>Case Management</td>
<td></td>
<td>Visit</td>
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<td>Onsite coordination</td>
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<td>$ 323.36</td>
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<td>Geriatric Assessment Team</td>
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<td>Visit</td>
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<td></td>
<td>2</td>
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<tr>
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<td></td>
<td>2</td>
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<td>Hour</td>
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<tr>
<td>Adult Day Service for Dementia (w exercise, support grp &amp; Bath)</td>
<td>01C</td>
<td>Full Day w bath</td>
<td>$ 86.71</td>
<td>5</td>
<td>65</td>
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<td>$ 5,636.15</td>
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<td><strong>Live-out caregiver</strong></td>
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<td>08A &amp; 08B</td>
<td>Hour</td>
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<td>Hour</td>
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<td>2</td>
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E.11 Vignette #29: C. Cameron

C. Cameron is not cognitively intact. C. Cameron requires some assistance with all ADLs (supervision with locomotion and eating; limited assistance with personal hygiene activities and toileting; extensive assistance with bathing). C. Cameron experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, transportation and phone use). C. Cameron has a live-in caregiver (a spouse or adult-child who provides advice/emotional support, assistance with IADLs and ADLs).

1) Cognition- Not Intact (short term memory problem; decisions consistently poor or unsafe, cues/supervision required at all times. Has difficulty finding words or finishing thoughts, prompting usually required).

2) ADL- Supervision/oversight, encouragement and cuing required with locomotion in the home and when eating; limited assistance with toileting and personal hygiene activities (client is highly involved in activity but requires some assistance/guided maneuvering); extensive assistance required when bathing (full performance of part of these activities performed by others).

3) IADL- Great difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in the activity is possible).

4) Caregiver (in home?) - Yes. (68% = Spouse, 24% = adult-child) Caregiver providing advice/emotional support and assistance with both IADLs and ADLs.
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<th>Ministry Code</th>
<th>Unit =</th>
<th>Cost/Unit for Ministry</th>
<th>Unit of Service for 1 week</th>
<th>Units of Service for 13 weeks</th>
<th>Total Ministry Cost</th>
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<td>Full Day w bath</td>
<td>$86.71</td>
<td>6</td>
<td>78</td>
<td>$6,763.38</td>
</tr>
<tr>
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<td>Caregiver Support Group (First Link® counselling)</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$60.19</td>
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<td>5</td>
<td>$300.95</td>
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<td>$31.77</td>
<td></td>
<td>15</td>
<td>$476.55</td>
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<tr>
<td></td>
<td>Friendly Visiting (dementia trained)</td>
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<td>Hour</td>
<td>$2.53</td>
<td>2</td>
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<td>Home Help/Homemaking</td>
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<td>$34.12</td>
<td>Price by that organization</td>
<td>3</td>
<td>$102.36</td>
</tr>
<tr>
<td>One Time</td>
<td>Emergency Response System W smoke alarm</td>
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<td>Client</td>
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<tr>
<td></td>
<td>Safely Home (Alz Wander Registry)</td>
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</tr>
<tr>
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<td>Pharmacy/Blister pack</td>
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<td>Unit of Service for 1 week</td>
<td>Units of Service for 13 weeks</td>
<td>Total Ministry Cost</td>
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<tr>
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</tr>
<tr>
<td>Professional</td>
<td>Case Management</td>
<td></td>
<td>Visit</td>
<td>$ 146.66</td>
<td>Onsite Coordination</td>
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<td></td>
<td>Geriatric Assessment Team</td>
<td>Visit</td>
<td>$ 161.68</td>
<td>2</td>
<td>$ 323.36</td>
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<tr>
<td></td>
<td>Occupational Therapy</td>
<td>17A</td>
<td>Visit</td>
<td>$ 115.00</td>
<td>2</td>
<td>$ 230.00</td>
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<td></td>
<td>Physio Assessment</td>
<td></td>
<td>Visit</td>
<td>$ 100.00</td>
<td>3</td>
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</tr>
<tr>
<td></td>
<td>(restorative/strengthening program to ADP/PSW)</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>PSW (CCAC In-Home Support monitoring meds, evening meals)</td>
<td>10A</td>
<td>Hour</td>
<td>$ 35.00</td>
<td>12</td>
<td>156</td>
<td>$ 5,460.00</td>
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<tr>
<td></td>
<td>Social Worker client &amp; caregiver (enhance w First Link®)</td>
<td></td>
<td>Visit</td>
<td>$ 147.00</td>
<td>4</td>
<td>$ 588.00</td>
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<tr>
<td>CSS</td>
<td>Adult Day Service for Dementia (w exercise &amp; Bath)</td>
<td>01C</td>
<td>Full Day w bath</td>
<td>$ 86.71</td>
<td>6</td>
<td>78</td>
<td>$ 6,763.38</td>
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<td></td>
<td>Caregiver Support Group (First Link® counselling)</td>
<td>08A &amp; 08B</td>
<td>Hour</td>
<td>$ 60.19</td>
<td>5</td>
<td>$ 300.95</td>
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<tr>
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<td>Caregiver Support Respite (Paid)</td>
<td>08C</td>
<td>Hour</td>
<td>$ 31.77</td>
<td>15</td>
<td>$ 476.55</td>
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<td>Friendly Visiting (dementia trained)</td>
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<td>Hour</td>
<td>$ 2.53</td>
<td>2</td>
<td>26</td>
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<tr>
<td></td>
<td>Home Help/Homemaking</td>
<td>09B</td>
<td>Hour</td>
<td>$ 33.45</td>
<td>13</td>
<td>$ 114.27</td>
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<td>Meals on Wheels</td>
<td>02A</td>
<td>Meal</td>
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<td>13</td>
<td>$ 114.27</td>
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<td>Transportation</td>
<td>04A</td>
<td>2-Way Trip</td>
<td>$ 34.12</td>
<td>3</td>
<td>$ 102.36</td>
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<tr>
<td>One Time</td>
<td>Emergency Response System</td>
<td>09F</td>
<td>Client</td>
<td>$ 343.00</td>
<td>Part of unit cost</td>
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<td>$ 35.00</td>
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<td></td>
<td>Safely Home (Alz Wander Registry)</td>
<td>Case</td>
<td>$ 35.00</td>
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<td></td>
<td>Pharmacy/Blister pack</td>
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<td>TOTAL</td>
<td>Supportive Housing ii Package</td>
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<td></td>
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<td>$14,393.87</td>
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</tbody>
</table>
E.12 Vignette #30: D. Daniels

D. Daniels is not cognitively intact. D. Daniels requires assistance with all ADLs (setup help required when eating; supervision required with locomotion in the home; limited assistance with toileting, personal hygiene activities, and extensive assistance required when bathing). D. Daniels experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). D. Daniels does not have a live-in caregiver. D. Daniels has an adult child caregiver who lives outside the home who provides advice/emotional support and support with IADLs.

1) Cognition- Not Intact (short term memory problem; decisions consistently poor or unsafe, cues/supervision required at all times. Has difficulty finding words or finishing thoughts, prompting usually required).

2) ADL- Set-up help required when eating (article/device provided within reach); oversight, encouragement and cuing required with locomotion in the home; limited assistance required with toileting and personal hygiene activities (client is still highly involved in activity but requires some assistance/guided maneuvering); extensive assistance with bathing (client perform only 50% of tasks on own, full performance required by others for part of tasks).

3) Caregiver (in home?) - No. (72% = adult-child) Caregiver provides advice/emotional support and assistance with IADLs.

<table>
<thead>
<tr>
<th>Vignette: D. Daniels 10.5%</th>
<th>SH 2 + Services</th>
<th>SH 2 + Services</th>
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</thead>
<tbody>
<tr>
<td>Not suitable for Supportive Housing i</td>
<td>Not feasible for Supportive Housing ii with no live-in</td>
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</table>

Note: No care packages were developed for D. Daniels, C. Cameron, I. Innis, or J. Johns as all were felt ill-suited or not feasible for either Supportive Housing program.