

**Don't Move Me There! Promoting Autonomy in the Provision of Long-term Care for
Seniors in Canada**

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ABSTRACT

Like many countries around the world, Canada's population is aging. Not only will there be a significant increase in the number of older adults over the coming years, but increasingly these seniors will fall into the oldest-old category, those over the age of 80. These elderly seniors are more likely than their younger counterparts to reside in long-term care facilities. The current system of long-term care in Canada leaves much to be desired by older adults who's overwhelming wish is to remain in their own homes as long as possible. Many older adults fear a move into long-term care because of the restrictions on their personal freedom and choice. More and more seniors will be looking to long-term care facilities to provide living arrangements that allow them to remain autonomous for as long as possible. The right to autonomy for residents in long-term care is a positive right that governments must protect. This right requires the provision of long-term care services and facilities that promote autonomy for Canadian seniors. A number of international models provide innovative ways to design and delivery long-term care. These examples provide a starting place for all levels of government to re-imagine long-term care in Canada. A movement away from the institution, to facilities and services that feel more like home and promote autonomy in the lives of seniors.

INTRODUCTION

Like many countries around the world, Canada's population is aging. The number of seniors (adults over the age of 65) in Canada is expected to double in the next 25 years resulting in 10.4 million seniors by 2036. By 2051, 1 in 4 Canadians will be over the age of 65 (Employment and Social Development Canada, 2014a). According to Statistics Canada, there are now more people over the age of 65 than under the age of 15 for the first time in Canadian history. The retirement of the baby boom generation will have serious impacts on social and economic life in Canada. Currently, many retired Canadians have large families that provide support to them in their old age, but family size is shrinking. Between 1971 and 2001 average family size declined from 3.7 to 3 individuals. (Employment and Social Development Canada, 2014b). This reduction in family size has reduced the number of available informal care givers for seniors over the age of 80. This is called the caregiver support ratio.

The caregiver support ratio is the number of adults between the ages of 45 and 64 who can provide care (the caregivers) to the number of seniors over the age of 80, who will require care (the care recipients). This ratio was developed by the American Association of Retired Person's (AARP) Public Policy Institute (Redfoot, Feinberg, & Houser 2). The caregiver support ratio in Canada is declining. Data from the 2011 National Household Survey conducted by Statistics Canada, was used by the author to calculate the current caregiver support ratio in Canada as being 6.8 to 1. This is number of available caregivers (Canadians aged 45 to 64) for every one person likely to require care (those over the age of 80). Further calculate reveals that this ratio is expected to decline to 3 to 1 by 2038 using a medium population growth projection. The implications of these findings suggest that current levels of informal care provision in Canada will not be sustainable. With almost 7 people for the average senior over 80 to rely on, informal care levels are helping to reduce the burden on our

formal care system by enabling seniors to stay at home longer. Informal caregivers are family and friends who provide unpaid assistance with transportation and personal care. They help keep seniors in their homes longer thereby reducing burden to Canada's health and long-term care systems.

Informal care allows for greater amounts of autonomy and self-determination in old age (Lum, et al., 2011; Fast & Keating, 2001; Turner & Findlay, 2012). When the ratio declines to 3 to 1, this will mean that many seniors over 80 will not have family or friends available to provide them with informal care, thereby increasing their social isolation and their dependence on the formal long-term care system.

According to the OECD (May 2011) Canada's expenditure on long-term nursing care was equivalent to about 1.5% of GDP with more than 80% of this expenditure going directly to institutional care. This is a significant proportion of public funds, to provide homes for those seniors with high care needs and/or low levels of informal support from family and friends.

However, there is a disconnect between the types of care seniors want and the care that is currently provided. Current statistics put the number of seniors that want to remain living in their own home as long as possible between 85-90% (Health Care in Canada, 2011; Redfoot, Feinberg, & Houser, 2013; RBC, 2013). Many Canadian seniors find institutional long-term care facilities an undesirable destination. A 2013 conducted by Ipsos Reid for the Royal Bank of Canada found that 56% of retired respondents (online interviews with a sample of 2,159 Canadian adults, 50+) found living in a retirement residence with care provided (i.e. assisted living) appealing, while only 12% felt that way about receiving care in a long-term care facility. A 2007 study by Clarity for The EAR Foundation out of the United States, found that seniors fear moving into a nursing home more than they feared death. These fears are equally believable in the Canadian context. Few adults speak favourably about the possibility of moving into long-term care in the future.

Long-term care homes are often seen as depressing institutions that many find it difficult to visit, let alone live in.

Why does this fear of long-term care facilities exist? At its core the fear of long-term care facilities may be directly related to a fear of death and facing one's own mortality. But another reasonable assumption may be the loss of independence a move to long-term care signifies.

Having lived the majority of their adult lives independently and with high levels of autonomy, many Canadian seniors dread the thought of moving into a facility that restricts their movement and personal choice.

This paper will attempt to probe deeper into the fear of long-term care facilities and proposes ways in which residential long-term care could be offered to promote autonomy and independence in living arrangements for seniors. From a public policy perspective, it is a reasonable expectation that ever effort should be made to offer the kinds of services that protect citizens' rights and promote their self-interests. Specifically, this paper will focus on autonomy; a crucial determinate of an individuals' quality of life. As an increasing number of Canadian adults enter old age with dwindling levels of social support, the reliance on long-term care facilities is be expected to increase. In their 2013 submission to the Minister of Transport, Infrastructure and Communities, the Canadian Medical Association (CMA) recommended an increase to public expenditure into long-term care (3). This increase was due to the increasing number of older seniors and their "increasingly complex care needs". The CMA also recommended the building of innovative residential models to "ensure residents are in the setting most appropriate to their needs (3)".

The current system of long-term care in Canada has not protected the right to autonomy for its' residents. In this paper I will argue that the right to autonomy in long-term care provision is a

positive right, that requires state action when seniors are no longer able to execute their autonomous decisions. States should organize and provide care to seniors that allows them to remain autonomous, for as long as possible. Focusing on autonomy also requires a shift in the framework of how care to seniors is delivered, and moves away from a paternalistic form of care to one that honours and values seniors' perspective on how their care is provided.

In this paper, chapter one will give an overview of the current system of care in Canada, and the ways in which the provision of care infringes on seniors' autonomy. Chapter two will focus on the definition of autonomy for seniors in long-term care and the positive nature of this right. Chapter three will provide three international examples of setting up living arrangements for seniors that promotes autonomy. To conclude, some suggestions on how public policy could shape the provision of long-term care that promotes autonomy will be offered.

CHAPTER ONE: THE CURRENT SYSTEM OF LONG-TERM CARE IN CANADA

In order to best understand how long-term care facilities could be designed to promote autonomy and make them more attractive to Canadian seniors, it is important to understand the system as it currently is. This chapter will begin with an overview of the long-term care system in Canada addressing the ways in which the delivery of care infringes on seniors right to autonomy. Long-term care facilities in Canada provide highly structured regimes of care that infringe on resident privacy. A focus on health and safety often leaves little room for personal freedom of choice for residents. Within these facilities the balance of power resides not with seniors, but with care providers, which can be a difficult adjustment for independent adults to make. For these reasons, most Canadian seniors dread the thought of moving into long-term care facilities. Operating more as an institution than a home, these facilities place little emphasis on the protection of seniors' autonomy. Perhaps most importantly the very framework that supports the systems of care for Canadian seniors is one that undervalues the role that seniors themselves can play in defining their final years.

Long-term Care (LTC) in Canada

Long-term care in Canada is often thought of as a continuum of care. It usually begins from the point at which individuals need regular assistance with activities of daily living (ADLs) such as eating, dressing and cleaning themselves, and can continue to include medical and other non-medical care. Loss of mobility, frailty and declines in cognitive and physical functioning are the main reasons older adults find themselves unable to live independently (“Global Health and Aging” 23). Many seniors who find themselves in this situation require some form of long-term

care: whether it's home care, community care or assisted living, residential or long-stay hospital care. There are substantial costs associated with these types of care that fall on families and societies. For the purposes of this paper, the term long-term care facility will be used to describe institutional settings, where seniors live and receive some level of social, medical or physical supports. Homecare is also discussed as an important component of the continuum of care that seniors receive as they age.

Unlike hospital and physician services in Canada, facility based and home based long-term care is not an insured service under the Canada Health Act (New Directions 9). This is due to the classification of facility based long-term care as not "medically necessary". Long-term care and homecare are instead viewed as "extended" health services which means that in Canada the various levels of government (federal, provincial and municipal) are under no obligation to provide a standardized approach to service provision. All Canadian provinces and territories have made arrangements to provide these services to seniors, but differences exist not only across the various provinces and territories but also within them. The provision of and access to long-term care and homecare services varies across the country, as does the co-payment or user fees charged. A lack of consistency across the country in terms of funding levels and the quality of care provided increases inequality in access to care for all Canadians (Berta, et al. 175)

Long-term care beds are typically for the oldest-old, those seniors over the age of 85. With the number of seniors over the age of 85 in Canada increasing, demand for long-term care beds will also be on the rise. In 2011, 7.1% of all seniors over the age of 65 in Canada were living in a collective dwelling that focused on care for seniors (Statistics Canada, 2011). The likelihood of residing in a long-term care facility in Canada increases with age. According to Statistics Canada, in 2011 only 1% of the seniors' population between the ages of 65 and 69 lived in a

long-term care facility while 29.6% of those aged 85 and over were living in some type of special care facility. Older seniors are much more likely to require space in a long-term care facility. As the first baby boomers reach the age of 85 in 2031, this age group will expand rapidly. This increase in the 'oldest old' will likely increase the need for beds in long-term care facilities.

Finding suitable living arrangements for aging baby boomers will require the creation of systems of care that allow for flexibility and choice. This approach is especially suited to the baby boomers' generation as Boomers are more likely than the current generation of seniors to want to remain in their own homes, with flexible assistance and to remain out of long-term care institutions (Howe, 2012). In fact, the majority (87%) of Canadians over the age of 55 want to remain in their own home as long as possible (Health Care in Canada 71).

Homecare

Homecare is one option that can help seniors stay in their own homes as they age and require increasing levels of assistance with household and personal care tasks. Homecare is worth examining for a number of reasons. First, homecare presents seniors with an opportunity to Age in Place (AIP). The Government of Canada defines AIP as "having the health and social supports and services you need to live safely and independently in your home or your community for as long as you wish and are able to." The concept of aging in place is beneficial to both seniors and governments looking to provide care.

Second, homecare offers seniors the opportunity to remain in a "self-determined home environment (Lee 1)", to hold on to a sense of "normalcy" and as much independence as

possible. Homecare can provide higher levels of autonomy for seniors, allowing them to be the authors of their own lives. They can sleep, eat, dress and bath on their own schedule. This independence is in opposition to a move to a long-term care facility where these activities tend to be highly scheduled and inflexible (Gibson & Singleton 240).

Finally, homecare is often a more affordable option for governments, if it means keeping seniors out of costlier long-term care beds (Romanow 2). All provinces and territories have increased their provision of home-care in order to meet the needs of Canada's growing senior's population that require support (Golant 3). In the last 25 years, government spending on homecare has grown much faster than all other healthcare spending. Between 1975 and 1992, it grew by 19.9% compared to 10.8% on total health spending. This trend is expected to continue, with a prediction that homecare spending will increase by 80% between 1999 and 2026. The provision of homecare by governments will help to allow those seniors requiring moderate levels of care to remain in their own homes longer.

For those seniors with higher care needs, however, homecare may not be the best use of provincial expenditure (Kane 170). Studies have found that under current pricing structures and service delivery models, homecare is only more affordable than institutional care for those seniors with higher levels of disability when the majority of their care is carried out by family members. Focusing on providing care in the home is best suited for seniors requiring minimal levels of support and/or for those seniors with high levels of informal support. As the caregiver support ration decreases, and fewer informal supports are available for Canadian seniors with high care needs, it makes economic sense for the state to provide care in a long-term care facility. For those seniors with substantial disability providing high levels of care at a central location, is far more cost effective than bringing the care into individual homes. As family size

decreases, and more seniors find themselves entering old age with little to no informal support, governments need to find ways to provide care in centralized locations for these seniors with high care needs.

The Drawbacks to Homecare

A senior's ability to receive homecare can be impacted by their financial situation. In 2009, 25% of seniors (just over 1 million) had received some form of homecare in the past 12 months and this percentage increased with age and poor health (Hoover & Rotermann 4). Seniors living alone were more likely to receive home care, and older women are more likely to be living alone. However, 63% of seniors reported unmet home care needs and attributed them to personal circumstances such as inability to pay. Women are more likely than men to have unmet needs (5% versus 3%) and unmet needs also tend to increase with age (3% between the ages of 65 and 74 compared to approx. 7% of those aged 85 and older). These findings highlight the fact that while homecare is helping many seniors to age in place, there are financial barriers to access for low income seniors. This represents a limitation in terms of the ability for autonomous decision making and self-determination available to low income seniors.

Homecare alone is not currently meeting all the needs of Canadian seniors. A study by Cohen et al. (2009) found that 80% of elder care is undertaken by family and friends (10). As the population ages and family size decreased, this high level of informal care will not be sustainable. Remaining at home will be increasingly difficult for Canadian seniors (Golant 6). The increase in the number of elders with multiple chronic impairments will place pressure on governmental budgets for homecare as demand for public funded home health care services

increases. Many provinces are experiencing a shortage in long-term care beds and so have raised the threshold to the frailest elderly for admittance (Golant 6). The reduction in supply of long-term care beds for those seniors with moderate care needs and the decrease in available informal care creates a demand for living arrangements that meet the needs of those seniors who can no longer remain in their own homes.

The Inequalities of Long-Term Care

The current system of long-term care in Canada is two-tiered. Those with the resources, both financial and social, can purchase or arrange the kind of care they desire while those without must make do with what the state can provide, or go without (Cohen et al. 10; Jansen et al. 7). Most Canadian seniors cope with the increasing loss of independence and frailty that aging can bring by relying on family, friends and community supports to remain in their own homes for as long as possible (Golant 6). The wealthiest seniors are able to purchase full-time caregivers to provide them support within their homes.

At the other end of the spectrum, seniors with limited health, wealth and social resources are more likely to experience barriers in accessing the kinds of care they want as they age (Health Care in Canada¹⁶). Low income seniors may have limited option when it comes to choosing a long-term care facility. While there are affordable options in long-term care, most are in high demand and have long waiting lists. These seniors are also more likely to end up in older nursing home offering basic accommodations (Health Care in Canada, 2005). For example, in BC a shortage of publicly-funded beds means that the only alternative is a private-pay facility. In 2005, less than 5% of unattached women and just over 11% of unattached men over the age of

65 could afford a private-pay facility. Those who can't afford to pay had to wait until a publicly-subsidized bed became available (Cohen et al. 17).

Disparate housing provision is the norm in our society as people move through the life cycle.

Those with more money often enjoy nicer homes. In the case of long-term care however, it is not just one's surroundings that are lacking when one has limited income. It can also be the level of care that is provided, and the amount of autonomy one has to give up. Inability to pay for long-term care services decreases seniors' ability to choose how and where they want to live. It reduces their ability to remain autonomous and be self-determining.

Before moving into long-term care, seniors have enjoyed a long adult life in which they were self-reliant and independent. Either living alone, with a spouse or other family members. Moving into long-term care may be a necessity based on frailty and/or health concerns but seniors shouldn't have to exchange their quality of life and their autonomy to get it. There are other ways of providing residential long-term care that are safe and supportive but that also allow for some level of autonomy for residents.

Current State of Autonomy in Long-Term Care

The current design of many long-term care institutes in Canada is undesirable to many seniors. A move to long-term care can symbolize a loss of independence and often requires seniors to live according to a pre-determined schedule (Gawande 74; Lidz et al. 113-114). It places limits on their freedom of choice and places them in a position of subordination to their care providers. A 2007 study on Aging in Place in America found that loss of independence was the number one fear that seniors faced. The majority of seniors feared moving to a nursing home more than they feared death (Prince & Butler).

Within the continuum of care in Canada, autonomy for older adults is something that can be purchased if one has the money to pay for private care within the home. For those seniors who lack the funds to purchase care within their own homes, there are a number of community assistance programs available across the country. Research suggests, however, that low income seniors and seniors living in remote areas have a harder time purchasing the kinds of care that would allow them to remain in their own home (Golant, 2001; Cohen, et al.). Often, when it is no longer possible for seniors to remain in their own home, they move (or are moved by their families) into long-term care facilities.

How Long-term Care Infringes on Seniors Autonomy

Long-term care systems today are modeled on medical care and hospitals, and so facilities tend to be more institution than home (Gawande 128). These institutions focus on the health care of the frail elderly without consideration of the factors that contribute to a significant life. Elderly residents are seen as infirmed; as passive recipients of care whose personal preferences are no longer top priority. The priority instead is placed on staying safe, and staying healthy. This focus on longevity and safety impairs a senior's quality of life because it denies their autonomy in making choices on how to live 'their best life'. The perception of the frail elderly as a burden on society, helps to perpetuate a system where seniors care needs are managed and seniors' wishes are marginalized. The following section addresses the many ways in which seniors' autonomy is compromised in the current system of care for seniors in Canada.

Scheduling

The structure of long-term care facilities is often one that denies the independence of residents (Gawande 115). Long-term care facilities function as total institutions, and are based on a medical model of care (Gawande 128). The medical profession is interested in prolonging life, but at what cost? When long-term care facilities are operated using a medical model of care, priority is given to prolonging the length of residents' life, instead of focusing on ways to improve residents' quality of life. Long-term care facilities tend to function more as hospital, than home. Scheduling is one way in which long-term care facilities rely on the medical model of care to ensure the efficient use of staff time. Unfortunately, this efficiency does not leave room for individual residents' freedom of choice (Sherwin & Winsby 187).

When seniors enter a long-term care facility, the range of choices that were formerly available to them are no longer possible. No longer being able to plan their own meals, enter and exit the residence when they desire or eat by themselves, can create feelings of dependency and loss of control among residence (West 78). Moving from your own home into a long-term care facility means giving up your own routine for the schedule of the institution. In their own homes seniors can decide when and what to eat, they can come and go as they please and accept or reject medical advice as they see fit (Kane 168; West 78). Life within a long-term care facility is often highly structured. When a few staff caregivers are responsible for a large number of residents, it is often easier and more efficient for everyone to follow the same schedule. This results in seniors being woken up at the same time, dressing, eating and washing, at the same time with little room for personal choice for seniors.

A medical model of care tends to make a procedure out of all tasks. In traditional nursing homes, there is little distinctions between taking medications and getting dressed, or brushing your teeth.

All tasks must be completed each day, by all residents. It is much easier for all residents to complete tasks at the same time; for instance, breakfast is served each day at the same time, and all residents must be awake and dressed in order to eat breakfast. This structured approach to each day limits residents' personal choice, regardless of any cognitive capacity.

Staff limitations within long-term care have been quoted as the reason for the highly scheduled nature of most long-term care facilities (Golant 3; Jansen 7; Lidz et al. 113-114).

Exceptions to the schedule, to accommodate residents' preferences, require specific permissions, thus leaving individual patients with limited ability to set their own schedule. Here efficiency has taken precedence over the needs of the patient. It is much easier for staff to cope if all residents are following a rigid schedule. These systems have been put in place because they make the most economical sense, especially in terms of staff time but come at great cost to residents' independence and their freedom of choice (West 78). Understaffing can put even more pressure on available staff to follow a strict schedule in order to ensure that residents have been properly cared for.

Long-term care facilities must offer a wide variety of services to an array of residence requiring varying levels of assistance. Though not standardized across the country there are rules and regulations in each province on how services should be delivered that staff must comply with. Long-term care staff must often work within limited budgets oftentimes with minimally trained staff who have an extremely difficult and demanding job (Sherwin & Winsby 188). It is not surprising then, that this highly pressurized environment has been highly regimented towards efficiency. Under these conditions the customization of care that would increase resident independence would also be time consuming for staff.

The needs of residents are not behind the decision to adhere to a highly structured system of care delivery within these facilities. The systems function to increase the efficiency of staff and limit labour costs. To structure a long-term care system that promoted autonomy for seniors and allows them be the author of their own lives would certainly result in a movement away from scheduled care to focus on providing the care that seniors need on their own timeline.

Limits on Personal Space

Limiting personal space in long-term care facilities can come in a number of forms (Sherwin & Winsby 187). Often, semi-private rooms are the only arrangement on offer, or private rooms may be offered for an additional fee, furthering the inequality between high and low-income seniors. In many ways, by entering a long-term care facility, residents are seen to have given up their right to privacy or personal control over any number of day-to-day activities such as meals, social interactions and even bathing. Close physical contact with care workers is often required and expected. This may be a difficult adjustment for adults who are used to taking care of themselves. It often leaves little room for freedom of choice over their personal space and autonomy over their own body.

The Prioritization of Health and Safety

The primary concern of long-term care facilities in Canada is with the health and safety of their residence (Gawande 117). In fact, all provinces and territories have devised some form of standards and have regulations in place for the operation of long-term care facilities. In Ontario, the provincial government reports on 11 indicators of the quality of their long-term care system: wait times, incontinence, activities of daily living, cognitive function, pain, falls, pressure ulcers,

restraint use, medication safety, health human resources and infection rates (Ontario). This focus on safety is often a legislated requirement. Ontario's Long Term Care Act, 2007, contains a vast array of regulatory requirements that facilities must abide by, leaving very little room for individualization and limited amount of risk taking.

All tasks within the daily operation of long-term care facilities has been regulated to ensure the safety of residents. Under Ontario's long-term care act, for example, food and drink is referred to as dietary services and hydration. Even the terminology demonstrates how long-term care facilities are more institution than home. In a home, you eat food and drink beverages. An institution concerns itself with dietary services and hydration. The long-term care act is viewed as a necessity to ensure that both public and privately run homes are providing adequate care and safety to their residence. The attempt to remove all risk has resulted in facilities that are more hospital than home, and seniors recognize this and are often put off by it. No one likes being in the hospital, so why would you want to live there?

The rules and regulations around nursing homes vary across the country but all are concerned with the health and safety of residents. There are often limits placed on residents' behaviour to ensure their own and other residents' safety. In some cases, blanket rules about what is permissible can be applied to all residents regardless of their level of ability. Deviations from prescribed safety measures can often be difficult and time consuming to achieve. Yet if these same seniors were living in their own home, and enjoying the level of autonomy they required to live the good life, the level of risk they would be willing to accept would be higher than that of the administration of a long-term care facility. Once the administration takes on the responsibility for the safety of residents, the level of risk taking they are willing to accept on the seniors' behalf is greatly reduced.

More serious conflicts between autonomous decision making and safety arise when residence experience cognitive impairments. A large proportion of long-term care residence in Canada suffer from some form of dementia that limits their ability to make decisions about their care (McGregor et al. 3). A system that focuses on health and safety often deems paternalistic treatment not only warranted but necessary in these cases (Sherwin & Winsby 187). There are many ways in which the mobility and personal choice of long-term care residents with dementia are restricted. Locked wards are a common occurrence in long-term care facilities where patients with dementia reside. Locking residents in, is deemed a necessary safety precaution, as dementia patient are prone to wandering, often in the hopes of going “home”. Locking doors restricts patients’ autonomy, but leaving the doors unlocked, and allowing patients to wander at will may not be the solution. Instead, finding creative ways to manage risk in long-term care may help. Germany provides an excellent example, where fake bus stops have been installed outside of dementia wards (De Quetteville). While dementia patients often suffer from short-term memory loss, their long-term memory often remains intact. This leads many long-term care patients longing to return to their homes, and causes some of them to wander from their care facilities. The fake bus stops at the Germany facility are attractive to the patients. They remember the bus and how it took them home in the past. They sit and wait for a bus that, in this case, never comes. After sitting at the bus stop for some time, they often forget why they are sitting they and are eventually collected by staff members who offer them a cup of coffee inside. In this way, the risk of wandering is managed, while still preserving seniors’ autonomy.

The focus on health and safety, to the exclusion of personal comfort or autonomy leaves little room for residence to live meaningful lives. There is no doubt that the safety of patients is important. Indeed, many seniors move into long-term care facilities because of the risk to their

safety that living alone can pose. With a traditional medical focus and a preoccupation with the health and safety, today's long-term care facilities have prioritized these values over autonomy and quality of life for seniors (Gawande 120).

The Imbalance of Power

Building on a medical model of care has implications not only for the operation of long-term care facilities, but also on the relationships between staff and residents. The medical model of care ensures an imbalance of care between care providers and care recipients. When care providers are seen as the embodiment of the health care system, residents have little power to negotiate the kinds of care and treatments they wish to receive. The relationship between residents and staff in long-term care facilities draws heavily on the normative structure of the doctor-patient relationship (Lidz et al. 72). Care providers are seen as being in charge of the facility and residents are the passive recipients of their care. In these roles care providers have an obligation to maintain resident's physical health. As patients, the residents' role is to follow instructions in order to get and stay well. In these traditional roles, physical health is prioritized and the balance of power resides with the care provider. Seniors are seen as passive recipients of care who have little say over their day-to-day lives. This power imbalance between staff and seniors infringes on the autonomous decision making ability of residents. When residents are not consulted about the kinds of care they wish to receive and how or when they wish to receive them, their personal autonomy is limited. Making residents subordinate to their care providers, seriously compromises their autonomy.

This chapter has offered us an overview of the current system of long-term care in Canada. The number of Canadian seniors with long-term care needs is expected to rise; this will mean that

governments will need to increase the provision of long-term care services. As it stands the institutional operation of long term facilities is a deterrent for most seniors. The strict scheduling, hospital like setting, coupled with the loss of independence and personal space make these facilities an unattractive destination for the majority of older adults. In these facilities health and safety concerns have been prioritized over personal choice and independence. Safety is important but there is a need to examine ways of running long term care that still allows for personal autonomy within a safe environment. Perhaps governments have gone too far in the name of safety. They have perhaps forgotten that these are homes, and not hospitals; that residents are grown adults who need to continue to be autonomous and independent in order to enjoy life. Fear of moving to a long-term care facility can be directly linked to the loss of independence it requires. Regimented schedules and institutional structures do not present an inviting environment for seniors to call home.

A revaluation of the framework behind the provision of care for Canadian seniors that focuses on the positive right of seniors to autonomy would recognize that the provision of care and assistance is often necessary in order for seniors to live their best life. Designing long-term care that promotes autonomy for seniors would provide care in helping them to carry out their personal choices. It would place the power with residents' themselves, and the role of care providers would be to assist in the execution of seniors autonomous wishes. In this way, schedules are no longer necessary, as care providers perform their duties at the request of residents. Under this new model, care providers come into seniors' personal space upon request for assistance.

Designing and operating long-term care facilities in such a way as to promote seniors' autonomy could go a long way in decreasing the fears seniors experience when thinking about a move to

long-term care. The next section formalizes the concept of autonomy for seniors in long-term care and highlights the positive nature of this right that requires action from states.

CHAPTER TWO: CANADIAN SENIORS RIGHT TO AUTONOMY

So far, I have argued that long-term care facilities in Canada neglect the legitimate demand of Canadian seniors to live autonomous lives. Chapter two addresses the right to autonomy of Canadian seniors living in long-term care facilities. Canadian seniors in long-term care have the right to autonomy, based on the argument that autonomy is a basic human right, one enjoyed by all Canadian adults, and one that should not be negated simply because one must move into a long-term care setting. The definition of autonomy, for the purposes of this paper, focuses on decisional autonomy. Autonomy that allows seniors to remain the authors of their own lives. I want to argue that in many cases, seniors in long-term care will require assistance in executing their autonomy. Requiring assistance is not problematic for the conception of autonomy that recognizes its relational aspects as I propose we should do.

Access to LTC in Canada

While it may very well be in the best interest of seniors to design long-term care facilities that are more like homes, do Canadian seniors have the right to have access to living arrangements that promote autonomy? Do we infringe on their rights to autonomy when the only long-term care options on offer require them to give up their personal choices and freedoms at the end of life? If we decide that seniors have the right to autonomy in old age, is it a positive right that requires states to provide living arrangements that allow seniors to remain self-determining as they age? Or a negative right that only demands states not interfere with the kinds of choices seniors make? The following section will examine seniors' rights to autonomy in long term care.

I will argue that Canadian seniors have a positive right to autonomy. This implies a responsibility on the state to provide, as much as possible, for all Canadian seniors the possibility to lead the kinds of lives they wish to lead for as long as possible.

Autonomy Defined

There are a number of different definitions of autonomy: the concept of autonomy as free action; the ability to live independently, free of infringement and limitations is of little use when considering long-term care residents (Gawande 140). Growing old often, but not always, leads to higher levels of dependence due to increasing levels of frailty and disability. This dependency is not in opposition to autonomy however, as I will discuss further on in this chapter.

The move to long-term care for many seniors, is an acknowledgement that living independently in their own home is no longer an option. Growing older looks different for everyone. Many seniors enter their retirement in good health and are able to remain healthy and active for many years. Other seniors may suffer from chronic conditions that can be exacerbated by age while still others may find that their independence is curtailed as they age due to a loss of mobility or illness. For this reason, seniors will require various levels of assistance as they age. Some seniors will require little to no help, and will be able to live independently until they die. Other seniors may require high levels of care for short or long periods of time. The variety of limitations experienced by seniors therefore requires a flexible definition of autonomy. While the amount of assistance seniors will require to help carry out their wishes may vary, most seniors are still capable of determining what those wishes are. They are capable of remaining the author of their own lives, in that they can make decisions and choices about how they want to live and may simply require assistance in executing their wishes. The idea behind this type of autonomy is that

seniors are capable of making decisions about their own lives, even if they must rely on others to help them carry them out. Atul Gawande in his book, *Being Mortal*, describes this kind of autonomy as “you may not control life circumstances, but getting to be the author of your life means getting to control what you do with them (210)”.

Philosopher Richard Dworkin describes this type of autonomy as:

“It (autonomy) allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent such a scheme of rights can make this possible, what he has made himself”.

The kind of autonomy described here fits best with the idea of decisional autonomy (Boyle 213).

Collopy classifies autonomy into two categories, ‘autonomy of execution’ and ‘decisional autonomy (1995, 10). Executional autonomy is the ability to carry out decisions independently.

In the case of long-term care residents, it is executional autonomy that requires state action.

Decisional autonomy, is the ability to make decisions, even if one does not have the ability to carry those wishes out. In the case of long-term care, research has found that residents’ ability to make small, everyday decisions are very important and contribute to resident’s sense of control and quality of life (Knapp 64). As an example, residents in long-term care may have the capacity to decide what time they want to wake up in the morning, when and what they want to eat for breakfast and where they want to eat it. In a traditional long-term care facility these decisions would have been made for them, in the form of a schedule that all residents must adhere too. Since residents must rely on care providers to assist them in dressing and eating, these basic choices remain outside of their control. In this way, because seniors are not capable of remaining autonomous in the execution of their choices about how and when to start their day, they also

lose the ability for decisional autonomy. These choices are made for them, and are implemented in the form of a daily schedule that leaves no room for personal preferences or choice.

For the purposes of this paper, autonomy will be defined as decisional autonomy as it applies to the day to day decisions seniors make while living in long-term care facilities. It is worth noting however that executional autonomy should not be overlooked as it applies to seniors in long-term care. Instead, I argue that it is the responsibility of the state to provide care that allows for the execution of residents' autonomous decisions.

The right to autonomy for Canadian seniors in long-term care is often contingent on the provision of assistance. Many seniors, as they age, will require increasing levels of assistance to carry out their wishes, choices, and decisions about how they want to live their lives. The Supreme Court of Canada, in their decision in *Carter vs Canada*, provided proof that the provision of care is often necessary to ensure individuals have the ability to remain autonomous.

The verdict in this court decision on assisted suicide stipulated that by denying terminally ill patients assistance in ending their own lives, patients were denied "the right to make decision concerning their bodily integrity and medical care and thus trenches their liberty." This extreme example, illustrates that in order to remain autonomous, individuals will often require assistance from others. The ability to be self-determining and the author of their own lives, even in matters as serious as death, will sometimes require assistance, when individuals find they are not capable of carrying their wishes out themselves.

This same right to assistance applies to Canadian seniors living in long-term care facilities. It is not enough to merely provide an environment that does not interfere in the realization of their autonomy. Instead the state has a responsibility to provide seniors with living arrangements, and care that assists them in remaining autonomous. This is not currently the case in the Canadian

system. Instead as seniors age, and become more and more dependent on others, they are often faced with a move into long-term care that robs them of their autonomy.

Why Autonomy Matters

The concept of autonomy as it applies to the older adult is an area that has been under researched (Boyle, 2008), particularly as it pertains to living arrangements within long-term care facilities. The limited research that has been done however, finds a link between autonomy and quality of life for seniors (Boyle 2004, 2005, 2008; Collopy, 1988; Kane, 2001; Milton; Gawande, 2014; Skemp, 2014). A 2005 study by Boyle, suggested that constraints on autonomy, synonymous with a long-term care setting, had a greater impact on residents' mental health than their physical impairments (743). The study found that the majority of seniors with high levels of autonomy had good mental health, even when high levels of physical disability reduced their executional autonomy. This would suggest that supporting decisional autonomy could contribute to higher levels of mental health for residents of long-term care. Tester et al. (2004) found that the exercise of autonomy had a positive effect on quality of life for seniors living in long-term care settings. The links between autonomy and quality of life are of particular importance when discussing long-term care, as a loss of autonomy is seen as a given when the decision is made to move out of one's home and into an institutional setting. Finally, while studying older Canadians in a community and institutional settings, Reker (1997), found that autonomy (the freedom to choose and be responsible for one's choices) was the "strongest predictor of the absence of depression" (709). Evidence suggests that even the perception of personal control is linked to long-term physical and emotional well-being (Kapp, 63). Enhanced autonomy is associated with fostering independence over time, reducing the risk for abuse and neglect and increasing client

satisfaction with services that are intrinsic to quality care. Perceptions of control positively affect residents' behaviour and tend to reduce feelings of helplessness.

A movement into long-term care is often seen as a loss of dependence and a need for protection. Seniors who are no longer able to live independently in their own homes are often fearful of the move to long-term care because of the restrictions on their freedoms that such a move can impose. As noted in the previous chapter, efficiency and safety are often the driving forces behind the design and operation of long-term care facilities. Respecting the autonomy of residents, as a means to improve on their quality of life is rarely part of the process when thinking about how best to set up living arrangements for seniors. This type of paternalistic approach has been seen as a necessity in ensuring the safety of residents, an argument that few have challenged, when security of the person is seen as the priority.

An important consideration then, would be to find ways of managing risk that would allow for residential autonomy in long-term care. A study by Mozley et al (2004), found that managing risk in order to provide activities and occupations to residents was crucial to promoting quality of life for residents (200). If autonomy is intrinsic to residents' well-being, then perhaps shifting the focus towards honouring autonomy would improve the quality of life of current residents, but also, go a long way in making long-term care more attractive to seniors who will require care in the future.

Autonomy as a Right

After defining autonomy for long-term care residents, and discussing why autonomy matters in these situations, the next step is to determine if autonomy is a right.

At the simplest level, the basic principles of social justice would demand that a fair and just society provide protection for the weakest and most vulnerable members (Stretch 18). Indeed, Rawls, in describing his “difference principle” demands that any inequality be so designed as to benefit the least advantaged (302). These duties are not grounded in morality but instead, he argues, that the “original position” would show that all individuals would chose this course of action in their own self-interest. As a society, we expect that our most vulnerable members, namely seniors, children, and persons with disabilities, should be protected by our social institutions.

In his theory of justice, Rawls argues that social institutions are the seat of “the social bases of self-respect” which are needed to install confidence in people that their position within society is respected and that their concept of what is good, is valid and achievable (Rawls 54). As social institutions, care for the elderly can be viewed as a basic structure of society that has a profound influence over residents’ lives and their autonomy. Adults have an expectation of autonomy, and a desire to be the “author of their own lives”. Their ability to act to fulfill this need is required in order to live the “good life”. Seen from the perspective of long-term care, autonomy for seniors is a necessity for their concept of the good, and long-term care facilities as social institutions have a duty to promote the self-respect and autonomy of residents.

Being autonomous is something Western society is deeply committed too (Lidz, et al. preface). Many Canadians when they enter old age, may become dependent on others to remain autonomous. But this dependency should not require them to forsake their autonomy in exchange for care. Indeed, a study by Boyle (2008), found that care providers in a long-term care setting often equated limits on executional autonomy with limits on decisional autonomy (303). In these situations, care providers often ignored or superseded residents’ decisions because of their lack

of ability for execution. Also, when some level of dementia is present, care providers can assume decision-making on behalf of the seniors, instead of distinguishing between decisions seniors are able to make versus those they cannot. The concept of 'minimal autonomy' as proposed by Doyal and Gough (1991) is to '*have the ability to make informed choices about what should be done and how to go about doing it*' (53, original emphasis). Morris (2005) suggests this definition should be redefined to include those people who require support in order to remain minimally autonomous.

In their work in *The Theory of Human Need* (1991) authors Doyal and Gough argue that autonomy is a basic human right which is fundamental to equality. The realization of a right to personal autonomy ensures individual freedom of choice and the ability to live the good life. Basic social rights include; access to high quality care services, the ability to directly purchase care services and the fundamental right to independent living (Boyle, 2008 306). Individuals require basic social rights in order to realize their autonomy, and in the case of older adults in long-term care, they often require assistance in accessing these rights. Autonomy cannot be achieved, however, when seniors are merely passive recipients of their social rights (Morris 243), as is often the case in long-term care facilities where care is highly regimented for efficiency. Autonomy for long-term care residents requires the removal of barriers, the provision of necessary support; and choice and control over that support (Morris 245).

Finally, there is an assumption that all individuals have the capacity for free choice, and within the liberal tradition, adults within our society exercise autonomy in the various choices they make (Morris 243). They are in charge of their own lives, allowing them the ability to participate and make a contribution to society. States are seen to have a duty to protect individual freedom of choice so long as they do not infringe upon the rights of others. Autonomy when taken from

the stance of freedom of choice would seem to be a negative right. It merely requires the state not to interfere into the lives of its citizens. However, when designing long-term care systems that increase autonomy for older adults, non-interference by the state will not be enough to recognize this goal because of the issue of dependency. It should be acknowledged that dependency and autonomy are not in opposition to each other. Seniors who are dependent on their care providers are still able to remain autonomous in their decision making, it is only in the execution of those choices that they may require assistance. Active state involvement is required to provide the kinds of assistance necessary to allow for seniors' autonomy when dependency on others arises due to frailty, cognitive or physical ailments, or other disability. As previously stated long-term care residents are often dependent on care providers to remain autonomous. Dependency is a factor which must be managed in order to realize autonomy for long-term care residents. Seniors in long-term care can remain autonomous even when they are dependent on care staff. Indeed, it is the role of the state, as purveyors of care, to provide assistance to dependent residents so that they can be autonomous.

When old age necessitates a move into long-term care due to frailty and dependence, the right to autonomy should not be negated. Instead, there should be an expectation that there is instead a duty placed upon the state to continue to ensure the right to individual freedom of choice, even when seniors require assistance to remain in charge of their own lives. This idea is best summed up by the Disability Rights Commission, in their definition of independent living for persons with disabilities:

“...all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean

disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations (Morris 242).”

While old age and disability are by no means synonymous, those that move into a long-term care facility often require practical assistance, and so in this way their aims are similar to individuals with disabilities.

Canadian seniors in long-term care have the right to autonomy, based on the argument that autonomy is a basic human right, one enjoyed by all Canadian adults, and one that should not be negated simply because one must move into a long-term care setting. Instead, the onus is on the state to provide care that allows for the seniors to remain autonomous even when they become dependent on others. The various ways that long-term care facilities infringe on seniors right to autonomy have been outlined in the previous chapter, most notably through the highly structured nature of care delivery, limits to personal space, the prioritization of safety over quality of life for seniors, and the imbalance of power between care providers and recipients.

In the next chapter, we will look at ways in which residential long-term care can be offered that recognized seniors' right to autonomy. Three international examples of long-term care systems that promote autonomy will be examined. Long-term care in Canada is funded and regulated by provincial and territorial tax dollars. There are many opportunities for governments to provide leadership in promoting autonomy in the field of long-term care. This will require a shift in the framework of long-term care delivery. A shift away from the medical model of care to one that allows individual residents to make their own decisions about their care. That allows residents to make decisions about how and when care is provided and increases their personal responsibility and the level of risk they are willing to assume, in the provision of care. All three international

examples also allow the seniors themselves to be instrumental in the development of their care plans, and living arrangements. Valuing the opinions of seniors and recognizing their role as author of their own lives, is an important first step towards increasing autonomy for long-term care residents.

CHAPTER THREE: RETHINKING LIVING ARRANGEMENTS

Chapter one outlined the current situation of long-term care in Canada and highlighted the desire by the majority of seniors to remain at home as they age. Many provinces and territories are now focusing on providing home care for seniors in order to help them remain in their homes and out of more expensive forms of care such as long-term care facilities and hospitals. Currently very few seniors over the age of 65 reside in a long term care facility, but the percentage of seniors in long-term care increases as seniors' age. As the baby boomers reach retirement, and the proportion of the oldest old, those over the age of 85, rapidly increases, so too will the need for more long-term care beds.

Long-term care facilities in Canada are highly institutionalized and bear little resemblance to the home seniors have left behind. The loss of privacy and autonomy and the regimented scheduling are just some of the reasons many seniors dread a move to long-term care. A lack of inclusion in the Canada Health Act also means that long-term care is not universally provided for all seniors and there is great variation in the types of residences that are available and the fees that must be paid. This has resulted in a two-tiered system of care that allows wealthy seniors the option of purchasing the kinds of care they want, while lower income seniors are often left with fewer choices.

Chapter two discussed the importance of autonomy to quality of life for older adults, especially those living in long-term care facilities. Autonomy as a right for seniors requires governments to provide the kinds of care that will allow residents to remain the author of their own lives.

Changing the way governments think of about setting up long-term care for older adults requires both policy makers and practitioners to shift their perception of older adults as passive recipients

of care (Leith 331). It requires a considerable increase in the amount of confidence placed in older adults to make decisions about their own lives, living arrangements and care provisions. Change would require a transition away from the medical model, as described in chapter two, that currently serves as the framework for delivering long-term care, and a commitment to promoting autonomy and aging in place as the philosophy behind long-term care policy.

One way to start to think about new ways of setting up care is to design long-term care to be more like a “real” home where residents can maintain their privacy and experience a “normal” lifestyle (Kane 168). The services provided must also address the current imbalance of power between caregivers and care receivers. As described in chapter two, a medical model of care places care recipients in positions of subordination to their care providers. As a patient, residents are expected to follow the orders of their health care providers in order to optimize health and increase their longevity. This relationship leaves little room for patient autonomy and personal choice in making decisions about their care needs. (Kane 168).

While homecare resources should not be abandoned, research has shown that under current pricing structures and service model provision, home care will actually be more expensive than long-term care facilities for seniors with high care needs (Kane 170). As the percentage of the oldest old increases, the number of seniors requiring high levels of care is also likely to increase. As our population ages, Canada will have to do both; continue to provide homecare to those seniors with limited care needs and/or high levels of informal support, while also increasing the number of long-term care beds.

Chapter three turns its attention to international best practices in promoting autonomy when designing long-term care systems. All three of these international examples provide opportunities

for states to fund care that promotes autonomy in ways that make long-term care more attractive to seniors.

International Examples

1. THE GREEN HOUSE® Project (US)

THE GREEN HOUSE® Project was started in 2003 in the US with the aim of deinstitutionalize the nursing home (Zimmerman & Cohen, 2010). The goal was to transform long-term care from “big box” nursing home, into small homes and communities that gave residents more privacy and control over their lives. The project received a \$10 million grant in 2005 from the Robert Wood Johnson Foundation and to date they have built 170 homes in over 27 states.

THE GREEN HOUSE® Project Vision states:

“We envision homes in every community where elders and others enjoy excellent quality of life and quality of care; where they, their families, and the staff engage in meaningful relationships built on equality, empowerment, and mutual respect; where people want to live and work; and where all are protected, sustained, and nurtured without regard to the ability to pay (Zimmerman & Cohen).”

THE GREEN HOUSE® Project’s mission and values project a view of long-term care that sees seniors as partners in the provision of their own care. The program aims to transform traditional long-term care models away from institutional care to one that creates a real home for residents. There is also a focus on improving working conditions for staff by increasing their ability to

make decisions, in partnership with residents and valuing their personal contributions to the living environment.

In a GREEN HOUSE (GH), privacy and autonomy are enhanced by the very design of the buildings; each resident has a private room, with their own bathroom (Sharkey, et al. 126). These homes are small scale, only 6-12 residents per house, often with a number of houses in the same area to share medical resources such as nurses and doctors. The bedrooms are spread out around a central communal room and kitchen where residents can congregate. Meal times are communal affairs, where staff and elders (as residence are called) come together to prepare meals. Staff, residents and any guests eat together around a large table. Elders are not required to get up, dress or eat at any specific time during the day. Their schedule is their own.

Staffing THE GREEN HOUSE®

THE GREEN HOUSE® Project has made significant changes to the staffing structure within the houses to put more power in the hands of the elders (The Green House Project Video). The Green House concept emphasizes autonomy, dignity, privacy, and reciprocal relationships between residents and staff (Loe & Moore 755). In this way they are attempting not only to balance the power between residence and staff but to also empower the direct care staff to solve problems on their own. In a GH, the care providers are called the Shahbazim, they are versatile workers who provide care directly to the elders (Sharkey et al. 126-127). In a GH, the hierarchical staffing structure has been flattened, Shahbazim are included in any decisions made about the seniors' care needs in conjunction with the other care providers such as doctors and nurses. The Shahbazim are encouraged to assist the elders in solving their own problems. In comparison to their counterparts in traditional long-term care facilities, the Shahbazim have

higher levels of involvement in problem solving and decision making. They manage the home, work in self-managed work teams (two each day, two each evening and one overnight), they partner with clinical team members (medical staff that are on call 24 hours per day) and they report to the Guide who offers support and accountability.

THE GREEN HOUSE® Research Findings

Initial findings suggest that THE GREEN HOUSE® model are saving the Medicaid and Medicare programs money (Horn et al. 2012). The difference calculated in cost per residents in a GH versus those in a traditional long-term care facility, over a one-year period range from between \$1300 to \$2300 depending on the state. These savings represent a reduction in both the cost of hospitalization and the daily care costs. An important contribution to these findings is the reduction in hospitalizations experienced by GH elders, they were 7% less likely to be hospitalized versus residents in the traditional home which represents a significant savings to the healthcare system.

THE GREEN HOUSE® case studies show a lower staff turnover rate than in traditional long-term care home, four times more engagement time with elders and very high levels of staff satisfaction (The Green House Project.com). Initial research suggests that staff efficiencies can be achieved in the smaller environment of a GREEN HOUSE® (Sharkey et al. 126). While the Shahbazim are required to take on more responsibilities than traditional nursing assistants, this did not negatively affect time spent on resident care. These findings suggest that it is possible to provide care on a smaller scale, which also allows care staff to move away from the regiments of scheduling that are the norm in traditional long-term care facilities.

A longitudinal evaluation of the first GHs conducted by Kane et al in 2007 found that in comparison to residents in a traditional nursing home, GH elders had statistically significant improvements in self-reported dimensions of quality of life. They reported on eleven domains of quality of life: privacy, dignity, meaningful activity, relationship, autonomy, food enjoyment, spiritual well-being, security and individuality. The GH elders also reported increased functional status which refers to the ability to perform activities of daily living (ADLs) such as bathing, dressing and eating, and instrumental activities of daily living (IADLs) such as taking medication, using a telephone and doing laundry, by themselves (832). Overall the results of the study “strongly favor” the GH model and suggest the model achieves the stated goals of creating a home like environment for seniors that will improve their quality of life (Kane et al. 837). GH elders had lower levels of depression than their traditional nursing home counterparts which could be linked to Reker’s (1997) research on autonomy and depression discussed in chapter two. Similar research by Grabowski et al., (2014) found that homes that follow the GH model were associated with better care than traditional long-term care facilities (35).

Initial research found conflicting results on the amount of social interaction experienced by GH elders. Zimmerman et al., found that while private rooms and bathrooms were important, an extra effort must be made to engage residents as they are at increased risk for social isolation under this new model of care. Unlike traditional nursing homes, GH do not provide scheduled social activities. It is expected that like a house, residents would chip in to help with household activities such as cooking, cleaning and folding the laundry. Zimmerman et al., found this was not the case however and that elders spent more time disengaged from the other residents. A study by Kane et al., however compared the sociability of seniors in a GH to those at traditional nursing homes and found that while sociability levels were at a similar level, the interactions

they experienced were different. There are various ways for seniors to remain social while living within a long-term care facility. Organized activities, organized group excursions, receiving phone calls and visitors, privately arranged trips away from the facility or having an overnight guest were all measures of social interaction in the Kane et al., study. In comparison the Zimmerman et al., study focused solely on organized activities within the home. The findings by Kane et al., suggest that while elders at the GH were less likely to participate in organized activities they were more likely to undertake excursions than their traditional nursing home counterparts and just as likely to engage in solo activities such as receive visitors and phone calls and participating in privately arranged excursions (837). These findings suggest that the social patterns of GH elders are more likely to resemble those of seniors living in their own homes. Since seniors living in their own homes are not likely to be involved in activities organized in their house, the GH model for social interaction is in fact doing what it set out to do, which is reproducing a home like environment.

2. Baba Yaga House (France)

The Maison de Babayagas or Babayaga House was the brainchild of Therese Clerc, a Parisian feminist who, in her 60s, began thinking about where she wanted to spend the rest of her life (VanAntwerp,a). After visiting local long-term care facilities Clerc decided to lobby her local government with a group of friends to set up an independent home, where the women would live together and take care of themselves, no professional staff required. Babayaga is the name of a witch from Slavic folklore (Johns 313). One of the main impetus expressed by the group for setting up their own accommodations was that they were not interested in living by someone else's rules or schedules as they grew older (VanAntwerp,a). It took 13 years, but the women

were successful in funding the construction of a six-story women's only seniors' home that opened in the Montreuil neighbourhood of Paris in October of 2012. The residence houses 20 elderly women and 4 young adults under the age of 30. While intergenerationality is not a focus of the project, the idea is to have younger residents on hand to promote solidarity and to provide mutual assistance.

A Charter of Living was created and voted in at the General Assembly Extraordinaire of the Association du Maison de Babayagas (Charter 1). It was reviewed by the local municipal government, The City of Montreuil and the public housing authority, OPHLM (Office Public de l'Habitat Montreuillaise, who run the facility in partnership with the Babayagas.

The Charter of Living set up by Babayaga House has four main values; self-management, solidarity, citizenship and ecology. The charter states, under the category of self-management:

“we will manage our house ourselves, accepting the least possible outside help, when necessary to compensate for our declining strength (Charter 2).”

One of the main difference in the Babayaga approach is that it was the residents themselves who were instrumental in setting up the house. They fought for their concept, and for funding from the local government. In this, their autonomy was both decisional and executional. The idea of the Babayaga House has sparked considerable interest here in Canada and has spurred a movement that has been called “Radical Resthomes© (radicalresthomes.com). The website provides space for seniors to talk about and propose solutions to the problems of aging in place; namely: where to go and who to live with. Seniors in search of others sharing a similar interest in finding new ways of setting up house as they enter old age can find others like them, and even potential housemates.

3. The Fredericia Model (Denmark)

The Life Long Living project is a model of home care that was developed in Denmark's Fredericia Municipality as a preventative measure that would allow seniors to remain in their own homes as long as possible (VanAntwerp b). Instead of providing traditional methods of care to seniors who require assistance, the municipality's social services department set up care teams who meet with the seniors in their homes and ask a simple question, "What would you like to be able to do again?" Then the team, in partnership with the senior, develop a plan to help the senior achieve their goal. This care system involves care professionals coming together in the seniors' home to co-create a rehabilitation program for the senior. The question is simple but the ideology behind it is a departure from the current provision of homecare in Canada. This model helps seniors direct the system of care instead of being a passive recipient of care. This kind of involvement can go a long way in improving quality of life for seniors.

The Social Services Department in the Municipality of Fredericia (Fredericia Kommune) has a vision of:

"a municipality with active and resourceful elderly, who through prevention, rehabilitation, technology and social networking can maintain everyday life for as long as possible (Heebøll 1)".

This initiative was one of seven radical innovation ideas the municipality introduced in an effort to strengthen the role of the elderly in the community and help them to get "as far as possible in life (Larsen & Svendsen 3-4)". The program focusing on helping elderly citizens become stronger so that they can master their own life, the epitome of autonomy. The ultimate goal is for the elderly to maintain a calm and meaningful life.

How the Fredericia Model Re-Imagines Old Age

The program represents a change in paradigm in practice for seniors' care. They advocate a number of different ways in which to provide homecare to seniors that restores their physical capabilities as they age. Specifically, they focus on a move towards early intervention as seniors begin to show signs of physical and cognitive declines. The program focuses on rehabilitation and prevention rather than the traditional help and expensive compensatory initiatives that were relied on in the past. The project aims to build seniors strength and capabilities instead of simply providing care for seniors as they age and become increasingly frail and dependent. Overall, the project flips the idea of seniors as a burden, to seniors as a source of strength in the community. The intent is to assist seniors in mastering their own lives by increasing their ability to live independently and to remain autonomous in decisions about the kinds of care they receive (Heebøll 5). The aim is to allow seniors to help themselves instead of being passive recipients of care. Empowering seniors to live independently with a high degree of self-care instead of creating long-term dependent relationships.

This is accomplished by providing training to seniors, in their own homes, to increase strength and resiliency and allow them to care for themselves. There are two components to the program; "The Everyday Rehabilitation Project" trains seniors in everyday activities such as cooking, getting dressing and taking a bath that the seniors desires to do on their own and is able to resume. This program targets seniors who are requesting help for the first time, typically after a hospital stay (Heebøll 5). Training is provided by occupational therapists in the seniors' home. If the training is successful, the seniors is able to resume self-sufficiency and assistance from the municipality is no longer required. Should the senior require more assistance, the "Independent

Living Project” has been developed for those who have already received some assistance from the Elderly Care Department. A “Citizen’s Rehabilitation Plan” is developed that describes a care needs and the seniors’ activity targets. Independent Living Trainers are carers and assistants who visit their senior in their home to help them increase their functional capacity to remain self-sufficient and independent (Heebøll 6). Help is intensive in the beginning with as many as 15 care trainers providing 31 days of intensive training but gradually tapers off, and staff eventually take on a monitoring role. The ultimate goal is ensuring that seniors who wish to remain in their own home are physically capable of doing so.

One reason for the program’s success is that it has re-imagined basic assumption that age is a mark of weakness and limited resources (EPSA). Instead the municipality recognizes that old age signifies a long and good life, that seniors have a future, and that ensuring they can look after themselves as long as possible is a worthwhile investment. This new framework recognizes the desire of all citizens, especially seniors, to remain independent as long as possible.

Fredericia Research Findings

The results are positive; the Life Long Living project has postponed and reduced the demand for long term care services in the Municipality (Kjelberg 2). Satisfied citizens express pride and have improved quality of life by building their capacity to remain self-sufficient in meeting their personal care needs. An initial evaluation of 778 citizens who received Everyday Rehabilitation, reported that 84.8% of program recipients expressed better quality of life and the resumption of the life they desired. 45.9% of them were able to live an independent life. Just over 38% of program recipients reported needing less help with daily activities than they had initially

requested. The program has also reported increased job satisfaction of care providers, decreases in absenteeism due to the improved working conditions the program creates. Seniors themselves are happier and express greater satisfaction with their lives which in turn creates a more positive working environment for staff.

Early evaluation of the “Independent Living Training” project was based on only 1 home care district in the Fredericia Municipality and 139 seniors were re-assessed (i.e. having been previously been assessed by the Everyday Rehabilitation Program) (Heebøll 6). Of those that were re-assessed 37% are estimated to have rehabilitation potential. This means that after completing this second stage of training, they will have full independence. It is still too early in the program to calculate the economic benefits of the Independent Living Project but citizens that are able to regain their self-sufficiency represent a savings of DKK 70,000 (just over \$13,000 Canadian) annually for the municipality. The program has received a number of awards including the European Public Sector Award (EPSA) and is being implemented in 90% of Danish municipalities. The program has saved almost \$3 million (CDN) per year over traditional and expensive compensatory initiatives (Kjelberg 7).

The Canadian Perspective

These three examples provide innovative ways of setting up homes for seniors to promote autonomy. But how different are they really? Just for perspective here is the vision, mission and mandate from Chartwell Nursing Homes. Chartwell is one of the largest nursing home corporations operating in North America. They own, manage or lease 212 properties in Canada and the US which hold a total of 30,008 suites (Chartwell 16):

Chartwell's vision is: Making People's Lives BETTER. Chartwell's mission is: To provide a happier, healthier and more fulfilling life experience for seniors. To provide peace of mind for our residents' loved ones. To attract and retain employees who care about making a difference in our residents' lives. Chartwell's values are:

- Respect - We honour and celebrate seniors.
- Empathy - We believe compassion is contagious.
- Service Excellence - We believe in providing excellence in customer service.
- Performance - We believe in delivering and rewarding results.
- Education - We believe in lifelong learning.
- Commitment - We value commitment to the Chartwell family.
- Trust - We believe in keeping our promises and doing the right thing (Chartwell.com).

While very well meaning, these statements provide insight into the current framework around how care is provided to seniors in Canada. Unlike the visions mentioned in the three international examples, nowhere in the Chartwell vision, mission or values is quality of life, independence, choice or autonomy mentioned. These statements provide a telling example of the current ideology behind care for seniors in Canada. One that is not focused on improving autonomy or enhancing quality of life for Canadian seniors.

The Differences

Chapter two identified ways in which the current system of long-term care in Canada infringed on seniors right to autonomy; highly structured nature of care delivery, limits to personal space,

the prioritization of safety over quality of life for seniors and the imbalance of power between care providers and recipients. The three international care models provide excellent examples on how to address these issues.

Unscheduled Living

All three models move away from the highly structured nature of care delivery. Indeed, the GH model shows that by providing care on a smaller scale and empowering care providers to take on a larger role, a movement away from regimented scheduling is not only possible, it improves the quality of care and makes elders and staff happier. As a model for congregate housing, Babayaga House, allows seniors to remain in their own homes, on their own schedules, while providing the safety net and social support of fellow seniors. As the central focus of the care plan, seniors in Fredericia municipality are able to design a rehabilitation program that fits into their own schedule.

Privacy

In both Babayagas House and THE GREEN HOUSE® residents have their own room, with their own bathroom and a lock on the door. Research into autonomy for seniors has stressed the importance of personal space when setting up living arrangements that promote autonomy (Kane, 168). In the Fredericia model, the goal is to have seniors remain in their own home for as long as possible, delaying a move into a long-term care facility that might infringe on their privacy.

Risk Management

Safety is rarely mentioned in any of the three models, which could suggest that safety is not prioritized in any of the models. Instead each example shows how risk can be managed rather

than avoided. In the Babayaga model residents live together in close proximity and check on each other regularly. They have included space for younger adults in the hopes of providing mutual support. One can imagine this involves asking the younger residents to assist with tasks that the older women find more difficult to perform. In GH's residents have their own space but medical staff are never far away should they be needed. The Fredericia model deals with risk preventively, by increasing the strength and capacity of seniors so they are able to remain healthy and active longer. These models demonstrate that risk can be managed and that safety need not be compromised in order to promote autonomy and quality of life.

Balance of Power

All three models address the power inequality in traditional care relationships where the care providers hold considerable power over care recipients. This form of legitimate power comes from a belief that care providers have the formal right to make demands from the care recipient based on the medical model that expects compliance and obedience from patients in order to achieve their health care goals. In each model, control has been given back to the senior, placing them in the driver's seat of their own lives. At the Babayaga House; by entering into a partnership with the municipality and local public housing authority they have established themselves on equal footing with the institutions that provide the funding and regulate their home. Their charter of living allows them to handle situations themselves that may arise over the management and organization of the home. In the Fredericia model, care is provided based on the requested needs of the senior, they define what care they would like to have provided. The care team helps them determine how best to reach their own goals. In Green Homes, elders are treated with respect and dignity, the role of the Shahbazim is seen as supporting the elder in ways that promote their quality of life.

Economic Equality in Long-term Care

One area of considerable inequality in the system of long-term care in Canada is the two-tiered system of care that is created when access to long-term care is not universally provided.

Currently in the Canadian system, those seniors with the financial resources are able to purchase the care they need, allowing them to remain autonomous for as long as possible. Low income seniors are more likely to find themselves in long-term care facilities that compromise their autonomy. Addressing the financial barriers to care may not be necessary if all long-term care systems in Canada aim to promote seniors' autonomy. If all long-term care in Canada was designed to promote seniors' autonomy, the inequality of care between the haves and the have nots would be addressed. It would no longer matter the type of care seniors could afford, because all care options would allow for autonomy, thus reducing the inequality for low income seniors. Low income seniors would no longer have to worry about not having enough money to pay for care that allows them to remain autonomous because all care options will allow them to remain autonomous regardless of income levels.

Increasing Autonomy

These three programs provide excellent approaches for increasing autonomy in later life for seniors. They do so in slightly different ways; but taken together, they provide some inspiration for tackling the growing needs for long-term care within the Canadian society. Beginning with innovative ways to help seniors remaining in their home longer to new ideas about setting up home for seniors. All three examples recognize seniors' right to autonomy and re-imagine not

only what it means to age but also the state's role in improving quality of life and autonomy for older Canadians.

All three examples improve quality of life by respecting the autonomy of seniors and allowing them to remain the authors of their own lives. These examples provide a high level of care and safety without compromising autonomy and dignity. Each model re-balances the care model, empowering seniors in the care they receive, and where and how they live. State funding for these models could ensure social equality so that seniors with limited financial and social resources are able to enjoy the same levels of autonomy as those seniors with higher incomes. Limited initial evaluations suggest the economic impacts to these alternatives are less expensive than traditional models of long-term care.

CONCLUSION

A shift is needed in the design and delivery of long-term care in Canada. One that moves away from facilities that are more institution than home. Long-term care facilities need to be designed in ways that promote autonomy for their residents. The right to autonomy requires government action in the funding of new and existing long-term care facilities. Promoting autonomy in long-term care requires a movement away from strict scheduling and the prioritization of health and safety. New models of care should offer increased levels of privacy and personal space for residents, and realign the balance of power between care givers and care recipients. With a greater number of seniors in general, and older seniors specifically, entering the Canadian demography in the years to come, governments at all levels must act now to deliver the kinds of long-term care needs that Canadian seniors require to live autonomous lives.

The following recommendations provide some suggestions on ways in which all levels of government could promote autonomy in long-term care for Canadian seniors.

- 1) The new Liberal Government in Canada has promised to increase investments in infrastructure at both the federal and provincial/territorial levels (Liberal Party of Canada 4). Funds will be dedicated to social infrastructure, prioritizing the building of new seniors' facilities and affordable housing. Provincial and territorial governments should look to THE GREEN HOUSE PROJECT™ and similar collective dwelling models when building new, or renovating existing, facilities to increase the autonomy of residents. This can be accomplished by building individual private rooms with common living areas. An excellent example has recently been announced in Ottawa. An “innovative” plan to integrate 42 low-income seniors' housing units into a Community Health Centre has just been announced (Laucius). The funds are being provided jointly by the Ontario Ministry

of Health and Ottawa Community Housing. Increasing the number of long-term care facilities that follow this model will provide greater access to Canadian seniors in living arrangements that promote and protect their autonomy.

- 2) Governments at all levels should also make it easier for seniors themselves to access funds to set up their own communal dwelling, much like the Baba Yaga's have done in Paris. The New Horizons Program is an example of a federal program, run by Employment and Social Development Canada, that provides one to three years of funding up to \$750,000 to promote activities that support social participation and inclusion for seniors. This money could instead be reorganized to target innovative housing projects at the provincial or municipal level. Increasing the number of collective dwellings for seniors would be an excellent way of reducing social isolation, while also ensuring there are a variety of housing options available for the growing number of seniors, that promote autonomy. Funds could be used to build new structures or renovate existing ones. Funds could be managed by municipalities with individual groups of seniors organizing themselves to design and build or renovate collective dwelling units. Additionally, the funds could be given to public housing authorities to target the delivery of senior specific public housing that allows residents to remain autonomous while also providing aid and assistance to each other as they age.
- 3) Finally, provincial and territorial governments should evaluate the homecare delivery model using autonomy as an outcome measurement. The inclusive of seniors themselves in the development of care plans and focusing the planning of care around the simple

question “what would you like to be able to do?” could have a profound impact on the re-imagining of seniors care in this country. Lessons from the Fredericia model could provide insight on the best ways to provide and delivery care to seniors in their own home, that values their personal choice and promotes their autonomy.

Building long-term care facilities that promote autonomy for residents would go a long way in changing the mindset of Canadian seniors when faced with the decision about where to live. While the fear and reluctance to move out of one's own home may never be completely extinguished, there is ample opportunity to design and delivery models of care that are more attractive to today's aging Canadians. Living arrangements designed to promote autonomy, whether in long-term care or homecare and opportunities to develop their own collective dwellings would be a welcome addition to the long-term care landscape in Canada.

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