

“Everyone needs a purpose”: Service provider perspectives on young adults in long-term care in
Northern Ontario

by

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Abstract

The purpose of this qualitative study was to gain an understanding of the experience of young adults with disabilities entering long-term care from the perspective of six long-term care staff and community-based service providers in Northern Ontario. This study was approached with a social constructionist and critical social theory of disability worldview. This study sought to understand the implications associated with young adults residing in long-term care homes in Northern Ontario and to gain a better understanding of what the most appropriate housing options are for this population. A number of themes emerged including, inadequate community-based services, complex health and social needs, need for integrating health and social care, and proposed solutions. These themes point to a fragmented health care system that denies young adults with disabilities the right to choose where they wish to live and receive care. Contributing factors such as limited staffing, lack of training and environmental barriers minimize the opportunity for these individuals' to live dignified lives while residing in long-term care homes. Findings from this study help identify policy planning needs for this population, from a Northern perspective. A number of recommendations are proposed including the creation of specialized units within the long-term care, increased staffing levels with specialized training, and collaboration of community partners for capacity building purposes. The recommendations also identify the need for a continuum of housing options to be available for young adults with disabilities and emphasizes the need for a province wide strategy for integrating health and social care.

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Chapter One

Introduction

The purpose of this qualitative study was to gain an understanding of the perspectives of service providers who work with young adults with disabilities in long-term care homes in Northern Ontario. A phenomenological approach was employed, with six semi-structured interviews completed with service providers who work with this population. The theoretical framework of this study utilized a social constructionist and critical social theory worldview. As illustrated in the literature review, there have been some international qualitative studies that examine the experiences of young adults with various diagnosis entering long-term care homes. In Ontario, there have been a number of reports that have examined the disparities in our health care system, including our long-term care homes, however, the motivation for many of these reports has been the looming crisis that is upon as the baby boomers age. To date, there has not been a qualitative study that draws upon a phenomenological approach to examine the perspectives of service providers who work with young adults in long-term care, from a Northern Ontario perspective. This paper also incorporates a structural analysis of the current social policies that affect young adults with disabilities.

Background

It is currently estimated that there are 4.4 million people living with a disability in Canada, which accounts for a total of 14.3% of the total population (Human Resource and Skill Development Canada, 2009). Over the years, Canada has made a number of strides in regard to the rights of those with disabilities. Significant policy developments over the last two decades include the protection of people with disabilities in the Canadian Charter of Rights and Freedoms (1982) and in the Canadian Human Rights Act (1977). As well, in 2010 Canada ratified the United Nations Charter for the Protection of the Rights of People with Disabilities (2010).

However, despite Canada having made a commitment to enable individuals and families to live as independently as possible in the community in a dignified manner, programs and practices have continued to fall short of allowing this possibility to be fully realized. Individuals' with disabilities continue to be marginalized and excluded from society. Since the 1990s, Canada's dominating ideology has been neoliberalism which has led to the development of policies that favour the free market and privatization (Harvey, 2005). In fact, Prince (2012) has identified frustration and disappointment as being the two dominant themes present among advocacy groups and community-based organizations when examining Canadian disability policy over the last two decades. Governments have become increasingly reliant on the non-profit sector to provide services for individuals with disabilities where gaps exist; however, these organizations are struggling to meet the demand, particularly in regards to the increasing number of young adults with disabilities who are in need of housing with personal care and support services. In particular, ongoing social exclusion has been reported as being most evident when examining Ontario's healthcare and housing policies, which continue to focus primarily on meeting basic physical needs and neglects to acknowledge the social care needs that need to be addressed in order to ensure well-being and social inclusion.

The need for housing options that integrate a range of supports including those required for activities of daily living (ADL) such as personal care like eating, dressing, bathing and supports for instrumental activities of daily living (IADL) such as housework, meal preparation, assistance with managing money, shopping and transportation, assistance with forms completion are essential. In Ontario, we have experienced an increase in life expectancy and there is an anticipated surge of ADL and IADL assistance required as the baby boomers age. Identified less frequently, is the increasing number of young adults with medical issues and disabilities who are

now living much longer as the result of advanced medical technology. According to a Canadian based survey on disability, 10.1% of Canadians between the age of 15 and 64 have a disability that restricts their ability to complete daily activities that requires ongoing support (Statistics Canada, 2017). Unfortunately, availability of community-based resources that offer these much-needed supports is limited with most waitlists ranging from five to 10 years (Harris & Scarfone, 2014). As a result, many young adults are being admitted to the hospital unnecessarily or to long-term care homes. This has been identified as an upward substitution of care as it is the most costly way to provide care and often results in further physical and mental decline (Walker, 2011).

This study consisted of six semi-structured interviews with professionals who work with young adults with disabilities in the community and long-term care sector. The purpose was to gain a better understanding of their perspective of the growing phenomena of young adults residing in long-term care. This study found that despite the goals of the disability movement and the philosophies undertaken by the independent living sector, where the aim is to help people with disabilities to “live as independently as possible with choice, opportunities, and the confidence of full citizenship” (Williams, 2017), services continue to operate from a medical model of care that is heavily focused on providing basic needs and neglects to meet client needs from a person-centered approach.

Participants in this study identified that social needs often go unmet in long-term care due to lack of funding and limited staff with limited time. Participants spoke about long-term care being a “catch all” where staff are increasingly expected to provide care to young adults who are increasingly complex socially, psychologically, and medically. Participants identified a number of environmental barriers that result in a lack of privacy and deny opportunity for young adults to

carry on “typical” friend and family relationships. The lack of age appropriate activities for disabled young adults add to their struggle relating to others. Participants also noted limited family support among this population as well.

Participants felt that there was a need for services to be offered in a more integrated way, recognizing both the social and medical needs of residents. Increased staffing, and capacity building to meet mental health and behavioural challenges were identified as key areas requiring attention. Participants felt that the government needed to reform service delivery within the health care system and seek to integrate health and social care. As well, collaboration between community partners to develop creative solutions as well as enhancement in caregiver support were all recognized as being imperative in improving the quality of life of young adults with disabilities and reducing the need for costly hospital stays and premature long-term care admissions.

Young adults with disabilities have been disregarded in policy making decisions as the looming crisis of the baby boomers has overtaken most discussions and policy planning initiatives. With the roll out of the Ontario Health Teams, it is important the government recognize the need to include young adults with disabilities on policy agendas. While deinstitutionalization demonstrated progress in regard to perceptions of people with disabilities, it is evident that many accommodations fall short of enabling inclusion and dignity. Interestingly, the results of this study along with the systemic review of the literature suggest that changes that would benefit young adults with disabilities would also be beneficial to the older adult population residing in long-term care as well.

Upon examination of our current context, it’s important to note that the COVID-19 pandemic has reinforced many of the stark realities presented in this report which point to a long-

term care system that is failing our most vulnerable populations (young and old) and the workers who care for them. The COVID-19 pandemic has had a devastating impact on Ontario's long-term care residents, who account for 75% of Ontario's COVID-19 deaths (Jabbar, 2020). This has resulted in a crisis situation and has exposed the government's neglect; shining light on the many gaps in the long-term care system. Significant underfunding often results in poorly paid staff members and inadequate staff to patient ratios. Both of these issues are significant contributing factors to poor quality of care. The COVID-19 epidemic has also drawn significant attention to the quality of care discrepancies between the non-profit and for-profit sectors of long-term care in Ontario. Currently, 59% of Ontario's long-term care homes are owned and operated by for-profit companies (Ontario Health Coalition, 2019). In a study conducted by the Ontario Health Coalition (2019), it was found that for-profit long-term care homes had poorer outcomes when compared to non-profit homes, and the coalition argued that this was due to lower staff levels in the for-profit sector. Findings of this study reinforce that many of the issues that COVID-19 has brought to light have been long-standing and have been overlooked by Government officials for years.

Need for the Study

According to Goffin (2017), approximately 6% of Ontario's long-term care beds are occupied by individuals under the age of 65. This includes approximately 2,500 individuals in their early 60s, 2300 in their 50s and 500 individuals in their 40s (Goffin, 2017). When we think of long-term care in our country, typically one would imagine a home that provides 24-hour care for our older adult population; however, the population of individuals residing in long-term care has been changing. According to the research, people under the age of 65 are being admitted into long-term care homes across the country because they have nowhere else to go (Canada's Health

Care News and Best Practices, 2015). It is critical to acknowledge and learn about the specific challenges and needs of young adults who enter long-term care as it is an under-researched topic that is often ignored. Advocacy work in the long-term care field has largely focussed on improving services for the senior population. Due to this phenomenon being under-researched, the ramifications associated with young adults residing in long-term care remains unknown.

Purpose of the Study

The research described below was designed to examine the experiences of young adults in long-term from the perspective of service providers in Northern Ontario and to understand the implications associated with having this population reside in long-term care homes. The research assists in raising public awareness about this growing phenomenon and will result in recommendations to improve the quality of life of young adults with disabilities.

Research Question

The purpose of this research study is to answer the following questions:

1. What are the implications associated with young adults residing in long-term care homes in Northern Ontario?
2. What are the most appropriate housing options for young adults with disabilities who have complex care needs in Northern Ontario?

Research Design

For the purposes of this study, a qualitative research approach was taken. As such, interviews were completed with professionals who work with this population in order to help contextualize the reasons that this is happening, identify the implications associated with this growing phenomenon and to explore what may be the most appropriate housing options for young adults with complex care needs in Northern Ontario. According to Denzin and Lincoln

(2008) “qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (p.4). According to Fossey, Harvey, McDermott and Davidson (2002), qualitative research should incorporate varying perspectives to create a breadth of knowledge and understanding about a certain topic. Qualitative research is an appropriate approach for this study as it allowed the participants to share their own perspectives and assign their own meaning from their experiences.

Chapter Two

Literature Review

Methods of Searching

The Laurentian University database and Google Scholar search engines were used to collect various peer reviewed articles and reports that explored the phenomena of young adults in long-term care. Within the Laurentian University database, various discipline categories were explored including; social work abstracts, social services abstracts, gerontology, psychology, and nursing. Within the Google Scholar and the Laurentian University database, the following words were included; (1) young adult, young person, non-elderly, non-geriatric, under 65, young disabled adult, (2) long-term care, nursing home, institutional care and aged-care facilities, (3) disability policy, history of disability, Ontario disability policy, and social policy. There were a few articles that focused specifically on the experiences of young adults in long-term care homes; however, when reviewing the literature it became apparent that more results would likely be produced if separate searches were conducted that focused on specific types of disabilities. The initial search revealed that certain diagnoses including multiple sclerosis, acquired brain injuries, Huntington's Disease, developmental disabilities, and mental illness were common among the young adults entering long-term care homes (Donovan, Regher, & George, 2013; Winkler, Farnworth, Sloan, & Brown, 2011). Therefore, the search was expanded to include the aforementioned diagnoses.

Theoretical Orientation for the Study

The theoretical framework employed for this research study is consistent with a social constructionist and critical social theory of disability worldview. Creswell (2013) defines social constructivism as being an interpretive framework where individuals search to understand their

world and attach their own personal meanings to their experiences. The goal of the research is to ascertain the participants' views of the situation (Creswell, 2013). Instead of applying an established theoretical framework (a positivist approach), theories or patterns of meaning are developed based on participants' perspectives (Creswell, 2013).

This framework also coordinates with an additional lens employed for the purposes of this paper, which is that of a critical social theory of disability. Critical social theory of disability seeks to analyze disability as a cultural, historical, social, and political phenomenon (Vehmas & Watson, 2014). As a methodology, this theory "involves scrutinizing not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations." (Schalk, 2017, p. 1). Critical social theory of disability also goes beyond the walls of academia and emphasizes the importance of activism and social justice work. In the field of social work, social justice, empowerment, and a commitment to advocating for marginalized populations are paramount and a critical social theory of disability allows for the construction of disability to be viewed through a critical lens (Hiranandani, 2019).

Review of the Literature

The literature search revealed a number of key themes that related to this study. These themes included the history of disability, paradigms of disability, social policy and disability, characteristics of young adults in long-term care and impacts on the individual residing in long-term care. The literature review provides an overview of each of these key themes that directly relate to the research topic at hand and assist in garnering an understanding of the historical experiences of individuals with disabilities while orientating the reader to the current realities faced by those with disabilities.

Defining disability

When we complete a cross-examination of the various sectors in Ontario, it becomes evident that there is no universal definition of disability. If we examine the Ontario Human Rights Code, the definition of disability provides a broad range of conditions that include physical disabilities, mental impairments and mental disorders, developmental and learning disabilities, or injury (Ontario Human Rights Code, 1990). Historically, legislation and policy discourses have characterized individuals with disabilities as unfit for society, functionally limited, and unable to contribute adequately to the workforce (Fleischer & Zames, 2001). In Canada, disability has been seen primarily through the lens of the medical model; however, the concept of disability being an individual problem has changed over time, with an increased acceptance that disability is a social construction where social, cultural, political, and environmental barriers imposed on individuals is more disabling than any physical or cognitive disability (Hiranandani, 2019). According to the Ontario Human Code (1990) disability is defined as:

any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device, a condition of mental impairment or a developmental disability, a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language, a mental disorder, or an injury or disability for which benefits were claimed or

received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997*.

Historical perspectives of disability

It is now widely accepted that disability is, in fact, a social construct that reflects the cultural, social, and political discourses present at the time (Oliver & Barnes, 2012). However, in order to understand the current context of disability in Canadian society, it is imperative that we examine the historical context in which the view of disability has changed and evolved over time. The systemic exclusion of individuals with disabilities from mainstream society is the result of historical underlying societal assumptions that discriminate and devalue their lives (Barnes & Mercer, 2003). According to Jongbloed (2003), an early paradigm of disability believed that disabled individuals were dangerous, deviant, and disruptive to society. Individuals with disabilities were previously cared for by family members and extended support networks in the community; however, this changed rapidly with the industrial revolution. This period of time was referred to as the establishment phase of the institutional cycle, and lasted from 1839 to 1899 (McCauley, 2011). The influential policies at the time focused on an approach that promoted confinement and control and came from a law-and-order approach when looking at policy development for this population (Jongbloed, 2003). At this time, individuals with mental disabilities were not separated from the criminal population; however, this changed as there was a push towards an asylum model of care during the years of 1860 to 1890 (Jongbloed, 2003). Initially, this was to be used as a last resort; however, this quickly changed as the dominant view of disability became that of the medical model, and the eugenics movement began to unfold (McCauley, 2011).

By the end of the 19th century, there was increased political pressure to create more institutions to house and confine individuals who had mental illnesses and intellectual impairments (Jongbloed, 2003). Older adults requiring support and individuals with physical disabilities (such as victims of roadside accidents) were not introduced to institutional care until around the mid 20th century (Jongbloed, 2003). The segregation of individuals with disabilities in Canada began to foster momentum as industrialization grew rapidly. During this time, individuals with disabilities were not seen to be contributing to the labour market. Those who required daily living assistance and care experienced increased marginalization in a changing society (Davis, 1997). Barnes and Mercer (2003) explained that individuals with disabilities were quickly categorized as being non-productive, sick, and unemployable in the wake of the industrial revolution. This allowed for easy exploitation of the poor as a division of the deserving and non-deserving poor was created, stemming from social policies at the time. As a result, state relief and government assistance were only afforded to individuals who were seen to be non-able bodied and created a sense of desperation for able-bodied individuals to work in factories (Barnes & Mercer, 2003). Anyone who was seen as not contributing to society was forced into institutions, hospitals and asylums (Barnes & Mercer, 2003). At this time, many children who were born with disabilities were unable to survive into adulthood due to limited medical technology, medicine, and the inability to perform procedures that would enhance quality of life and increase longevity (Jongbloed, 2003). Individuals with disabilities were viewed as being physically dependent on others and were therefore, in many ways, denied the ability to exercise their civil rights (Galer, 2015).

By the beginning of the 19th century, the entrenchment phase of Ontario's institutional cycle had begun. A medical and economic model of analyzing disability had evolved

(McCauley, 2011). At this time, there was an emphasis on establishing hospitals and disability pensions for individuals who had returned from World War I (Galer, 2015). Many injured and disabled veterans returned to Canada and were unable to contribute to the workforce upon their return due to having acquired various mental and physical disabilities (Galer, 2015). Eventually there was a push towards deinstitutionalization and increased pressure to move towards community-based supports for individuals with disabilities (McCauley & Matheson, 2015). McCauley and Matheson (2015) explained that the movement towards deinstitutionalization wasn't triggered by one specific policy but was partly a response to public challenges being made to the way institutions were run. In their paper, McCauley & Matheson (2015) cited Pierre Berton's column (1960) in the Toronto Star which was titled, "What's wrong at Orillia: Out of sight—out of mind." In his article from January 6th, 1960, he spoke about the conditions of one of the institutional facilities that his friends' son had resided at stating the following,

Orillia's real problem is one of public neglect. It is easier to appropriate funds for spectacular public projects such as highways and airports than for living space for tiny tots with clouded minds. Do not blame the present Department of Health for Orillia's condition, blame yourself. Remember this: After Hitler fell, and the horrors of the slave camps were exposed, many Germans excused themselves because they said they did not know what went on behind those walls, no one had told them. Well, you have been told about Orillia. It is, of course, no Belsen. In many respects, it is an up to date institution with a dedicated staff fighting an uphill battle of despairing conditions. But should fire break out in one of those ancient buildings and dozen of small bodies be found next morning in ashes, do not say you did not know what it was like behind those plaster walls, or underneath those peeling wooden ceilings. (p. 196)

It was around this time that we saw a shift towards the reform phase of Ontario's institutional cycle. Many parents of disabled children, professionals, and disabled individuals began to partake in social movements and coalitions aimed at increasing inclusion and equality of individuals disabilities (Barnes & Mercer, 2003). In the 1970's, there was a revolution of individuals with disabilities seeking to form their own groups to advocate for civil rights. Some notable groups that were established during this time across Canada included, the United Handicapped Groups of Ontario, British Columbia Coalition of the Disabled, and League for Equal Opportunities in Nova Scotia (Galer, 2015). The community living movement had been initiated through pressure from advocates and a strong surge towards deinstitutionalization began to gain momentum (McCauley, 2011). In 1975 the United Nations issued a declaration on the Rights of Disabled Persons which encouraged member countries to develop legislation that would emphasize and promote initiatives that sought to protect the rights and promote opportunities for individuals with disabilities (Galer, 2015). During this period, individuals with disabilities were moved to community-based settings; however, concerns regarding the quality of care that was being provided in the community continued to be a significant concern as the non-profit and community-based organizations were underfunded (Galer, 2015). So, while there was a movement towards individuals returning home to reside with family or in other community-based settings, there was a significant lack of community support provided to create a dignified quality of life for individuals with disabilities (Galer, 2015).

By 1981, the United Nations' International Year for Disabled Persons was celebrated and there was a pursuit to address disability rights in Canada (Galer, 2015). By 1982, disability was included in the Charter of Rights and Freedoms (Galer, 2015). In 1987, Ontario declared that they would close the remaining institutions in Ontario, which marked the inception of the

dismantlement phase of the institutional cycle (McCauley, 2011). In 1991, the Federal government announced a national strategy of persons with disabilities, which was a cross-government initiative to promote social and economic inclusion of individuals with disabilities. However, according to McCauley (2011), evidence of a number of social barriers and the existence of discrimination continued to prevail with poverty and limited access to support services. In evaluating the national strategy, a leading text on Canadian social policy concluded that, “Canada has no overall framework for social justice for persons with disabilities and, unlike for seniors or the unemployed, has never aspired to build one (Armitage, 1996 as cited in Prince, 2004, p. 65).

Throughout the process of deinstitutionalization, the rhetoric of community living began to move towards an approach that supported the need for social inclusion (McCauley & Matheson, 2016). However, the literature reviewed indicates that the concept of social inclusion and equality has not yet been realized. Governments continue to claim that they have a vision for disability issues and people with disabilities (Prince, 2004). Although there have been advancements in the disability domain, there continue to be significant gaps where discrimination and marginalization persist (Prince, 2004). According to Prince (2004),

A close and critical examination of governmental depictions of Canada’s disability policy +record reveals there has been more advancement in certain jurisdictions, in certain policy sectors, and in certain time-periods than in others. Some progress has been made in the areas of shelter and transportation but relatively less in income maintenance and home support services. (p. 70)

Attitudes and understanding of disability issues continue to reinforce cultural bias, which are embedded in various programs, policy designs and service delivery systems (Prince, 2004). Over

the last 20 years in Canada, we have experienced fiscal austerity and a heightened focus on reducing the financial deficit in our country (Prince, 2004). This period included two recessions in the Canadian economy, which contributed to a shift away from state intervention and social concern towards an approach that has been reliant on the market and issues related to the economy (Prince, 2004). As a result, limited funding allocated to community-based services for individuals with disabilities continues to persist, resulting in many adults ending up in costly institutions such as in alternate level of care (ALC) beds and premature entry into long-term care homes in Ontario.

Paradigms of disability

Historically, the dominant view of disability has been that of the medical model, which locates the “problem” of disability as being within the individual and is thought to be the result of individual deficits (Oliver, 1996). Later, the social model of disability emerged. This next section will explore the two paradigms that have heavily influenced policy planning and decision making in Ontario.

Medical model. From the perspective of the medical model, disability has been seen as problematic and as something that is in need of fixing (Oliver 1996; Rioux & Valentine, 2006). It has been argued by many disability advocates that individual pathology, which emphasizes medical intervention and a need for rehabilitation, is heavily aligned with this ideology (Rioux & Valentine, 2006). Within the medical model, able-bodied individuals are seen as the norm and individuals with disabilities are perceived as requiring professional intervention and in need of charity, but not necessarily equality (Rioux & Valentine, 2006). The consequence to individuals with disabilities is that treatment and care are seen as necessary in order to bring the individual to a more “normal” level of functioning or to assist them in adapting and learning to function

regardless of the disability (Goering, 2015). However, many individuals do not feel that their disability is problematic or in need of fixing but struggle with the environmental barriers that limit their ability to function and contribute to society in a way that is equal to those without disabilities (Goering, 2015). Research has demonstrated that when a medical model is employed, individuals with disabilities are often feel excluded, undervalued, and feel significant pressure to align with what is seen as the norm (Goering, 2015). Critics argue, however, that for individuals with disabilities, the most significant disadvantage that they encounter is the social attitudes and norms that effectively exclude them (Goering, 2015). Goering (2015) cites Lois Keith (1996) who stated that:

Doing disability all day long can be an exhausting process. I don't mean having an impairment, in my own case not being able to walk. Like most disabled people, I can deal with this. I mean having to spend a significant part of each day dealing with a physical world, which is historically designed to exclude me and, even more tiring, dealing with other peoples' preconceptions and misconceptions about me. (p. 1)

As the medical profession evolved, it provided a form of legitimacy for the individual pathology approach to understanding disability (Barnes & Mercer, 2003). The concept of medical professionals having control over the lives of individuals has been disabling and oppressive. Many professionals including the social work profession, which is founded on the basis of "helping" individuals to adjust to their disability, effectively enforced the need for the individual to adapt and perhaps engage in rehabilitation (Barnes & Mercer, 2003). With the industrial revolution, capitalism as well as the development of science and medicine, disability has continued to be seen as a tragedy. The view that a person with a disability has limited functioning and therefore a loss of quality of life, continues to dominate in today's society

(Oliver, 1996). Oliver and Sapey (2006) argue that the individual model of examining disability is a matter of political convenience as it emphasizes that responsibility lies with the individual person to create adjustments and endure rehabilitation strategies, rather than on society to actually re-organize and shift in ways that create accessibility and openness to difference.

Social model. The social model was brought forth around 1976 when the Union of the Physically Impaired Against Segregation was initiated (Oliver, 1996). The social model does not see impairments as being a deficit or something that requires fixing. Instead, the social model argues that impairments occur naturally and should be seen as a matter of human difference and not as a tragic occurrence or as something that requires medical intervention (Oliver, 1996). From this lens, disability is simply seen as being a variation in human genetic make-up. It also examines the way in which industrialization and capitalism has led to the development of structures in our society that reinforce barriers, which can be disabling to certain individuals (Oliver, 1996). For example, individuals who have been born blind have reported that they find that their blindness is a relatively neutral way of being in the world and do not necessarily associate this with being problematic (Goering, 2015). In Goering's (2015) article, she references a quote from Deborah Kent (2000) who states that:

From my point of view, I wasn't like a normal child – I was normal. From the beginning, I learned to deal with the world as a blind person. I didn't long for sight anymore than I yearned for a pair of wings...I premised my life on the conviction that blindness was a neutral characteristic. (pp. 57-58)

According to Oliver (1996) the social model acknowledges that society has failed to provide services that are appropriate to ensure the needs of individuals with disabilities are fully taken into consideration within our social organization. Disability, therefore, includes a number

of restrictions and limitations that are imposed on individuals, including negative social attitudes and beliefs regarding disabilities and environments that are inaccessible (Hiranandani, 2005). Using a social model approach, we are able to examine and deconstruct labels assigned to individuals with disabilities, enabling us to recognize the ways in which culture and economy produce disability. When the problem of disability is, instead, seen as being largely linked to cultural and economic climates, then the situation of people with disabilities can be re-politicized in a way that recognizes collective experience and reflects the needs and lived experiences of individuals with disabilities (Oliver, 1996). Many social model theorists have challenged the idea that having a disability is a tragedy. They have instead reframed this assumption to highlight the biggest tragedy as being related to the economic and social exclusion that individuals with disabilities face in our society as they are denied or misperceived to lead lives that lack quality or that are not “as good” as able-bodied individuals (Oliver, 1996). Oliver (1996) has brought an alternative worldview of disability highlighting that people with disabilities can and do live good lives and they often do not have a desire to be cured or fixed, contrary to popular belief.

Social policy and disability

Social policy in Canada has been shaped partly by the socio-historical and cultural context of the country (Shier & Graham, 2014). Canadian social policy has been primarily focussed on addressing social conditions of Canadians with a particular focus on income inequality, housing, immigration, labor market attachment and health care (Shier & Graham, 2014). Over the course of Canadian history, social policy frameworks have been adopted that seek to address the sociopolitical rights of marginalized individuals in our society as well as implementing ways to alleviate negative conditions that marginalized individuals live through (Shier & Graham, 2014). This includes national and provincial programs that have sought to

provide social support and economic support programs (Shier & Graham, 2014). Unfortunately, these programs have often fallen short of their intended purpose.

Canadian social policy has generally been regarded as being ingrained in neo-liberal worldviews and public policy frameworks, asserting a free-market capitalist economy (Esping-Anderson, 1990 as cited in Shier & Graham, 2014). According to Stanford (2008), inequality is a deeply embedded characteristic of a capitalist society. This is evident when we examine home care services in Ontario. Aronson and Neysmith (2001) completed a study on home care in Ontario and found that the marginalization of the elderly and persons with disabilities "is deepened by the neo-liberal conceptions of citizenship that prize self-sufficiency and independence, disparage need and dependence and, thus, permit receding state intervention and greater privatization of care" (p.153).

Neo-liberalism also advances disturbing beliefs around citizenship, where individuals with disabilities are viewed as being sick patients with spoiled identities (Prince, 2012). The foundation of social welfare policy in Canada goes as far back as the 1600s, when the Elizabethan poor laws were passed, resulting in a delineation of the 'deserving' and 'undeserving poor'. Remnants of the Elizabethan Poor laws continue to remain within the context of our social welfare systems. Policies continue to value individuals who can work, over individuals who cannot. Income-security programs continue to be tied to strict eligibility criteria, and income support that individuals receive is based on their ability to participate in the labour market (Shier & Graham, 2014). Over the last decade, development of social policy in Canada has led to more restrictions to accessing various programs for individuals who are poor and unemployed, which happens to be disproportionately represented by individuals with disabilities (Prince, 2006). Privatization accompanies the belief that programs for individuals with disabilities are not seen

as being deserving of investment for future return from a market-based perspective (McDaniel, 2002 as cited in Prince, 2012).

Social policy and social welfare in the 21st century have been described as the 'post-institutional' or 'market-state' period (Graham, Swift, & Delaney, 2012). There has been an increasing decentralization of social responsibilities heavier reliance on local communities by the non-profit and voluntary sectors (Shier & Graham, 2014). Canada has seen a relative decrease in the amount of social spending by senior governments since the mid-1970s (Graham et al., 2012). Recent studies have shown that community-based organizations in Canada are now taking on a larger role in responding to the needs of marginalized individuals (Karabanow, 2003 as cited in Shier & Graham, 2014). Over the last three decades, governments have been slow to implement changes to policies affecting individuals with disabilities. Where there have been gains, they have been minimal and have progressed in a long drawn out fashion (Karabanow, 2003 as cited in Shier & Graham, 2014).

According to Evers (2009), as cited in Shier & Graham, (2014), Canada may be evolving into a new welfare state era that has an emerging empowerment and participation-based model. Within this model, advocacy, needs assessments, as well as promotion of inclusion and citizenship is taken on by third-sector organizations (Evers, 2009 as cited in Shier & Graham, 2014). Levesque & Langford (2016) identify the importance of government officials seeking to engage citizens with disabilities as well as the disability organizations who represent them. Disability organizations play an integral role in providing necessary information on specific policy areas, challenging particular approaches that governments may intend to take. They also work to break down stigma and discrimination (Levesque & Langford, 2016). Engaging with service-users allows an opportunity for real narratives to be linked to the policy planning

process. As such, service users should be included and governments should seek to engage in citizen groups in policy and program development. This allows for the boundaries between the private and public domains to become linked. The result is real life issues identified by service users turn into policy issues and “draw attention to the inclusion/exclusion, interrogating conventional models and practices, attacking oppression, and advancing citizenship” (Prince, 2016, p. 8).

It is important to note; however, that 'participation' in policy development and implementation does not necessarily equate to meaningful changes, as adequate resources are required in order to continue to ensure the inclusion of individuals in the disability sector. Much of the financial and human capital of disability organizations, which is often derived on a voluntary basis, comes from supporters as government funding has been minimal given the austerity measures put into place by government officials (Levesque & Langford, 2016).

Long-term care in Ontario

Long-term care homes are facilities that provide care to individuals who have needs that exceed what can be provided within the community or retirement home setting (CIHI, 2013). Individuals who are admitted from the community or from the hospital usually spend the remainder of their lives in these facilities. Those residing in long-term care pay a fee for accommodation, which is established by the government and is based on the type of accommodation that is chosen (basic/standard, semi-private, or private room). In order to be eligible for entry into a long-term care home an individual must meet the defined criteria in the Long-Term Care Homes Act (2007). The act outlines that individuals must be at least 18 years old, must be insured under the Ontario Health Insurance Plan and also require either of the following:

(a) 24-hour access to nursing care, (b) assistance with activities of daily living at frequent intervals through the day or (c) require constant supervision to ensure the individuals safety and well being (Long-term Care Homes Act, 2007).

The average age of residents in long-term care in Ontario is 85 years old and they are characterized as having multiple morbidities, with a high prevalence of dementia and disability (Canadian Institute for Health Information (CIHI), 2013). Long-term care homes do not fall under the terms of the Canada Health Act, they are not required to be publicly funded and fall under provincial jurisdiction (Berta, Laporte & Wodchis, 2014). Long term care homes in Ontario consist of not-for-profit (municipal, charitable, non-profit nursing home) and for-profit homes. A total of 58% of long-term care homes in Ontario are privately funded, 24% are non-profit/charitable and 16% are municipally run (Ontario Long-term Care Association, 2019). A total of 40% of Ontario's long-term care homes have 96 or less beds and 45% of these are in rural communities. Funding provided by the province to these facilities is linked directly to resident care requirements and is therefore paid per standardized patient, regardless of whether it is a for-profit or not-for-profit home (McGrail, McGregor, Cohen, Tate, & Ronald, 2007).

Young adults in long-term care

Despite the widespread belief that we have effectively moved away from institutionalization and towards community inclusion for individuals with disabilities, reality tells a different story. The population of young adults being forced into long-term care homes has been increasing in Canada. Typically, when we think of long-term care homes in our country, we imagine a home that provides 24-hour care for our older adult population; however, across Ontario, people under the age of 65 are being admitted into long-term care homes because they have nowhere else to go. The Canadian Institute for Health Information (2013) reported that

seven percent of individuals' residing in long-term care homes in Ontario are under the age of 65. Research has demonstrated that there is a growing number of younger people with serious medical conditions and physical disabilities, who are now living longer than they would have in the past due advanced medical saving technology (Williams, 2017). According to Statistics Canada (2013), one in ten Canadians who are between the ages of 15 and 64 has a disability resulting in a significant restriction of their daily activities and require support on an ongoing basis. Currently, in Ontario, there are 627 long-term care homes with a total of 78,120 beds (Ontario Association of Non-Profit Homes and Services for Seniors, 2015). The literature review demonstrates that certain diagnoses were commonly seen among young adults who reside in long-term care homes. Diagnoses include multiple sclerosis, acquired brain injuries, cerebral palsy, Huntington's Disease, developmental disabilities, and mental illness (Donovan et al., 2014; Winkler et al., 2011).

Issues resulting in the placement of young adults into long-term care

The reasons leading to a young adult entering long-term care varies and each person and family unit present with their own unique challenges; however, the most commonly identified theme as contributing to a young adult being admitted into a long-term care home was a lack of available housing options with the required supports (Harris & Scarfone, 2014). For example, Jervis (2002) conducted a study of younger adults with psychiatric disorders in long-term care homes and asserted that downsizing of state mental hospitals were part of the agenda of deinstitutionalization, and although the goals of deinstitutionalization were well intentioned, there continues to be a lack sufficient funding for appropriate alternatives. Public, community, and social housing resources have been described as being insufficient to meet the needs of the deinstitutionalized population (Dorvil, Morin, Beaulieu, & Robert, 2007). In addition, the

advancement of medical technology has resulted in many individuals receiving medical care that has extended their life expectancy. The research demonstrates that consumers and disability activists felt that placement into long-term care homes was often premature and would be unnecessary if there were more housing and community-based supports to meet their needs (Harris & Scarfone, 2014). The lack of community-based resources, has resulted in an “upward substitution” of a more expensive model of care, where an increased number of individuals occupy acute care hospital beds due to a lack of a better and more appropriate option in the community (Harris & Scarfone, 2014).

A number of provincial reports have been released over the years that have identified increased pressure on our health care system as the baby-boomers continue to age. Three significant reports were developed that focused on the growing needs of older adults. These reports include Dr. Walker’s ALC report (2011), Don Drummond’s economic recommendations (Drummond, Giroux, Pigott & Stevenson, 2012) and the Seniors Strategy developed by Dr. Sinha (2011). All three reports spoke about the importance of investing the community-based sector. Walker (2011) spoke about the need for a continuum of care and emphasized the need to work towards avoiding premature admissions into nursing homes. Drummond et al. (2012) brought attention to strategies that were implemented in Denmark where the government stopped creating new long-term care beds in the late 1980’s. Instead, they focused on building a wide variety of dwellings that were adapted for older people. Now approximately 80% of the elderly live independently in the community, receiving home care, community social supports, and practical help around the house. Drummond et al. (2012), Sinha (2012), and Walker (2011) all emphasized the need to improve the quality of the system in Ontario by shifting our system from one created to address the needs of acute care to one that that recognizes support required for

chronic care. Drummond et al. (2012) also identified that health care services were fragmented and confusing for consumers. He strongly urged that existing service silos be more integrated and emphasized the need for a reduction in “administrative red tape” that ultimately affects the efficiency and effectiveness of care required. The argument made by Drummond was that integrating approaches to health care could result in savings of health care dollars (Drummond et al., 2012) Unfortunately, a decade has passed and there has been little improvement since the release of these documents. In fact, we are seeing increased waiting times for community-based supports and long-term care beds. We have also entered into an era that is too commonly defined by “hallway medicine,” a problem that has been many years in the making. According to the Star Editorial Board (2019), overcrowding in hospitals has increased and some patients are left in chairs as there are no beds available to provide treatment. Doctors are regularly providing care in hallways and storage spaces. Meanwhile, there are a number of people in hospital who could be home if there were more community services available. Despite warnings and recommendations, the issue is anticipated to get much worse.

Issues and problems experienced by young adults in long-term care homes

The increasing number of young adults entering long-term care has been identified as an international issue (Winkler et al., 2011). As a result, much of the literature available on the lived experiences of young adults in long-term care have been completed in countries outside of Canada. The literature available identified that young adults often struggle in long-term care homes, which have been designed to provide care to the older adult population, because they are at a different life stage and therefore assign meaning to what constitutes a quality of life based on identified age norms (Marshall & Baffour, 2011). Participants in a study by Jervis (2002), who were under 65 years of age, discussed how being in a long-term care home at such a young age put them at odds with mainstream age norms. Age norms were also challenged by the lack of

age-appropriate activities among young adults in long-term care. It is reiterated throughout the literature that programming and recreational activities in long-term care homes do not target the interests and needs of young adults. Participants in a study completed by Marshall and Baffour (2011) asserted that more could be done to ensure that a stimulating environment is provided for all individuals in long-term care. In addition, access to community and civic life is highly compromised for young adults residing in long-term care homes. In a study completed by Winkler et al. (2007), 45% of participants who were young adults, almost never had the opportunity to participate in leisure activities that were community-based.

Another common issue that was identified throughout the literature pertained to a lack of privacy and self-determination. Lack of privacy and the structure imposed on residents in long-term care were identified as compounding behavioural issues that are often associated with individuals who have an acquired brain injury or mental illness (Jervis 2002). Winkler, Farnworth, & Sloan (2006) support this claim as well, indicating that managing challenging behaviour was the most common issue for young adults residing in long-term care. The literature also found that staff are often inadequately equipped to deal with challenging behaviour that young people can present (Cameron, Pirozzo, & Tooth, 2001; Jervis, 2002). Jervis (2002) describes behavioural issues as a significant contributor to a diminished quality of life and argues that staff lack the necessary training to manage these behaviours on an ongoing basis. Jervis (2002) went on further to note that participants in his study experienced a diminished quality of life due to “invasions of personal space, disregarding resident preferences, loss of the right to make decisions, and a demanding and rigid environment” (Jervis, 2002, p. 174). Although many staff in long-term care have experience and training in managing behaviours associated with dementia and Alzheimer’s Disease, McLean and Koppang (2010) explain that these interventions

or approaches do not necessarily translate to individuals with other disorders. Jervis (2002) indicates that individuals who were found to be disruptive or abusive were often in need of more psychiatric help than that provided in the home.

Chapter Three

Method

Purpose of the Study

Researchers have identified young adults with disabilities being admitted into long-term care homes as an issue in Canada and other developed countries; however, there is limited qualitative research that examines the experiences of young adults in long-term care homes especially in Northern Ontario. Advancement of medical technology, in combination with limited community-based housing options, has resulted in many young adults with a wide range of disabilities being admitted into long-term care homes, as they have no other housing options available to them. The current research available, although limited, demonstrates that the population of individuals that our society usually associates with long-term care homes in Ontario are older adults, but the reality is that there are many young adults living in long-term care homes as well, both nationally and provincially.

Research Questions

The purpose of this research study would be to answer the following research questions:

1. What are the social implications associated with young adults residing in long-term care homes in Northern Ontario?
2. What are the most appropriate housing options for young adults with disabilities who have complex care needs in Northern Ontario?

Research Design

For the purposes of this paper, a qualitative approach was used. The specific type of inquiry employed for this study was a phenomenological approach. This was an appropriate approach to this study as it focusses on describing the common meaning experienced by several

participants in relation to a specific concept or phenomenon (Creswell, 2013). Generally, participants are asked two broad questions that examine the participants' experience with the phenomenon and another that seeks to understand the situations and contexts that affect the individual's experience of the specific phenomenon (Creswell, 2013). In addition, Creswell (2013) indicates that it is best to interview between five and 25 people who have experience with the phenomenon. For this paper, a phenomenological approach allowed for experiences of individuals who work with young adults in long-term care in Northern Ontario to be explored in a way that deepens our understanding of the implications associated with young adults residing in long-term care homes.

Sample

According to Patton (2002), purposeful sampling is a technique that can be used in qualitative research that allows for the selection of individuals who will be able to provide rich information regarding the topic at hand. In order to engage in purposeful sampling, one must identify and select individuals or groups of individuals who have well rounded knowledge and experience with the phenomena under study (Patton, 2002). Purposeful sampling mitigates the possibility of recruiting participants who may not have knowledge of the topic and are therefore unable to contribute in a way that might be as meaningful. Patton (2002) also explains that there are different types of purposeful sampling that can be used. For this study, a criterion sampling method was employed, which involved selecting participants who meet predetermined criteria. Specifically, I sought to recruit participants who met the criteria of having worked with young adults with disabilities, both in long-term care and community-based settings in Northern Ontario. As a Social Worker who has worked in the long-term care and community-based organizations providing support to individuals with disabilities, I had knowledge of who the

potential participants could be. Participants came from various educational backgrounds including gerontology, nursing, and human services. A detailed description of the research participants can be seen in Appendix A. In regard to sample size, Sandelowski (1996) suggests that it should be large enough to generate a rich and new understanding regarding a topic but small enough to allow for a deep, case-oriented analysis. Morse (2000) expands upon that, suggesting that fewer participants are required if there is sufficient usable data.

Participant Selection

Using the criterion sampling method, I contacted potential participants by e-mail with details of the research along with the terms and conditions of Laurentian University's Research Ethics approval for the research. I offered to have a phone call follow up to answer any questions that the participants may have about their interest in participating in the study. For individuals who expressed an interest, I followed up with a consent to participate form (please see Appendix B), which outlined that the study was voluntary and explained that participants were free to withdraw from the study at any time. The consent form also explained the procedure for completing the semi-structured interviews, which could be completed in person or by telephone, depending on the preference of the participant. In addition, the risks and benefits of participation in the study and measures to ensure confidentiality were explored. Clients were also requested to select whether or not they were agreeable to having their interview audio recorded and whether or not they would provide permission for the use of anonymous quotations to be used in the thesis. To maintain confidentiality, potential participants were informed that pseudonyms would be used and their specific place of employment and job title would not be shared in the written report in order to protect the interests of all concerned.

Data Collection

The process to begin collecting data for this study was initiated with a submission of a research proposal that was reviewed by the Laurentian University's School of Social Work for a 10 day period. This is a requirement by the Master of Social Work (MSW) Program committee. After this approval was granted, the next step was to submit an application to the Laurentian University Research Ethics Board. Approval for this study was granted on August 18, 2017.

All of the participants in this study, except for one, requested that interviews be conducted by telephone. One interview participant requested that the interview questions be sent to her and she would respond to the questions electronically via personal e-mail. Interviews were conducted with questions in a semi-structured format. A series of questions were generated by the researcher as part of the development of a semi-structured interview schedule (Appendix C). A semi-structured approach to the interviews allowed me to probe and explore additional questions in response to points that participants made that warranted further exploration. The majority of the questions were open-ended and allowed the participant to provide their own perspectives and detailed responses.

Data Analysis

Immediately after completing the interviews, I began the process of transcribing the interview recordings verbatim and organizing the documents into password-protected computer files. The interview transcripts were then read several times to get a sense of the data as a whole. Creswell (2013) explains that it is important to read the transcripts entirely several times, trying to get a sense of the interviews prior to beginning the coding process. For the purpose of this study, an inductive thematic analysis approach was employed. Braun and Clarke (2006) have argued that thematic analysis is a method that is useful when examining the perspectives of multiple research participants, working towards generating valuable insights. For the purposes of

completing the thematic analysis, I followed the six phases identified by Braun and Clark (2006). Once familiar with the data (step 1), I proceeded to step 2 and began to use coding to identify important sections and concepts, indexing them as they related to a specific theme (King, 2004). I completed a colour scheme to help identify information that appeared to be pertinent within the transcripts as well as making electronic notes along the margins of the document. In the third step, I began identifying specific themes that seemed to emerge from the corresponding codes that were identified. An additional colour coding process was implemented where parts of the interview transcripts were extracted from the data and placed in a different document according to the colour codes that seemed to relate to one another. I then proceeded to step four, where I reviewed potential themes to gain an understanding of what the data and codes were indicating. Braun and Clarke (2006) define this process as “quality checking” (p. 82). By step 5, I began to assign specific titles to the themes that were emerging. It was at this time that themes and sub-themes developed and were linked back to the research questions (Braun & Clarke, 2006).

Role of the Researcher

According to Creswell (2013) it is important that researchers “position” themselves within their writings. This allows the writer to be aware of their potential biases and values, and to “position” themselves explicitly. Creswell (2013) speaks about the importance of engaging in “bracketing” as a means of the researcher identifying their biases in relation the phenomena being studied and aiding them in setting these aside in order to be fully immersed into the experiences of the participants. For the purposes of this study, I am a student researcher; however, I have been employed as a Social Worker in various organizations that provide support to individuals with disabilities since 2013. I spent several years working in the long-term care sector and became aware that there were increasing numbers of young adults (under 65 years of

age) entering long-term care. Many of these individuals made their way to my office, expressing frustrations regarding having to be in a long-term care home given the lack of alternatives. Many of them had limited family support and all were limited with what they were able to do outside of the home due to being on a fixed income through the Ontario Disability Support Program. They frequently reported feeling lonely and depressed. While I was employed in the long-term care field, young adults were often a point of discussion as staff and management were unsure how to meet their needs, which seemed to be quite complex, especially with increased rates of mental illness and addiction issues present among this population. Along with this, these individuals expressed feeling cut-off from the outside community and sometimes described the long-term care home as a “prison.” Given the limited staff and resources in the long-term care home, it was extremely difficult for staff to promote a dignified quality of life for these individuals and extremely challenging to facilitate integration into the community. Lack of staff training often meant that services provided in the long-term care home were task oriented and made it challenging to support young adults from a holistic perspective. Staff often expressed frustration regarding this as they tried their best to support the residents residing in these homes. I often found myself feeling frustrated with the social policies in place that were denying young adults (and the older adults as well) the right to live in a home of their choice, stripping them of the opportunity to be included in wider society. In addition, I also recognized that being a Social Worker in a long-term care home was uncommon. Most homes in Ontario do not have a Social Work staff member and I found this to be concerning in light of the issues I was observing with both young and older adults. Many of my days were spent with clients offering emotional support and seeking to engage family members in the care of the client. I always felt that there was a need for more emotional and case management support within these homes. I specifically

recall a young gentleman moving into the home who had a neurological disorder. He hadn't had one visitor during the 18 months that I worked with him. The staff had difficulty with his outward expressions of anger regarding the lack of flexibility within the home. He had spent years playing in bands prior to his disability, and spoke about wanting to go out to concerts and music shows but because he had limited family and a limited income, he rarely saw the world outside of the long-term care home. He required an escort to attend these programs with him and the staff at the long-term care home were unable to provide this. In addition, he was in a four-bedroom ward and had experienced four roommates pass away in six months. He struggled with developing connections and friendships with others and struggled, understandably, with anger and depression. It was based on these experiences that I decided to complete my research in this area. It was imperative that I be reflexive and engage in bracketing strategies throughout the research process. In order to do this, I wrote a journal entry outlining what I felt were my pre-existing thoughts and beliefs in regard to this and made a commitment to engage in a self-reflective process where I set these beliefs aside in order to focus on the participants' experiences with an open mind.

Strategies for Validity

Creswell (2013) identifies the researcher clarifying their biases at the beginning of the study as being an important validation strategy. The researcher's past experiences and biases are believed to likely shape the interpretation and approach to the study (Creswell, 2013). In the personal biography and reflexivity section of this paper, I have articulated my known biases and values and have engaged in the process of "bracketing." In addition, Creswell (2013) identifies member checking as being another important validation strategy. This process includes taking the data and analysis back to the participants to allow them to judge the accuracy of the

information provided. To assist in validating the findings of the study the research participants were offered the opportunity to review their written transcript from their recorded interviews. Time was allowed for participants to review it and they had the option to provide feedback or clarification on anything that may have been misunderstood or to expand on anything that they felt was missing. The use of open-ended semi-structured questions during the data collection phase also serves as a useful validation strategy as participants are not limited in terms of what information they can share.

Ethical Considerations

The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) (2014) outlines an ethics framework with three essential principles to consider when engaging in research. First, the framework outlines the importance of respecting individuals through recognizing and acknowledging their autonomy. The process of ensuring autonomy is sought through voluntary, informed and ongoing consent with participants. This becomes possible when participants are made aware of the research topic and volunteer their consent to participate in the study. They must be aware that they can withdraw their participation at anytime. Participants in this study were provided with a consent form which specified their rights when agreeing to partake in the study. Participants were also offered the opportunity to review their transcribed interviews in order to ensure that they had an opportunity to examine what was recorded and provide additional feedback if they felt that it was warranted.

The second guideline is concerned with protecting the welfare of the participants. In order to do so, the consent form outlined the potential benefits of participating in the study as well as the possible risks (TCPS2, 2014). For example, the risk that an interview question may be emotionally triggering was identified as a possibility and the contact information for local

resources who could provide support was outlined. In addition, participants were told that no identifying information would be recorded in the study and pseudonyms would be used to protect participant confidentiality. The third principle considers justice and this refers to the researcher's obligation to treat people fairly and equitably (TCPS2, 2014). Each participant was offered the opportunity to have the interview conducted in person or face-to-face. One interview participant requested to provide an electronic response to the questions via e-mail and this was permitted. I attempted to be flexible and was able to meet with the participants at times that were most convenient for them.

Chapter Four

Findings

All interviews with the study participants were coded throughout the process of collecting emerging themes. Four themes emerged from the data, along with eight subthemes. The major themes included inadequate community-based services, complex health and social needs, need for integrating health and social care, and proposed solutions. The inadequate community-based services theme was divided into four sub-themes, including 'best worst-case scenario', 'away from home', 'the catch all', and 'lack of caregiver support'. The complex health and social needs theme was divided into six sub-themes, including 'environmental barriers', 'difficulty relating to others', 'age appropriate activities', 'lack of family support', 'lack of mental health and specialized resources', and 'environmental triggering'. The need for integrated health and social care had one sub-theme of 'limited time, limited staff' and the proposed solutions included two sub-themes, 'creative collaborations' and 'Northern considerations.' The themes are identified in Table 1.

Table 1

Identification of themes and sub-themes

| Theme | Subtheme |
|-----------------------------------|---|
| Lack of community-based resources | <ul style="list-style-type: none"> • best worst case scenario • away from home • the “catch all” • lack of caregiver support |
| Complex health and social needs | <ul style="list-style-type: none"> • environmental barriers • difficulty relating to others • lack of age appropriate activities • lack of family support |

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| | <ul style="list-style-type: none"> • lack of mental health support and specialized resources • environmental triggering |
| Need for Integrated Health and Social Care | <ul style="list-style-type: none"> • limited staff, limited time |
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Lack of Community-Based Resources

Each participant in the study identified a lack of available community-based housing options with the necessary supports required for young adults with complex medical and psychological needs. It is well known that there is a lack of community-based resources for seniors across Ontario, including services for personal care and assisted living; however, this is also a significant problem faced by young adults with disabilities, although this is not commonly acknowledged in the media or literature. As a result of limited alternatives, many young adults with disabilities are left with no choice but to be admitted to long-term care. All of the participants in this study felt that admission of young adults to long-term care was inappropriate and would often be unnecessary if there were more options available to support them in a community-based setting. Participants in the study brought forward concerns about long waitlists for community-based services including assisted living and supportive housing. Mary drew attention to this stating,

We have 93 people on our waitlist right now for supportive housing or assisted living and many of them are in the older range from 40s to 60s, and we really don't want them going into long-term care because if you look at the average age in long-term care, it is 88 and it's mostly frail elderly with dementia or related disorders.

Participants in this study clearly pointed to the lack of alternative options available for young adults with complex medical and psychological needs. Sally identified a reliance on the costly hospital system due to lack of community-based resources stating,

They just need 24-hour care and there is a lack of facilities to do that. We are building a second home (supportive housing) here in (name of city) for 24 hour care and already, I have a feeling that our 15 year waitlist will be ignored because there are people living in the hospital that need to be moved out.

Participants spoke specifically about the limited community-based resources that are available and highlighted the service complexity of these individuals whose care requires significant collaboration efforts among community partners. Mary spoke about some of the barriers encountered with collaborating which highlights the need for ongoing support for those dealing with chronic disabilities stating,

There have been a couple of situations where we can bring all of the parties to the table and everybody is committed to getting in the same canoe and going in the same direction and doing this wrap around. It (in those situations) worked really well but what we see happen time and again is that everybody is working together to support his person then the mental health worker will say well you know they seem to be stable now so we are going to walk away. Then the aftercare that may be in place around substance use.....they are attending AA and NA and it's all good so there's no need for us to be involved because of course they are all busy and they have people on their waitlist that they need to see. They walk away, and then the wheels fall off that bus because they've walked away and then were left holding bank. Then what happens, there is a crisis for this individual and they are back in the emergency department and they are being readmitted

to the mental health unit or some other nasty thing happens. Or they do something, and they get involved in the criminal justice system and now we have to deal with that system.

Best worst-case scenario

Some participants felt that although long-term care wasn't an ideal place for young adults with disabilities, it was felt that it was at least better than living in the hospital. One participant shared that she believed that long-term care was the "the best worst case option." Participants recognized that many young adults with high care needs would alternatively end up in hospital for long periods of time if they were not able to get a long-term care bed. Participants felt that the hospital was the least suitable environment and certainly the most costly for our health care system. Another participant, Janet, spoke about the concept of long-term care being a best worst-case scenario for many young adults indicating that,

I think that a 50 year old in a setting where most people are 70-90 is not ideal...you can compare an adolescent in a setting with small kids 24/7, it's just not ideal. On the other hand, if their care needs are high it's the best option we have, so it's better than someone trying to live at home and not getting good care I think, but ideally being with people their own age would be best.

It is important to note as well, that there are a number of young adults who are in need of 24-hour care who are further limited in their housing options because they have been rejected from long-term care. This often occurs due to complex mental health, addiction, and/or responsive behaviour issues. These individuals have high care needs and unfortunately, end up in the hospital system for extended lengths of time because there is not a suitable alternative that can provide the care and support they require. John spoke to this stating,

They end up on our psychiatric units for a very long time. We often end up getting BSO (Behavioural Supports Ontario) involved and working with them. So, one example, we had a lady, that's where she ended up (hospital) and her husband could no longer care for her at home and there were all sorts of behaviours so she ended up in the hospital but because of her responsive behaviours, long-term care would not agree to take her.

Being rejected from a long-term care home can happen if the long-term care home feels that they lack the physical environment or staff expertise to meet the clients' care needs.

Participants shared that when young adults with responsive behaviours (particularly those associated with mental health issues resulting from a brain injury) are rejected from long-term care homes they either become homeless, end up living on the streets, become incarcerated or are admitted to hospital for a lengthy period of time.

Participants expressed frustration regarding the current state of our health care system and highlighted that young adults with disabilities cross multiple ministry jurisdictions—especially individuals with acquired brain injuries. Participants shared that individuals with acquired brain injuries are often most in need of the service but seem to engage the least with providers. As a result, one participant indicated that these individuals often remain in hospital and “cost the system millions of dollars.”

Away from home

A subtheme that emerged from the data noted that many young adults reside in long-term care homes that are in communities far from their friends and family members. This often occurs because there is nowhere else for these individuals to go. One participant from a rural region explained that young adults from other parts of Ontario, particularly urban centres where the long-term care waitlists are long, move into this particular rural long-term care home because

there isn't a bed anywhere else and there is no family capable of looking after them back home.

Janet emphasized this, stating:

They are in (the) hospital and may have been living on the street or whatever and there is just nobody to look after them, so they end up in long-term care. That kind of goes back to another point where locally we tend to get young adults transferred here from elsewhere because of the long waitlists in urban settings. They are nowhere close to their family or place of residence or anything else but there is a bed there, so they get sent there.

Mary also touched on this as well, recalling an individual who had a power wheelchair because he had been viciously assaulted in a gang situation and "essentially left for dead". The participant explained that the client required total care and was, therefore, unable to go home to his community, accessible only by air, to visit. They were unable to get the equipment that he required on the plane that flies into his home community. Participants expressed concern, stating that there isn't a priority system to have individuals who are placed in long-term care homes far away from their loved ones to be reunited with their family members and moved to a long-term care home or another living environment that is closer to friends and family. Janet spoke to this stating,

There seems to be a lack of effort for people that are moved to a remote area, because there is a bed, to be prioritized to be returned to their family elsewhere. I feel like once these people get a bed, they kind of get stuck there. I can think of two or three cases where it's like they will probably die here because they are still in their 60's – because even if they're on the list, no one really makes it a priority to try and get them closer to

home. There are some situations where they are stuck there, and it doesn't seem to matter how badly they want to move.

The “catch all”

Young adults entering long-term care come from all different backgrounds and walks of life, however, participants felt that the inadequacy of mental health services in the community was a significant contributing factor resulting in someone ending up in long-term care as a young adult because of such limited alternatives for these individuals. Simon spoke about this and stated,

People who are having mental health and addiction issues – they have nowhere else to go so they will end up here. The homeless people in the community, what's their alternative – long-term care!

Participants felt that overall there was a lack of community-based supports for these individuals resulting in long-term care becoming a “catch all.” Simon identified gaps in community-based mental health support, stating “alcohol related illnesses and drugs... those are the big ones. Lots of people coming in with addiction issues and that goes hand in hand with mental health issues and the lack of support.” Many of the individuals may be experiencing a medical condition while dealing with a mental health or addiction issue, which participants felt made their care even more complex than is typically seen among older adults. Several of the participants spoke specifically about the challenges and limited alternatives for these individuals stating, “there is an increase of mental health and addiction issues and no residential facilities in the North to provide the required services.”

Lack of caregiver support

Lack of caregiver support was clearly identified as being problematic by the research participants. Family and friends provide a significant proportion of the care required to support young adults with disabilities whose needs may be complex. Informal supports are integral to the quality of life of the individual with a disability and often allow for these individuals to live and age in the place they choose; however, if these supports break down, long-term care or a hospital admission can quickly become the only response in a crisis situation. The lack of respite services available to relieve care partners was acknowledged as being a significant concern, particularly respite services that can support individuals with mental health and behavioural issues. John highlighted this concern indicating,

I have had people who have been denied respite in long-term care because of (responsive behaviours) so the family just can't get a break no matter how hard they try and where they turn and there isn't any other level of tertiary care between community, hospital and long-term care.

Complex Health and Social Care Needs***Environmental barriers***

Several of the participants spoke about the way that the long-term care environment creates barriers for young adults to carry out what would be seen as a normal, age appropriate relationships. One participant felt that the dynamics of family relationships are often different among young adults, compared to older adults who reside in long-term care just by nature of developmental needs throughout the life course. One participant, John who works with individuals who have Huntington 's disease explained that,

Some of these individuals may have families, and young families... they may have young kids so this type of setting may be a barrier to bring your kids to. We've had it where a husband visits and they don't have that time or privacy to themselves.

Another participant also highlighted that many young adults do not qualify for a private room because they are recipients of ODSP and therefore receive a subsidy from the government. Participants explained that this only covers the cost of a basic accommodation, which typically consists of a room of two people; however, in some older buildings it can be up to four people in a room. Lack of privacy being a barrier to carrying on a "normal" life with family members, was reiterated by Janet who stated,

I think there is just a lack of opportunity in long-term care in general, but there is a lack of opportunity for privacy for younger adults who have spouses and family so that they can carry on some sort of a normal relationship. Same thing for family members; they may still have young children or teenagers that come to visit and it's just not a normal family situation anymore because of the lack of privacy. This is similar for older adults as well but often their children are grown and they would normally come visit and chat, it's just a bit of a different dynamic when you're younger.

Unlike a "natural" home environment, participants seemed to describe long term care as not being conducive to facilitating family connections and was in fact a barrier to young adults maintaining relationships in a way that they would probably more easily be able to do in a community based setting that was designed to be more of a home like environment.

Difficulty relating to others

Another theme that emerged from the data pertained to participants feeling that the social needs of young adults were different in some ways from those of the older adults residing in

long-term care. All of the participants in this study felt that many of the social needs of young adults with disabilities are not adequately met in long-term care. Janet explained how she felt that there were differences between the two groups of individuals, stating,

I do feel that young adults' needs differ. The basic needs are the same. All people need food, warmth, rest and security but young adults are at a different life cycle with different dynamics and different life goals. Like younger children at home versus older children who may be able to offer a different level of support. They have different needs in terms of intimate relationships and friendships. With older adults, they have experienced loss of friends and family and young adults haven't necessarily had that experience just the same. They are at a different level in terms of their esteem needs and they may continue to work towards goals in their career and personal life as opposed to older people who are more in that review stage of their life more or less. So, I think this makes the two groups outlook and their needs different.

Janet shared how she felt that the long-term care environment made it difficult for young adults to develop close friendships due to the limited number of individuals their own age. She explained,

There is a lack of development of close friendships related to the number of others their own age. You know how you see in a long-term care home where there are a few older ladies who may or may not know each other before being admitted but become friends and it can be a good support for them but for younger people because there are so few they don't really have a chance to develop close friendships.

Lack of age appropriate activities

Long-term care homes are required to provide a wide range of programming for the residents based on their individual needs. This is determined through various assessments and inputted into their personalized care plans. Regardless of this required standard of personalized approaches to care, most of the participants felt that there was an inadequacy of age appropriate activities that meet the needs of young adult's who reside in long-term care. Janet elaborated on this indicating,

I think of one lady. She says she has always enjoyed bingo, but I don't have the same interest in going to join these activities because when I go, I'm like the only young one there so (there is) just a general lack of interest because of the age difference. You're going there (community bingo hall) to win a few hundred and there you're going to win a chocolate bar (in a long-term care home) so it's a different experience.

John felt that, "it's all about gearing some of the activities to a wider range of ages – it makes a big of a difference." Betty, who had previously worked in long-term care as an activity worker, explained that it was very challenging to develop appropriate goals and activities to meet the needs of individuals due to the wide age range that now exists in long-term care homes. Betty stated, "It was challenging to provide adequate programming for 234 individuals from the age of 40-102."

Some long-term care homes have incorporated "young adult programming" into their recreational activities as a means of engaging the young adult population in more age appropriate activities. Some of these activities include attending different events in the community as well as shopping or restaurant outings; however, there are other barriers to attending these programs as

well. When asked if the participants felt that the needs of young adult's were met in long-term care, Simon indicated;

From a social stand point, no - unless there are young adult programs – but like money.....that's the other thing too – like they have a comfort allowance per month and a lot of them smoke so unless families are footing the bill then they may or may not be able to go to the Imax or for an outing. Like we do have a young adult program and they do have a lot of fun things going on, but some of them also have such high behaviours that you can't take them in a group setting. So now you're reaching out to...you're not dealing with the ones who may have high behaviours, you're now dealing with the ones who are easy going and have funding, have money. Like Imax or let's go to Red Lobster...oh well I can't go to Red Lobster, there's only a handful that can.

Some homes have adopted an approach that provides some integration into the community; however, most young adults in long-term care are recipients of the Ontario Disability Support program and are therefore on a low income. This presents them with a significant financial barrier which can prevent them from partaking in activities that have a cost associated with them, therefore, further isolating them. Participants emphasized the importance of young adults (as well as seniors) being integrated into their community while residing in long-term care. Some long-term care homes have a formal friendly visitor program where people come in and take the residents out in the community.

In addition, it became apparent from the research that many of the young adults who are entering long-term care are often both medically and psychologically more complex than the older adult population that reside in long-term care. The responsive behaviours and mental health

issues that are often typical of the young adult population present quite a challenge for long-term care homes, and research participants felt were often ill prepared to manage.

Lack of family support

Many of the participants indicated that young adults who enter long-term care often experience a lack of family support and therefore have more difficulty navigating the system. Participants felt that there was a better quality of life for individuals who had family support; however, they identified that these supports were less common among the young adult population. Simon spoke to this, stating,

We have one girl that goes to community programs that she really enjoys, and she has great family support too and she goes out shopping and there is nothing stopping her. We have a lady in her 50's who goes out to turkey dinners and things like that with the March of Dimes program but you have to have family that is really pulling for you and getting you involved in these programs to make sure you have transportation, money to get there and have the supervision required, someone to go with you and to advocate for you with the long-term care home. Like how do you get your daughter who is in university and working to meet you and take you to programs, she doesn't have the time.

Janet also highlighted this as being a pattern that she sees among young adults in long-term care homes as well indicating,

there is a lack of family or contacts that are willing to accept the caregiving role. I have a few in mind where they don't really have family members or a contact person who is willing or able to look after them.

Participants felt that young adults who enter long-term care tend to have a history of complex historical family dynamics, particularly among those who have mental health and addiction issues prior to entering long-term care.

Lack of mental health and specialized resources

The data that emerged clearly emphasized that many of the young adults who enter long-term care are both medically and psychologically complex, and struggle with mental health and addiction issues. Helping young adults cope with these challenges was acknowledged as a challenge for staff. Participants explained that there is a significant lack of mental health staff and specialized resources to support this complex population of individuals once they are admitted to long-term care. Although there are outside agencies who can service individuals in long-term care, the availability of these services can be limited and participants felt that more in-house support would be beneficial. John stated, “Like, I haven’t come across any home that has any therapy support or psychology support on staff.” This theme emerged from others as well who indicated, “they need more help with coping with the circumstance that they are in.” Simon pointed out that mental health issues could be treated with medication but that this would be less necessary if there were therapy or mental health and addiction staff readily available,

Mentally, they like to treat mental health with medication where maybe it could be eased up if they were more involved in more social programs and had more support, like professional support and social support – like professional people. Like you just don’t need your activity worker who is splitting themselves among an entire unit, you know what I mean? Even some type of therapy specializing in mental health and addiction, or something that would help them feel good about themselves. Everyone needs a purpose. Like people would feel better and good about themselves and feel less pain at the end of

the day and feel satisfied that they have done something good for themselves and for somebody else.

Specifically, some participants felt that a social worker on staff would be helpful in addressing the needs of this population. It was felt that not only do the individuals residing in long-term care require this additional specialized support but so do their families to assist with providing education, advocacy and caregiver support. This was reinforced by Simon who stated,

I just think more family support – having a social worker with the younger people because the family does need the support and they need to know what is available and they need to know how to support their loved one. It's not always that they don't want to.

Simon went on to share that he felt that working with the resident and their family would be helpful stating, “I think a social worker on a unit, I think social workers – we don't have one... We often say... Anybody would say that a social worker would help.”

It was also identified that the role of specialized mental health support would not only be beneficial to the young adults entering long term care, but also for the older adults, as transitioning to long-term care is a significant time of change and loss. John captured this indicating, “But just that therapy piece, dealing with change, dealing with the loss and having a professional that understands that there are cognitive changes.” There are some outside mental health services that come to long-term care facilities; however, a staff member specializing in this area, who is employed by the long-term care home is rare.

Environmental triggering

Responsive behaviours are often thought to be associated with individuals with dementia; however, a number of young adults entering long-term care home have responsive behaviours as a result of their disabilities. Responsive behaviours can include screaming, grabbing onto people,

agitation, repetitive sentences or questions, and striking out (Alzheimer's Society, 2017). Typically, these behaviours are a result of changes that have occurred in the brain that have affected memory, mood, behaviour, and judgement (Alzheimer's Society, 2017). Many individuals with acquired brain injuries often have responsive behaviours as well as mental health issues, which do not necessarily fall into a one-size fits all approach. A theme that emerged from the participants, emphasized that the environmental make up of many long-term care homes can be a trigger for responsive behaviours that can cause significant distress for all individuals involved. The lack of privacy and shared accommodations seemed to be a significant contributing factor for the exacerbation of responsive behaviours. John explained,

When the complex individuals are in the community and say somebody, and this happens frequently, someone is sent to a facility to live because there is no other 24-hour place to live - across the province the waitlist for individuals for 24-hour care homes is a 15-year wait. So, they get admitted into a long-term care home and next thing you know there's been an assault. Maybe a senior has wandered into the room and has dementia and gone into the things of the person with a brain injury, or maybe they are having a bad day and they assault a senior.

Some participants felt that some young adults, who enter long-term care have a lack of understanding or patience for issues that older seniors deal with, such as those with dementia. Simon felt that there was often limited understanding of older adult issues stating, "like dementia, they don't seem to understand dementia. They are angry, they get frustrated, issues with privacy – like "she came into my room and she took this." This lack of understanding of the needs and issues that different age groups face was also shared from a young adult's perspective. John shared that

Residents don't always understand if you go into a larger long-term care home, like why is this younger person here? So, it can cause problems when we look at the responsive behaviours and we look at someone who has more strength and different things happening mixed in with a more senior population.

Need for Integrated Health and Social Care

Many of the participants in this study spoke about the needs of young adults with disabilities as multi-faceted. Participants felt that there was a significant lack of community-based resources that integrated the clients' health and social care needs. It was felt that within the long-term care setting, the services provided are heavily focussed on the medical needs of clients and neglect to address their social needs. Participants spoke about the importance of keeping individuals residing in long-term care integrated into the community and socially connected.

John elaborated on this indicating,

If you look at rehab and best practices, you are supposed to integrate people with disabilities into the community to the best that can happen... even seniors should be kept integrated into the community not barricaded in long-term care.

One participant in this study alluded to the integration of health and social care as necessary to enhance quality of life and referenced a program that allows for this to be possible for some individuals. Simon indicated that individuals with developmental disabilities who enter long-term care are sometimes in receipt of additional funding through programs such as the PASSPORT program. Simon identified that this additional funding allows recipients the opportunity to go out and participate in activities that allow them to remain integrated into the community as much as possible. Simon explained, however, that applications for this funding are

only accepted from individuals with developmental disabilities, and even for those who are eligible to apply, there is a long waitlist to secure the funding.

Participants also highlighted that young adults with disabilities are at a significant disadvantage because many are on a low income and receive assistance through the Ontario Disability Support Program (ODSP). Participants explained that this limited income presents significant barriers when in the community and in the long-term care setting and impacts the ability of young adults with disabilities to meet their basic needs. Mary stated, “Well one of the biggest barriers is just having rent geared to income with barrier free housing attached to it.” Limited access to transportation was also identified as being a significant barrier for young adults with disabilities being able to engage in meaningful activities and participate actively in their communities. Mary stated, “Well I think the biggest thing is around their mobility. They want to remain active and have a quality of life, but transportation is a major barrier.”

Participants spoke about the multiple needs of young adults with disabilities and affirmed that integrated care was necessary to enhance their overall quality of life. However, frustration was expressed regarding the lack of ministerial integration, with Sally stating, “and the ministries never meet, even when they want us to meet and work together.” Participants emphasized that the complexity of many young adults with disabilities, particularly those with acquired brain injuries, inevitably fall through the cracks when services are provided in silos. The client emphasized the need for communities to look at collaborating and working together but also emphasized that the ministry must also be speaking with each other and seeking opportunities to collaborate.

Mary spoke about collaborative approaches that their community-based organization engaged in stating, “We have certainly had discussions with (local long-term care home) around,

could we at least have one of these resident care units dedicated to young adults with neurological impairments.” This particular participant works for a community-based program servicing individuals with acquired brain injuries. She indicated that they hope that their organization could train and support front line staff in terms of developing effective strategies for managing common responsive behaviours that are exhibited. Mary went on further to state,

You want to keep them (young adults with disabilities) active and then maybe we can work on coming on site and doing some quality of life stuff in terms of day programming or take them offsite for activities. We’ve had those discussions and they (a local long-term care home) are open to it but they have grown so big so fast and there is a real shortage of PSWs.

This participant went on further, to explain that these collaborative conversations have been halted for one particular company which owns many long-term care homes, as members have launched a class-action lawsuit, claiming that their family members have received poor care.

Limited staff, limited time

There has been quite a bit of information published about the lack of staff in long-term care homes and the consequences that this has on the residents in general. This theme was also reinforced by interview participants who spoke about the negative implications that poorly staffed long-term care homes can have on those residing in these homes. Janet spoke about the lack of follow through on recommendations she provides to address mood related issues that some of the residents experience. Janet stated that,

Depending on the facility, I can write 10 recommendations and there isn’t even an effort to do any of them. And sometimes it’s as simple as making a room more personable. I

recall seeing some people whose rooms were completely bare and I've suggested getting pictures or something on their wall that shows their interests at one point. I remember one guy, who ended up in long-term care and was totally French speaking and one staff member worked nights and could speak to him but he was in a bubble as it is because he couldn't talk to anyone – his room was totally bare and a few simple suggestions like putting up a car magazine or calendar in his room....it seemed easy to do but that never happened. And there are other ideal recommendations you would try to make that are more difficult to arrange but sometimes it's just...is there enough staff to do it?

It is well documented that the longer an individual is left alone, the more their responsive behaviours will increase. One participant spoke to this and explained how the limited amount of staff in long-term care increases behaviours and, decreases their rehabilitation potential. Sally stated,

If you're a personal support worker and you have a whole half floor to get out of bed and to breakfast in the morning, you don't have time to encourage self-care to people and when you're rehabbing people you don't want to put them in a diaper right away because that is the most convenient thing you can do. You want to help them maintain their skills in toileting, but you don't have the time. Then they are left alone for hours and then the behaviour increases.

The increase in behaviours being directly related to the limited staff in long-term care was also highlighted by Mary who indicated,

Well I mean, I think that you know because their care needs are high, the staffing ratios – they just can't meet their needs. So often what we see happen is... like, we have one woman who is in her later 40s or early 50s in a long-term care facility and the only way

that they can manage her is to put her in a chemical restraint. She wants to be busy and she wants to do stuff and she keeps trying to motor around but they have to curtail her because they can't provide the level of supervision and support for her to be able to be active, so they put her in a chemical restraint.

Mary also spoke about the complex dynamics that staff in the long-term care home are confronted with, and the difficulties in managing these dynamics when staff levels are low. She stated,

Well first of all, they don't have the opportunity to do some of the activities that they would like, that are stimulating. Again, they are often... I think of one young man in a small facility, and I think the staff feel bad for him because he is a young guy. So I think they go out of their way to try and enhance his quality of life and make sure he gets up and about and all of those kinds of things, but once again, they are limited because they also have to look after the other 19 older people that are there. And they must try and keep the older people safe because when he gets really pissed off, he uses his motorized wheelchair as a weapon, so it's a real catch 22 for them...so that's the biggest issue.

There just isn't the kind of one-on-one staffing that these individuals require to ensure that these individuals have a good quality of life.

It was also clearly identified that not only were there limited personal support workers available but it can also be challenging for recreation staff to have the required time to spend with individuals as well. This often denies young adults the opportunity to achieve goals that they would like to work towards. Simon shed light on this indicating,

So, this one gentleman came in and he wanted to put a presentation together about equipment he used to work on when he was in mining. I said that's great, I'll bring it to

the attention of the person who runs the men's group, but there just isn't enough time and enough staff to work one-on-one with individuals and this gentleman does not have a lot of family support. The whole idea that he wanted to help out (and connect with) older men that used to work in the mines shows that he cares about other people and wanted to take some initiative but then we don't the time to roll with it.

Although participants frequently alluded to the need for the Ministry of Health and Long-Term Care to work toward a way of meeting residents' social care needs, limited staffing levels was frequently referenced as a critical barrier to achieving a more integrated approach.

Proposed Solutions

Participants felt that there is a significant need for supportive housing accommodation that can meet the complex medical and psychological needs that are commonly seen among young adults with disabilities who enter long-term care, especially individuals requiring 24-hour support. Participants felt that this would prevent inappropriate admission of young adults with disabilities into long-term care and would alleviate pressure on the hospital system as well. Mary referenced a program called 'Mind Forward' as one possible approach to providing better care to young adults with disabilities living in the community. This is a program that currently services individuals with acquired brain injuries in southern Ontario. It offers a day program, case management services, seniors' services, supported independent living, clinical services, caregiver and family services, and assisted living.

All of the participants indicated that a smaller version of a long-term care home, specifically designated for younger adults with disabilities, may be beneficial. When asked what other possible housing alternatives would be best suited to meet the needs of young adults with disabilities, Janet highlighted the need for a continuum of services stating,

The only thing I can think of is more facilities like ICAN, or supportive and assisted living facilities, and having wings in certain long-term care homes that are more focussed on providing care for younger people. You know how they have dementia care units, well having units just for younger people.

Another participant spoke about a similar initiative, taking place in an urban centre 'down south', to develop a separate unit in a long-term care home for individuals with acquired brain injuries. She explained that the local health integration network and the brain injury services had been in discussions in regard to this; however, she believed that it didn't move forward because it required the Ministry of Health and Long Term Care to approve it. Sally stated,

I feel it is totally inappropriate (for young adults with disabilities to reside in long-term care). In fact, at one time, there was something going in the (city name) area where the LHIN had approached the brain injury services there, as they were renovating a long-term care facility, and they decided to do something about the residential needs of people with brain injuries - and (they) actually built an extension onto the building. I forget the exact number of beds; some were going to be transitional and some would be permanent. They were going to lump them (the clients) together in one unit, separate from the seniors so that they could have day care access and be more community orientated but living under the long-term care home. And I think to this day, the reason it did not come to fruition is because the Ministry of Health and Long-Term Care had to approve that they were brain injury beds... You want to have these individuals clustered together so that you can have extra staff added in to meet the needs of these people, because the way long-term care is staffed, it won't meet the needs.

This participant went on further to propose that if this were to happen, the basic funding model through the Ministry of Health and Long-Term Care would remain the same; however, it would require the Local Health Integration Network to “top up” for increased staffing to offer the rehabilitation components. This same participant felt that creating a unit for young adults would involve risk management and would have to be based on the appropriateness of the individual to function within that certain environment. The participant identified that some of the clients with acquired brain injuries have suffered brain damage in a way that can make them violent at times, which may put other young adults with disabilities at risk.

Creative collaborations

Some participants in the study highlighted ways that community-based service providers were able to collaborate with long-term care to enhance services for this population. Through collaborative efforts, community-based service providers identified instances where they would come into the long-term care home and would provide on-site education and training for staff. Usually this would involve incorporating behavioural intervention strategies to better support young adults with particular disabilities, especially those that are neurological in nature.

Participants also identified the need to be creative and to look to private developers in the community to seek collaborative opportunities to provide appropriate housing for certain populations of individuals. One of the participants spoke about an outreach program in Southern Ontario that collaborated with a private property owner to allocate certain apartments for individuals with Huntington’s Disease, who were attached to their assisted living outreach program. Another participant spoke about a collaborative opportunity that arose with a private developer who purchased an old hospital and dedicated a large portion of it to seniors assisted living; however, through this specific program they were able to negotiate for 25 units to be

designated for people with physical disabilities who were receiving assisted living supports. The location has also become a hub of sorts with commercial space being occupied by the Centre for Addiction and Mental Health, a restaurant, and a fitness club. The benefit to collaborating with the private developer meant that more affordable housing units were created without needing significant public funding to develop a new building from scratch. Instead, publicly available assisted living services were provided in a building that already accommodated young adults with disabilities with wide hallways, doorways, and bathrooms.

Northern considerations

Although all of the participants felt that it would be beneficial for long-term care homes to have designated units and programming designed for young adults, several of the participants also felt that this may not be financially feasible in rural and remote locations where the percentage of young adults in long-term care might be quite low. John indicated,

I think the other biggest challenge is if you had something like that, do the communities have the volume for it because you don't want to end up with one home and their family is four to five hours away and their family can't visit them. Even if there was a wing within a long-term care home, because the system does work to a degree but just how do you modify a wing of it because you want people to be able to stay in their communities and have their families come and go.

Participants noted the unique needs and service issues facing northern communities. Mary explained that there is a much higher incidence of brain injury in the north west and north east regions, increasing the need for support in these areas. Mary attributed this to the geography of these regions. She explained that Northerners often have to travel further, in more severe weather conditions, increasing the risk for accidents. Northerners more commonly engage in

higher risk activities such as snowmobiling and quadding, which can result in debilitating accidents. In addition, Mary noted that Northerners have more individuals working in the mining and forestry industries, which exhibit high risks of injury, increasing the chances of acquiring a disability. Overall, she noted that there is a higher risk of mental health and addiction as well in the Northern regions.

Chapter Five

Discussion

Lack of Community-Based Resources

The results of this study echo concerns that have been identified in the limited literature available on this topic. As articulated above, the percentage of young adults residing in long-term care is on the rise. Participants felt that the-lack of community-based resources and alternative housing options has resulted in an increase in young adults being forced into long-term care homes, because they have nowhere else to go. Participants felt that admissions to long-term care homes were often inappropriate and would be unnecessary if community-based alternatives were available. Current community-based support programs that are available to young adults with disabilities in Ontario include assisted living/supportive housing, outreach attendant services and the direct funding program (Harris & Scarfone, 2014). Table 2 highlights the services provided under these three programs.

Table 2

Current Housing Support Programs for Young Adults with Disabilities

| Assisted living/Supportive Housing | Outreach Attendant Service | Direct Funding Program |
|--|---|---|
| Created in 1994 by the Ministry of Health. | Developed in 1996 by the Ministry of Health | Became a permanent program in 1998. |
| Delivered by non-profit organizations. | Helps people remain in their homes and receive needed services. | Administered by the Ontario Network of Independent Living Centres |
| Clients maintain their own lease. | Supports people to maintain independence. | |

| | | |
|---|---|---|
| | | Individual managers their own budget and hiring and supervising their own attendants. |
| Can be an apartment building or a home located close to the providers. Apartment units designated as supportive housing are typically clustered together. | Assist individual to maintain employment or engage in educational pursuits | Receive the same assistance as the Attendant Outreach and Supportive Housing models of care. |
| Services include: personal hygiene, homemaking, housecleaning, laundry, shopping, paying bills, banking, shopping, security checks. | Prevents inappropriate admission to chronic care facilities and helps people leave institutions where possible. | Provides flexibility for service times and the individual is able to receive consistent service from the same person. |
| Clients must direct their own care services. | Attendants provide services as supportive housing and must provide a minimum of 3 hours per day of service with many requiring more than 6 hours a day. | Provides clients with choice, control and flexibility. |

Note. Reprinted from *The Roadmap to Independent Living in Ontario – May 2014* by Toby Harris and Valerie Scarfone, retrieved from <http://guelphindependentliving.org/wp-content/uploads/2014/07/The-Road-to-Independent-Living-Final-May-2014.pdf>

Harris & Scarfone (2014), found that the waitlists for these programs were quite long, ranging anywhere from 2.5 to 7 years long. In regard to supportive housing services, wait times were reported to be up to 10 years long (Harris & Scarfone, 2014). In 2013, it was found that the North East region had 49 people waiting for direct funding services, 60 people waiting for

outreach attendant services, and 87 people waiting for supportive housing services (Harris & Scarfone, 2014).

Participants in this study noted that many long-term care homes have long waitlists as well, resulting in many individuals ending up in 'alternative level of care' beds in the hospital until a long-term care bed becomes available. Sometimes, the long-term care bed that becomes available is in a different community than the one the individual is from, which means that many young adults must move to communities, sometimes hours away from their family, in order to receive the medical care they need. Janet, a participant in this study felt that once an individual was placed in a long-term care home there seemed to be a lack of effort to have that individual prioritized to return to be closer to their family, no matter how badly they wanted to move. A similar issue was recently highlighted in a news article published in CBC by Melissa Mancini (2019). The article spoke about an elderly couple who had been separated when the husband required more nursing and personal care than the wife did. The couple were unable to reside together based on the policies of the long-term care home because her needs were not high enough to be admitted. The article highlighted that most provinces do not have long-term care homes that accommodate spouses who do not have higher care needs. Even in instances where both spouses require higher levels of care, they are often separated, depending on the availability of beds. This speaks to the growing need for more appropriate housing support that provides individuals with choice and the ability to remain in their home communities, close to their family.

Participants in this study felt that long-term care was often a “best worst case scenario” in the absence of more appropriate accommodations. Interestingly, in an article written by Gibson et al., (2011) none of the 19 study participants interviewed in that study suggested that they

would prefer institutionalization to living in the community. The study was completed in Ontario and included younger adults (ages 18-55) with mobility disabilities as well as policy makers, program administrators, and discharge planners. Instead, institutionalization in a long-term care home was continually cited by participants as being a worse-case scenario by individuals who had lived in these environments, as well as by those who feared that this could be a possibility if they were unable to sustain themselves in the community (Gibson et al., 2011).

Although participants in our study did not feel that long-term care homes were the most appropriate for young adults with disabilities, they felt that it was better than having these individuals remain in hospitals indefinitely. For example, Weidner (2019) profiled a 41-year old man named Paul McLay who spent two years in a Southern Ontario hospital waiting for an admission to a long-term care home that could accommodate the use of a ventilator. Paul had spina bifida and required a ventilator at night, something most long-term care homes were not trained to support. When expressing her feelings about her son being in the hospital for this long period of time, Paul's mother stated, "Quality of life is really what's the problem here. It's not living." (Weidner, 2019, p. 1). Participants also highlighted complex cases where young adults with disabilities were rejected from long-term care homes due to issues related to mental health, addictions and/or responsive behaviours. Participants noted that these individuals remain in the hospital and that it becomes a challenge to have them moved to other forms of accommodations, resulting in a significant expense to the health care system and a lack of required support for the individual. This is also a contributing factor to the overcrowding in Ontario hospitals, which has become a major concern, creating what is now widely known as the era of "hallway medicine" (Crawley 2020). Crawley (2020) echoes the concerns of participants in this study who felt that community based housing supports would be more cost effective than unnecessary options like

the hospital and premature entry into long-term care. Crawley (2020) spoke about this in his article stating,

One out of six hospital beds is occupied by a patient who doesn't need to be in the hospital, but cannot be safely discharged home. This is a long-running phenomenon in health systems across Canada and known as "alternative level of care" (ALC). Lengthy waits for long-term care spaces are the chief cause, but a lack of available home care and other forms of continuing care also contribute. (p. 1)

Table 3 highlights the average yearly cost associated with a stay in a hospital, supportive housing, attendant outreach programs, and self-managed care (Williams, 2017).

Table 3

Compared cost associated with staying in a hospital bed, supportive housing, attendant outreach, and self- managed care.

| Service Location | Average Cost per Person |
|---|--------------------------------|
| Hospital Bed | \$500,000/ year |
| Assisted Living Services in Supportive Housing (averaged 4 hours per day) | \$60,000/ year |
| Self-managed Attendant Services – Direct Funding | \$31,000/ year |
| Attendant Outreach Services (2.5 hours/day) | \$27,000/ year |
| Long Term Care | \$74,000/ year |

Note. Reprinted from *Building Community-based Capacity to Meet Ontario's Needs* by A. Paul Williams (2017) retrieved from <https://www.ilssimcoe.ca/wp-content/uploads/2017/04/OAILSP-Building-Capacity-Brief-April-2017.pdf>

The available reports and literature demonstrate that housing and care options like long-term care and the hospital are the most expensive options for those requiring care. They are in fact more costly than programs including assisted living services, direct funding services and attendant outreach services, yet our long-term care homes and our hospitals continue to be filled to capacity. The current literature reinforces the reality that access to appropriate housing, transportation, and personal care are insufficient and inadequate in Ontario (Gibson et al., 2011). Despite Ontario's adoption of the Accessibility for Ontarians with Disabilities Act 2005 (AODA), Ontario continues to fall behind a number of other countries including Japan, Sweden, Germany, Australia, and parts of the United States when it comes to the inclusion of people with disabilities. AODA (2005) argued that this is most obvious when examining the intersections of health care and housing policies that directly affect individuals with disabilities. Participants also spoke about the lack of options for respite care available for family or friends who provide care to their loved one. Sally spoke to this experience stating that she works with one client who cannot go to a long-term care facility for respite services because he has seizures and requires a specific type of bed that long-term care will not accommodate. Janet spoke about the experience of family caregiver burnout, noting that the caregivers can often manage for part of the day but not on a 24-hour basis. The Canadian Medical Association, as seen in an article published by the Canadian Healthcare Association (2012) also reinforced what participants identified stating, "much of the burden of continuing care falls on (unpaid) caregivers" (Canadian Healthcare Association, 2012, p. 30). Participants in this study highlighted the need for a wide range of options, inclusive of increased community-based supports to meet the specific needs of each individual as opposed to being heavily reliant on a "one size fits all" model in long-term care.

Complex Health and Social Care Needs

An Ontario based report titled "Disability and Dignity Enabling Home Environments: A Key Message from an Ontario Study" was prepared by Gibson et al. (2011). The report highlighted the conditions necessary for a home environment to be considered dignity-enabling for individuals with disabilities. The conditions are highlighted in Figure 1.



Figure 1. Conditions Necessary for a Dignity Enabling Home Environment. Adapted from Disability and Dignity-Enabling Home Environments: Key Messages from an Ontario Study by Gibson et al. (2011).

<http://jcb.utoronto.ca/research/documents/DignityEnablingHomeEnvironments-Report2011.pdf>

Based on the results of this study, along with available literature on the topic, we can clearly identify ways in which long-term care environments in Ontario, undermine the dignity of young adults with disabilities as perceived by individuals who work with this population (Gibson et al., 2012). It was felt by several of the participants in this study that although the environment supports clients from a medical perspective, it often fails to meet the social and emotional needs of young adults with disabilities, which has a significant impact on their ability to lead dignified lives. Participants in this study felt that the medical model continues to prevail in long-term care homes and addressing the social care needs of young adults with disabilities was imperative in order to improve their overall quality of life.

One of the dignity enabling factors identified in the aforementioned report was the ability to form and sustain meaningful relationships (Gibson et al., 2011). The participants from this study highlighted the challenges that young adults in long-term care encounter in maintaining meaningful relationships with family and friends. Participants identified a lack of privacy as being a significant environmental barrier. This was comparable to other available literature, including the results of a study by Cameron et al. (2001) with individuals under the age of 65 who had an acquired brain injury and were residing in long-term care. They found that 19% of study participants described a lack of privacy in their current living arrangement (Cameron et al., 2001). Similarly, in Jervis' (2002) study, a 52-year old woman indicated that she felt "ashamed at the prospect of having sexual relations with her boyfriend in the nursing home because there is so little privacy" (p.86). This is similar to the statement made by Janet (participant) who indicated that there is a "lack of opportunity for privacy for younger adults who have spouses and family so that they can carry on some normal relationship. Same thing for family members who may still have young children or teenagers that come to visit." Gibson et al. (2012)

reinforced the importance of young adults with disabilities living close to their family members and being able to maintain meaningful roles as parents and spouses. Long-term care homes often consist of rooms of two to four individuals. Many individuals with a disability who are under the age of 65, receive financial support from the Ontario Disability Support Program and, therefore, are unable to afford a semi-private or private accommodation. As a result, they struggle with increased difficulty in carrying on “normal” relationships with their family and friends given the environmental barriers in long-term care. It has been reiterated throughout the literature and in this study, that young adults with disabilities require the opportunity to develop and maintain relationships, as do those without disabilities, but the current context of long-term care presents environmental barriers that do not allow this to be fully realized.

Many of the participants in this study noticed that young adults often lacked family support. Marshall and Baffour (2011) spoke about this in their article, indicating that participants in their study of young adults residing in a long-term care facility had a lack of social support from immediate family, friends or significant others since their admission. Due to the lack of family support, this population of individuals are often lonely and isolated. Participants in this study described it as common for young adults to have complex historical family dynamics, which result in a lack of support. Participants regarded this as common among young adults with a history of mental health and addiction issues. Jervis (2002) interviewed residents under 65 who had a psychiatric disorder and were living in a nursing home, and found that most of these younger residents had minimal contact with their family. The staff who participated in Jervis’ study felt that family members may have been alienated by the individual’s negative behaviours and that the stigma which accompanies a psychiatric disorder may have induced avoidance behaviour by family members (Jervis, 2002).

Participants in this study noted that families play a key role in advocating for residents in long-term care homes. Participants indicated that when it came to young adults, family play a critical role in ensuring that they are able to get out into the community and partake in activities that are age appropriate and of interest to the person. Experience indicated that when families are actively involved, young adults are more likely to spend time in the community as opposed to being confined to the home. Unfortunately, given that participants felt that young adults seemed to have less support from family members, their ability to be engaged and included in the community at large is often limited.

In this study, Simone spoke about how the long-term care home in which she worked had made efforts to incorporate young adult programming into their recreational activities; however, financial constraint was identified as a key limiting factor to being able to partake in community activities outside of the home. Study participants explained that young adults entering long-term care are typically recipients of Ontario Disability Support Program. After the client has received a rate reduction for their accommodation and services in long-term care, they are allotted approximately \$150.00 a month as a comfort allowance, which is barely enough to cover the cost of basic amenities, such as telephone, cable, haircuts etc. Study participants felt that low income prevented this population from being included in society and from participating in meaningful activities and events outside of the long-term care home.

Participants in this study felt that the social needs of young adults with disabilities are in some ways different from older adults. Janet explained how the basic needs of all individuals are the same; however, different needs have priority depending on where they are in the life course. This has also been identified in the literature. Putman (2011) quoted a participant from her study who stated,

I think there is also the idea that the needs of people with disabilities are the same as senior citizens. Well, we know that's not true for younger people...the whole philosophy of independent living is wanting people to get out in the community to work; to have an independent life. Well, for a senior citizen, they are working harder to be able to stay in the home and maintain their independence that way. (p. 332)

In an article published by Canada's Health Care News and Best Practices (2015), a 24-year old man named Michael Wedemeyer, who resided in a long-term care facility, spoke about his difficulty relating to the older adults in the home explaining that his interests and theirs were not comparable. Marshall and Baffour (2011) discussed how young adults in long-term care are often socially withdrawn and they argued that this was premature in the context of the life course. Marshall and Baffour (2011) also felt that age norms were challenged by the lack of age appropriate activities among young adults in long-term care. As reiterated throughout the literature, and echoed among the participants in this study, programming and recreational activities provided by long-term care homes typically fail to target the interests and needs of young adults. Jervis (2002) found that feelings of boredom were common among the participants interviewed in his study, which included young adults with psychiatric disorders in long-term care homes. One of the participants in his study was 36 years old and stated "sometimes, for the younger ones like myself, there's nothing that really could interest someone my own age" (Jervis, 2002, p. 84).

Repeated exposure to death and dying was also identified as being a challenge for young adults. This was highlighted by participants in this study and similar findings were identified by Cameron et al. (2001). He indicated that the psychological and social implications of this ongoing and repetitive experience of loss are not being properly recognized or addressed. In a

moving article published by Goffin (2017) in the Toronto Star, a woman named Deborah Star spoke about her experience living in a long-term care home in Ontario at 52 years old. In her interview she spoke about the emotional difficulty she has experienced watching co-residents pass away on a regular basis, stating,

I've watched friends I've made pass away over and over again, and it's really distressing. I never wanted to get used to people dying, and it happens all the time. I can't help but be aware of it, because it's right there in front of me. (p. 1)

The social and psychological complexity of young adults with disabilities was explored further by participants in this study who identified a higher prevalence of mental health and addiction issues among this population. Fullerton, McGuire, Feng, Mor, and Grabowski (2009) found that the percentage of residents under the age of 65 who were admitted into long-term care with a primary diagnosis of mental illness was almost three times that of those residents who were above 65. Participants in this study felt that staff were not trained or equipped to meet the complex mental health needs of this population and that these unmet needs created significant problems and quality of life concerns. Participants said that although there are some outside agencies that can support individuals experiencing mental health and behavioural issues, more in-house support was required. In 2010, the Ontario government launched a program called Behavioural Supports Ontario (BSO) that aimed to enhance services for Ontario's seniors as well as caregivers and families caring for their loved one experiencing responsive behaviours that are associated with dementia and other neurological conditions. While some homes have in-house BSO, many homes (especially in rural communities) operate from a mobile BSO model. In this study, Mary highlighted that in the Northwest LHIN there was a consultation where regional and community providers identified that BSO should not only address the needs of individuals who

are elderly, but also needed to include those with acquired brain injuries and developmental disabilities. This participant went on to say that it can be challenging because it is a service that is much needed among older adults stating, “they have more than enough business to keep them busy.” Mary also identified a gap in specialized supports for those in long-term care identifying that she hadn’t come across any therapy support or psychology support on staff. Simon explained that mental health issues were often treated with medication, but that therapy or other social support would be beneficial. Some participants noted that many long-term care homes do not have a social worker on staff, and it was believed that this could be beneficial to better address the social needs of this population and to support their families as well. Participants felt that it was important to have professionals available who could assist clients to cope with change and loss, while being aware of the effects of cognitive changes on the individual as well. Although there are some programs that address these concerns, they are typically not in-house.

Participants also spoke about responsive behaviours that are often exhibited by young adults. It was argued that the environment, in of itself, could trigger responsive behaviours and mental health difficulties. This is particularly true for individuals with an acquired brain injury who often exhibit responsive behaviours and have accompanying mental health and/or addiction difficulties. Jervis (2002) argued that behavioural issues were the most significant contributor to a diminished quality of life. Jervis (2002) reinforced the concern that staff often lacked the necessary skills and training to manage these behaviours on an ongoing basis. The passive nature by which care is provided in long-term care homes can lead to frustration and loss of independence among individuals with acquired brain injuries, many of whom are capable of completing their own care routines (Phabis, 2006). However, if an individual with an acquired

brain injury is in a passive environment that creates frustration, this can lead to disruptive and severe behaviours as well as an erosion of independence and self-confidence (Phabis, 2006).

Several of the participants in this study noted that there was limited staff in long-term care, which makes it challenging to meet the social and rehabilitative needs of all residents, let alone those of young adults with disabilities. This was identified in the literature as well. For example, a pilot project completed by the Peel Halton Acquired Brain Injury Services (PHABIS) and a long-term care home in that region, examined the integration of a scaled down program based on neuro-behavioural programming principles, which could be used in long-term care homes where lower staff ratios exist (Phabis, 2006). The goal was to transfer an individual to the long-term care home from a supportive living environment in the community. The pilot project was executed using a three-phased approach where the PHABIS staff (who specialized in acquired brain injuries, and who were familiar with the individual) modeled the program and routines for the long-term care home staff. They then supported the staff as they practiced the routines and observed the long-term care staff as they worked with the individual (Phabis, 2006). The pilot project found that the staffing ratios in long-term care homes were time-limited, inconsistent, and did not allow for a neuro-behaviourally based approach to care to be possible (Phabis, 2006). The study found that ongoing “acquired brain injury supplementation” of staff resources, training and expertise were required in order to appropriately serve the acquired brain injury population (Phabis, 2006). Again, limited staffing levels were found to impede the engagement of individuals with acquired brain injuries socially, vocationally and recreationally within a long-term care facility (Phabis, 2006). This is quite alarming, given the fact that many of the individuals entering long-term care as young adults are suffering from neurological

disorders and are in need of neuro-behavioural programming principles to enhance their overall quality of life.

The difficulty in meeting the complex social needs of young adults in long-term care due to the limited staffing was identified by participants in this study as well. In the current context, the social needs of young adults continue to go unmet and have significant negative consequences for their overall health and well-being, and prevent them from living dignified lives that emphasize some degree of autonomy and social inclusion. Lack of properly trained staff, availability of opportunities for social engagement, or specialized supports make it extremely challenging to create and achieve appropriate interventions and goals. The literature shows that this is true for the older adult population in long-term care homes as well. This past January, the Unifor and the Ontario Health Coalition (2020) published an article titled “Caring in Crisis: Ontario’s Long-Term Care PSW shortage.” They held a total of eight consultation forums, across Ontario. There were 350 participants which included managers, administrators, PSWs, family council members, municipal councillors, advocates for the elderly as well as PSW program staff to allow them to speak about their experiences and propose potential solutions. PSW shortages has been identified as a provincial epidemic and the negative impacts on care and safety are significant (Ontario Health Coalition by Unifor, 2020). The PSWs who spoke at these meetings, “painted a vivid and disturbing picture of the conditions of their work and the quality of life for the residents” (p. 4). Participants at these meetings shared that unfortunately the media does not display the positive contributions that staff provide when working within a system that is failing the workers and the residents. It was noted that the PSW crisis was worse in Northern Ontario and rural areas (Ontario Health Coalition by Unifor, 2020). In summary, the PSW shortage was linked to a number of systemic issues including poor wages, few full-time

opportunities resulting in staff having to work two part-time jobs, lack of benefits, heavy and unmanageable workloads, high staff turn-over and burn-out, high tuition rates, vacation time being denied, high injury rates etc. As a result of these poor working conditions, the report identified long-term care homes as increasingly risky and less safe places in which to live and work. Participants also noted an increase in acuity of conditions among residents within long-term care homes, yet the actual hours of care provided to residents by front line staff has declined. According to this report,

Half of Ontario's long-term care homes have no in-house BSO resources to help manage the increasing behaviours including aggression among long-term care residents. There is no minimum care standard that would ensure a safe level of care residents and staff.

(Ontario Health Coalition by Unifor, 2020, p. 6)

The Registered Nurses' Association of Ontario (2018) echoed many of these same concerns stating that the funding and staffing standards in long-term care homes has not changed despite an increase in responsive behaviours and an increasingly complex long-term care population. The RNAO has urged the Ministry of Health and Long-Term Care to provide adequate funding and staffing to safeguard our most vulnerable population. Although staff strive to provide high quality care, limited resources and complex resident conditions create a significant strain on the system (RNAO, 2018). When staff levels are low, responsive behaviours and mental health issues are exacerbated. According to the long-term care association,

These combinations can lead to some very challenging behaviours, which can make it difficult to provide care and may pose a risk to other residents. People with these challenges typically wind up in hospital, without the appropriate environment and

supports where they are often heavily medicated, because there is nowhere else for them to safely live. (p. 11)

Reports have also demonstrated evidence that violence within Ontario's long-term care homes is escalating as the complexity of care has increased and the care levels have declined. During the COVID-19 pandemic, the media has drawn attention to the fact that the standard of care provided to residents in for-profit nursing homes is lower than not-for-profit homes. Berta, LaPorte & Valdemanis (2002) conducted an Ontario based study and noted that government operated facilities provided more hours of direct patient care per resident when compared to for-profit facilities, although it was identified that public-sector facilities care for residents with greater health needs. McGrail et al. (2007) explained that all long-term care homes receive the same level of funding and staff costs become a natural place to realize cost savings among the for-profit long-term care sector. McGrail et al. (2007) argued that a Canadian study that analyzes the differences between for-profit and not-for-profit long-term care homes was necessary in order to gain a better understanding of patient outcomes. McGrail et al. (2007) argued, however, that the preliminary findings suggest that public investment in not-for-profit, rather than for-profit, delivery of long-term care results in more staffing and improved care outcomes for residents.

Participants in this study identified the possibility of creating a unit that specialized in providing care to young adults entering the home with complex health and social care needs, and felt that increased staffing levels with specialized training on these units would help mitigate responsive and violent behaviours while promoting quality of life. The Ontario Long Term Care Association has suggested a similar approach for the geriatric population in long-term care homes. The Ontario Long Term Care Association completed a report which highlighted the need

for specialized units for individuals with diagnoses of dementia and psychiatric conditions. They identified a need for a new type of long-term care home that implements a psychogeriatric model (Ontario Long-term Care Association, 2018). They spoke about an example of a home creating a separate and secure eight-person psychogeriatric unit where the Local Health Integration Network in that area provided \$500,000 in funding. The unit was comprised of additional care staff who were able to provide more one-on-one support, and all staff were provided with specialized training on how to respond appropriately to responsive behaviours. This resulted in the home being able to transfer someone who had been in hospital in an alternate level of care bed for two years into the specialized unit. The Ontario Long-Term Care Association (2018) indicated that,

We've seen tremendous benefits from the additional staff. It's not necessarily the physical care they provide, although that's absolutely part of it; it's that we now have more staff who can engage our residents in activities that have meaning to them – and as a result, their behaviour is more stable. (p. 12)

The Ontario Health Coalition (2019) goes on further to indicate, “this is a policy choice, not a necessity, and this data (increased rates of violence) should raise a serious question for policy makers.”

A Need for Integrating Health and Social Care

The participants in this study noted the many ways that our health care system is currently failing this population. The increase of young adults being forced into long-term care due to lack of alternative options, is a reflection of the underfunded community-based human service sector, but it is also a significant reflection of the fragmented and complex health care system in Ontario. Drummond et al. (2012) emphasized the need to improve the quality of the health care system in order to benefit all Ontarians. He argued that it is critical for our health care system to shift from being mainly focussed on addressing the needs of those requiring acute care, to a system that recognizes the supports required for chronic care, which is constantly growing—especially given the number of young adults with disabilities who are living longer along with our aging population. Drummond et al.(2012) emphasized the need for integrated health care, which is now consistent with objectives of the Local Health Integration Networks in Ontario; however, what we learned from the participants in this study is that in order to better support young adults with chronic and complex care needs, a medical model approach to care will not suffice. Integrated care is necessary, but not a model that simply integrates health care. Instead, a system is required that provides a continuum of housing options and where each option truly incorporates a social model approach and integrates health and social care, ensuring that dignified home environments exist for all—including young adults with disabilities.

Participants in this study spoke about some of the challenges that young adults with disabilities encounter when trying to navigate the long-term care and health care systems. These barriers include lack of family support, poorly staffed long-term care homes that are heavily focused on medical approaches to care, and financial limitations. It was acknowledged that young adults in long-term care who manage to have their medical needs met while remaining integrated with their community tend to have family support who assist with arranging or

providing transportation, assist financially with the costs for outings, provide supervision on outings, and advocate on behalf of the resident. Participants alluded to the fact that the health care system is highly complex and individuals without family support (reported to be common among young adults) have less opportunity to have their social needs met.

Individuals with disabilities are much more likely to be faced with a wide array of challenges in regard to the social determinants of health, including low income, difficulty accessing education, lack of affordable housing, inadequate social supports, limited transportation etc. The many social challenges that these vulnerable populations face can make it difficult to adhere to a personal medical plan, as it may become a secondary priority when basic needs such as food or housing security are a problem (Shier, Ginsburg, Howell, Voland & Golden, 2013). It is therefore increasingly necessary for young adults with disabilities to have access to health and social care that is integrated and is able to meet a multitude of needs.

Participants in this study felt that if there were more supports in the community that integrated health and social care needs that less people would require long-term care or lengthy alternative level of care hospital stays. Hepburn (2019) recently published an article in the Toronto Star referencing a new program called the Social Medicine Initiative, which was launched in September of 2019 by the United Way Greater Toronto and the University of Health Network (including Toronto Western, Toronto General Hospitals, Princess Margaret Cancer Centre and Toronto Rehabilitation Institute). The new initiative emphasizes the importance of integrating health and social care in order to improve the social determinants of health for individuals that present to the health care system. The goal of the initiative is to co-ordinate systems so that it is easier for individuals to access the services that they require and thereby decrease the number of patients who may need to be transferred to higher levels of care

(Hepburn, 2019). A recent report titled, “Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation’s Health” (National Academies of Sciences, Engineering, and Medicine, 2019), argued that taking into account social risk factors was imperative in order to improve both primary prevention and the treatment of acute and chronic illnesses. The report recognized that social contexts significantly influence the delivery and outcomes of health care. The impact of social issues has been directly linked to a number of individual health outcomes. For example, being unable to access transportation or having difficulty accessing housing has been shown to result in higher use of health resources. Emerging research in this area has demonstrated that social and environmental circumstances are significant contributory factors leading to unplanned hospital admission (Clark & Glicksman, 2012). Integrated care systems that seek to engage clients, community partners, social care workers, and clinicians in care planning are crucial in promoting quality of life, while reducing health care costs (National Academies of Sciences, Engineering, and Medicine, 2019). Social care workers were recognized as being integral to a team-based approach to designing and delivering health care (National Academies of Sciences, Engineering, and Medicine, 2019). In regard to long-term care homes, participants in this study noted that most long-term care homes do not have social workers but felt that this would be beneficial in addressing some of the issues that young adults present with, including complex mental health and behavioural issues, difficulty navigating the system, lack of family support and difficult family dynamics.

This report also highlighted varying degrees of assistance ranging from what they defined as “lighter-touch” assistance activities to more “intensive assistance”. “Lighter touch” activities included providing information or vouchers for patients to obtain certain resources, or sending a patient home with food if they reported having limited food security. More intensive assistance

activities are often required for individuals that are more medically and socially complex (National Academies of Sciences, Engineering, and Medicine, 2019). These more complex individuals require time to build rapport and relationships with care providers. They are often in need of a comprehensive bio-psycho-social needs assessment, care planning, interventions (including ongoing case management, resource connection, and behavioural activation strategies) and long-term community-based support (National Academies of Sciences, Engineering, and Medicine, 2019). The report suggests that many of the young adults at risk of entering long-term care are likely in need of more intensive assistance activities to maintain and support them in the community.

As we know, the social determinants of health approach is in direct alignment with social models of disability as it attributes differences in health and well being inherently related to social conditions and features of society (Gatrell, Jennaway, Manderson, Fangalasuu, & Dolaiano, 2016). It denies the idea that health and well-being are related specifically to individual impairments and personal characteristics. Since we know that factors such as social support networks, social environments, income, etc., influence health, it makes sense that integrating health and social care in community-based and institutional settings could significantly improve the health and quality of life of young adults with disabilities.

Participants in this study identified many ways in which the social needs of young adults are going unmet in long-term care. Winkler et al. (2006) also found that this was the case stating that, “although social contact and community participation are basic expectations for most people, young people in high level care are effectively excluded from life in the community.” Simon (participant) felt that a program such as the PASSPORT program (for individuals with developmental disabilities) allowed recipients the opportunity to remain connected to their

community, and provided opportunities to participate in social and recreational activities, thereby offering an opportunity for health and social care to be integrated for recipients. It was felt that this would be beneficial if it was extended to all young adults with disabilities residing in long-term care.

Proposed Solutions in a Northern Context

The participants from this study were from various Northern communities in Ontario. Some participants worked in urban Northern communities while others worked in rural communities. All participants referenced a lack of community-based housing supports for young adults with disabilities in the Northern communities where they work. Several of the participants in this study felt that a unit specifically designated for young adults within existing long-term care homes could be beneficial. However, several participants noted that this would be particularly challenging in more rural and remote locations, as smaller communities may not have enough individuals requiring this level of care to justify the resource. Participants feared that if there were a designated young adult home or unit within in a long-term care home setting, that it may be far away from family and friends. These concerns highlight the unique challenges that are faced by young adults with disabilities who reside in rural locations.

While there are common issues experienced with the health care system for all of Ontario, there are specific elements that make service provision in the North unique, and which require creative and innovative approaches to providing care. The McMaster Health Forum and the Centre for Rural and Northern Health Research (Wilson, Gauvin, & Ploeg, 2015) released a report that examined some of the unique challenges that are faced by health care providers and individuals with disabilities in Northern Ontario, which is home to more 565,000 people spread out over a region that is approximately 400,000 km (Wilson et al.,2015). Within the eastern half

of this region, the North East Local Health Integration Network (NELHIN) plans, funds, integrates, and monitors health care systems. The NELHIN is responsible for aligning their strategies and plans with major provincial priorities, including those identified in the Patients First: Ontario's Action Plan for Health Care (NELHIN, 2016). The NELHIN covers a total of 44% of the Ontario's land but is home to only 4% of Ontario's total population (North East LHIN, 2016). Within the NELHIN region there are five main hubs including the James and Hudson Bay Coast Hub, Algoma Hub, Cochrane Hub, Sudbury/Manitoulin/Parry Sound Hub and the Nipissing/Temiskaming Hub. In addition to this, these northern communities are culturally diverse with 23% of individuals being Francophone and 10% of individuals being Indigenous (Wilson et al., 2015). As well, 20% of the population in the North East region is over the age of 65, which is higher than the provincial average of 16% (NELHIN, 2016). Northerners more commonly have higher rates of chronic disease, substance abuse, and complex chronic conditions (NELHIN, 2016). Studies have demonstrated that there is an association between poor health status and the geography and environment in rural locations (Statistics Canada, 2019). One of the participants from this study spoke about the higher prevalence of brain injuries in the North Western and North Eastern regions of Ontario. The participant explained the differences in Northern geography, the distances people drive, the increased risk for wildlife collisions as well as the type of outdoor activities that Northerners participate in, increase the risk for brain injuries. The participant also alluded to the fact that Northerners have higher rates of individuals with concurrent disorders who are engaging in these risky behaviours and activities. Table 4 is information identified in the NELHIN Integrated Service Plan 2016-2019. It speaks to the overall demographic differences among the North East Region in comparison to the rest of the province.

Table 4*Demographics in the North East Region in Comparison to Ontario*

| | North East LHIN | Ontario |
|--|-----------------|---------|
| Proportion of Aboriginal Identity | 11% | 2% |
| Proportion of Francophone | 23% | 4% |
| Proportion of people living in rural areas | 30% | 14% |
| Proportion of people over 65 | 20% | 16% |
| Percentage of residents with multiple chronic conditions | 21% | 15% |

Note. Reprinted from *North East LHIN Integrated Health Service Plan 2016-2019* by North East Local Health Integration Network. Within the Integrated Health Service Plan 2016-2019 (2016).

The NELHIN's mission is to strengthen the coordination of health care services and improve access. They have promoted the leveraging of several key areas, including technology, enhancing programs and services, transportation and housing models to help maintain people in their homes, education to help Northerners more easily find support that they need, and enhancing partnerships to increase coordination of health care were identified as integral to their plan (NELHIN, 2016). Based on surveys completed by the NELHIN, respondents consistently identified the need for increased service. One quote from the report highlighted that it is also important to "take a step back, look at the services that already exist, define why they aren't working, and then make changes needed to create an integrated patient centered model of care." (North East LHIN, 2016, p. 18). In terms of key areas that the NELHIN should focus on, 91% of respondents felt that more housing options for "special population groups" was important, as well as more integrated care models (NELHIN, 2016). Although, "special population group" is not defined in this study, it is essential that the specific needs that are faced by young adults with disabilities are not ignored.

Lower population density, widely dispersed, means that it is more challenging and expensive to create and maintain comprehensive service infrastructure as compared to urban areas (UNECE Policy Brief on Ageing, 2017). As a result, individuals in rural regions have less access to services and activities. Vulnerable populations such as those with disabilities are at a greater risk for social isolation, reduced mobility, lack of support and health care, which requires innovative and integrated approaches to care (UNECE Policy Brief on Ageing, 2017).

Several of the participants in this study spoke about the benefits of working collaboratively with partners in the community to create more housing options and higher quality services for individuals with disabilities, despite a lack of funding from the government. John spoke about an organization with an outreach program that collaborated with a private property owner to attain and allocate certain apartments for individuals with Huntington's Disease who were already attached to the assisted living outreach program. Mary spoke about a collaborative opportunity that arose with a private developer who purchased an old hospital and dedicated a portion of it to seniors assisted living; however, through this specific program they were able to negotiate for units to be designated for people with physical disabilities who were receiving assisted living supports. The location also became a "hub of sorts" with commercial space being occupied by the centre for addiction and mental health, a restaurant and a fitness club. The benefit of collaborating with the private developer meant that more affordable housing units were created without needing significant funding to construct a new building that already accommodated young adults with disabilities with wide hallways, doorways and bathrooms.

Interestingly, "hub" models have been showing promise in supporting individuals with complex care needs. In fact, the 2010 the Rural and Northern Health Care Framework/Plan Stage 1 Report recommended a 'local hub' model of health planning, funding and delivery in rural,

remote and northern communities, which integrates services across health sectors at the local or multi-community level, and includes broader social services, where feasible. Currently, the independent living service providers are demonstrating success with innovative approaches to support individuals with multiple chronic conditions and social needs to allow them to remain closer to home. Some of these include ‘hub and spoke’ models, mobile supports for daily living, and regional provider networks that are eagerly working towards bridging gaps and growing capacity (Williams, 2017). Such ‘hub’ models may be adaptable to rural northern regions. Contrary to the typical medical model approach to care, independent living providers do not aim to cure underlying chronic health conditions but, instead, work within a philosophy that helps individuals with disabilities live as independently as possible “with choice, opportunities, and the confidence of full citizenship” (Williams, 2017, p. 6).

Across Ontario, there are a number of “hub and spoke” models that have been rolled out. Essentially, resources from a particular location are leveraged (such as a supportive housing building) to “radiate” services to individuals who are living independently in their own homes within a given geographic area. According to Williams (2017) adult day programs and long-term care homes can serve as hubs as well. Assisted Living Southwestern Ontario (ALSO) has provided an elaborate “hub and spoke model” that offers services to hundreds of individuals of all ages to allow them to live independently in the community for as long as possible (Williams, 2017). The program offers a comprehensive range of supports within 11 supportive housing units, which are identified as ‘hubs’ (Williams, 2017). The basket of services provided within this model seeks to meet a wide range of social needs while supporting the client’s medical needs simultaneously. Services include specialized acquired brain injury support, vocational services, counselling, referral, and navigation, as well as social and recreational activities to help

individuals to remain active and integrated into their community (Williams, 2017). From these 11 supportive housing units, mobile services and outreach services are used to serve clients and caregivers who remain within the community by providing several visits a day on a scheduled or on-call basis including availability over night if needed. This would be comparable to what they would normally receive in a supportive housing unit but it mitigates the need to build more costly supportive housing buildings and it can extend to rural locations by helping individuals in those areas as well (Williams, 2017).

It is particularly important that policies are flexible and sensitive to the cultural and physical realities in which people with disabilities are living. Programs to support individuals are best designed and implemented at a local or regional level and should be supported by higher levels of government (UNECE Policy Brief on Aging, 2017). Sally identified collaboration and integration of care among service providers as essential; however, Sally expressed frustration that the different ministries did not seem to collaborate and integrate themselves. Many of the reports have highlighted the importance of rural and remote areas building strong collaborative relationships between public and private service providers to improve service provision in a cost-effective way (UNECE Policy Brief on Aging, 2017).

One example of a unique and innovative program that has been established to help support the social care needs of individuals with disabilities residing in rural and remote locations is the French postal service in France, La Poste, which includes letter carriers facilitating free-of-charge visits to isolated older and disabled individuals (UNECE Policy Brief on Aging, 2017). This was facilitated with the town hall and the municipal social action centre. This idea was motivated by the fact that a number of post men/women come into contact with older adults and disabled individuals on a daily basis.

Another initiative is the Village Service in Austria. This service brings together volunteers who can provide assistance with daily life activities such as transporting someone with a disability with limited transportation to a doctor's appointment, doing the grocery shopping, or simply providing companionship. In essence, the programs seeks to connect individuals with their community and combat issues of loneliness (UNECE Policy Brief on Aging, 2017). Sally referenced a long-term care home, which has set up volunteers to provide friendly visits and to take residents' out to community events and socials. Sally felt that it was an excellent program that promoted social interaction and community integration.

Another possibility that could assist individuals with disabilities to remain in the community is having a "foster family" such as the program that evolved in Russia. This involves a person with a disability residing with a foster care family who would provide companionship, assistance with meals, laundry, outings etc. (UNECE Policy Brief on Aging, 2017). The intent of the program is to minimize risk of admission to hospital or long-term care and to help individuals remain in a familial social environment (UNECE Policy Brief on Aging, 2017). These concepts are options that could prove to be valuable within the rural and remote regions of Northern Ontario. These are creative solutions to enhancing support for both young and older adults with disabilities, while promoting community integration, inclusion and increasing the choice of where they wish to live and receive care (UNECE Policy Brief on Aging, 2017). Interestingly, many of the programs identified above would be suitable for older adults with disabilities as well.

Implications for Social Work Practice

Social workers are responsible for promoting social justice, empowerment, self-determination, and are committed to advocating and supporting marginalized populations,

including young adults with disabilities (Ontario College of Social Workers and Social Service Workers, 2008). Social workers support the idea that disability is a social construct and believe that social, cultural, political, and environmental barriers are more disabling than physical or cognitive disabilities (Oliver, 1996). Social workers draw upon theoretical frameworks that promote empowerment, strengths, and resilience when working with individuals who are marginalized in our society (Saleebey, 1997). Empowerment theory recognizes that oppression and power imbalances negatively impact underserved and underrepresented groups, which includes young adults with disabilities. Social workers are also attuned to the person-in-the-environment relationship and are aware of the silos that exist between economic, health care, and housing programs (Donovan et al., 2013).

The participants in this study highlighted the complex social needs with which young adults entering long-term care present. These needs often go unmet and this further exacerbates the individual's mental health and behavioural symptoms, and ultimately their physical health as well. Participants in this study felt that long-term care continues to focus primarily on the physical and medical needs of individuals. Several participants felt that having a social worker on staff in long-term care homes would be helpful in addressing resident needs in a more holistic way. In particular, social workers could provide additional specialized support to young adults with disabilities, referrals to community resources, while assisting family members in coping and supporting their loved one. They could also provide (or refer clients to) needed counselling and therapy, given their complex mental health issues. This would be particularly important for younger disabled individuals who are struggling with cognitive changes and loss of independence. Social workers are often experienced in providing mental health support, and work towards engaging formal and informal supports to enhance overall quality of life. For

younger adults in long term care, who lack family support and therefore have more difficulty navigating the system, social workers could play a vital role in promoting communication between family members and enhancing informal relationships.

Social workers should be meaningfully engaged in social and political action that seeks to ensure that all individuals in society have equal access to resources, services, and opportunities in order to meet their basic human needs and to promote optimal development (Morgaine, 2014). They must have an awareness of policies and their implications and must advocate for changes in policy and legislation that improve overall social conditions and promote social justice (Morgaine, 2014). It is essential that social workers strive to advocate and empower young adults in long-term care homes and those at risk of entering long-term care to create policy changes that enhance service provision in a way that ensures inclusion, dignity, choice, and autonomy. In order for this to be possible, they must support persons with disabilities in bringing attention to this growing issue and advocating for the need for a range of living options to be available for young adults with disabilities, where social and health care are integrated simultaneously.

There are several promising developments internationally that have demonstrated success integrating health and social care. These developments have direct implications for social work practice as each of these developments has drawn upon skills that are within the social work scope of practice. In the United States, the Ambulatory Integration of the Medical and Social Model (AIMS) links individuals with the necessary nonmedical supports and services that they require to improve self-management and health care utilization (Rowe et al., 2016). The AIMS model recognizes the importance of assessing social care needs, providing case management services and referral to valuable social service organizations; however, it goes beyond this by employing Master's level social workers who are also trained in providing mental health support

with services including individual counselling and motivational interviewing (Rowe et al., 2016).

Rowe et al. (2016) suggest that social workers are well positioned to assess the complexity of a client's non-medical needs due to their extensive training and knowledge of mental health, system navigation, care coordination and ability to link patients with appropriate resources.

Table 5 shows the steps that are essential to making the AIMS model successful.

Table 5

Steps to a Successful AIMS model

| Patient Engagement | Assessment and Care Plan Development | Case Management | Ongoing Care as Needed |
|---|--|--|--|
| Develop rapport and trust | Complete comprehensive biopsychosocial assessment | Assist client with implementing the care plan | Ensure community-based resources are in place to support the patient long-term |
| Explain care coordination process | Identify strengths, social and environmental factors | Provide ongoing case management and monitor goal progress | Encourage client to contact social worker should new challenges arise and close the case |
| Engage client to identify immediate non-medical concerns | Use motivational interviewing techniques | Problem solving issues and linking clients with needed services and supports | |
| | Help client set goals to meet social care needs | Monitor care plan, weekly check ins | |

Note. Reprinted from *The Ambulatory Integration of the Medical and Social (AIMS) model: A*

retrospective evaluation. by Rowe et al., 2016, retrieved from <https://www.tandfonline.com/doi/abs/10.1080/00981389.2016.1164269>

An unpublished evaluation of the AIMs program was completed internally which found that patients were satisfied with the health care services they had received and that they were better able to manage their chronic conditions (Rowe et. al, 2016). A retrospective evaluation was completed and it showed that individuals who participated in the program had fewer hospital admissions, emergency department visits, and 30-day readmissions compared to the larger population (Rowe et al., 2016).

An integrated health and social care model which has garnered favourable attention is in Torbay, United Kingdom (Thistlewaite, 2011). Within Torbay, there is a joint commitment from the social services and health care services to work together to provide better quality care for individuals with complex social and medical problems (Thistlewaite, 2011). They learned early on that health and social care co-ordinators were critical to maintaining this innovation (Thistlewaite, 2011). The partnership that developed between the health and social services generated unexpected benefits not only in enhanced quality of care but also with significant cost savings. With its integrated management structure, Torbay Care Trust saved approximately £250,000 pounds or \$425,465 thousand Canadian dollars in the first year. This money was in turn used to further develop social services (Thistlewaite, 2011).

Study Limitations

When considering the limitations of this study it is important to acknowledge that the responses by participants are representative of their views as professionals supporting clients with disabilities; however, the responses they have provided are not necessarily reflective of the

perspective of young adults with disabilities. Research has shown that when it comes to policy development and meaningful change in the disability sector, service users must be consulted as personal narratives provide a more accurate description of their current experiences. While consulting with individuals who support those with disabilities, self-representation by those with disabilities is essential. Mechanisms of self-advocacy networks have been shown to be generally feasible and are valuable within service systems (Law Commission of Ontario, 2010).

Another limitation present within this study was that participants were interviewed by telephone and one person responded with an electronic e-mail response. Unfortunately, face to face interviews were not conducted with the participants for various reasons including geographic distance between the participant and the researcher. This can be seen as a limitation as facial and body cues were missed and might have yielded cues that would have led to further exploratory questions.

Recommendations

We are at unique time in Ontario when it comes to health care as the Ford government moves towards the creation of Ontario Health Teams. According to the Ontario Ministry of Health and Long-Term Care, the intent of the Ontario Health Teams is to integrate the public health care system by coordinating the existing provincial health agencies and programs (Ontario Health Team, 2019). The Ford Conservative government believes that this will help ensure health care dollars are used in an effective way by removing any overlap in infrastructure and administrative cost (Ontario Health Team, 2019). It has been said that health care experience and service will change so that there is one integrated team of health care providers that work diligently together to meet each individuals' needs (Ontario Health Team, 2019).

The Ontario government released a document to provide guidance to health care providers and organizations making application to become an Ontario Health Team (Ontario Health Team, 2019). The government acknowledges that our health care system is complex, and admits that families, patients and service providers have found it to be confusing, challenging to navigate, and certainly inconvenient (Ontario Health Team, 2019). The Premier's Council on Improving Healthcare and Ending Hallway Medicine identified that the current state of health care does not always make effective use of resources therefore making the system unsustainable (Ontario Health Team, 2019). The document highlights the need for innovative approaches to providing care and identifies that there are some areas in Ontario that are experimenting with collaborative approaches and producing good results (Ontario Health Team, 2019). It suggests that the Ontario Health Team model will build on these innovative approaches and will enhance service integration so that it reaches far beyond a few sectors and is fully inclusive of an entire continuum of care (Ontario Health Team, 2019). This is relevant to Northerners, and particularly those in rural and remote locations, as the government has said that its' intention is to have care redesigned at a local level in ways that best meet the needs of specific communities (Ontario Health Team, 2019).

The research garnered in this study draws attention to the needs of young adults with disabilities. Some of the recent policy and planning initiatives that have been spearheaded by local health integration networks in Ontario have been focussed on the needs of older adults. Unfortunately, this has negatively affected young adults with disabilities as their needs have gone unrecognized in policy planning initiatives (Harris & Scarfone, 2014). It is evident that despite our province having identified a commitment to enable individuals and families to live as independently as possible in the community, leading to productive and dignified lives, our

policies and current practice continue to focus on meeting the basic physical needs of individuals with disabilities (Government of Ontario, 2010). With the introduction of the Ontario Health Teams, it is critical that this at-risk population not be forgotten. The following is a list of recommendations compiled based on the information shared by participants and the available literature on this topic.

Recommendations to support community.

1. Increase funding for community-based resources and a develop a continuum of housing options for young adults with disabilities: There is a significant need for an increase in funding for community-based resources for young adults with disabilities including assisted living, direct funding services, supportive housing/assisted living models and outreach attendant services. This will allow for pressure to be taken off of our hospitals and long-term care systems. The available literature that reinforces these findings has been primarily focussed on older adults, with increased pressure being anticipated as the baby boomers age. It is important, however, that policy makers recognize and prioritize the needs young adults with disabilities as they too are increasingly in need community-based supports and are contributing to the cost of “upward substitution of care.” In addition, increased community support options should allow individuals to have a choice about where they choose to live. In particular, it is important that young adults with disabilities are granted the opportunity to reside with or as close to their families as possible, should they wish. Due to a lack of resources, young adults are increasingly being moved to communities far from their families, simply because there is an available long-term care bed. Developing local strategies where investments are made to support community providers in increasing supports for young adults with disabilities would assist in ensuring that this population of individuals has the opportunity to receive care in a place of their choice.

2. The Ontario Government should move towards a province wide strategy that integrates

health and social care: It is becoming increasingly obvious that many of our health care institutions remain heavily reliant on the medical model care. This can be seen within the home care and long-term care sector who are struggling with being able to meet even the basic needs of the residents' they serve - due to lack of funding - resulting in limited staff with limited training. Operating from a medical model approach effectively minimizes the potential of social inclusion, and this was identified in the results of this study as a failure in the long-term care system. As articulated by McCauley and Matheson (2016), social inclusion is not something that occurs simply by having someone reside in the community as opposed to an institutional setting. Aronson and Neysmith (2001) spoke about this in their article where they examined how health care policies that guide home care services, reinforces social exclusion. They cited Barnes (1997) who argued that,

if community care is to be successful then it has to involve more than the production of individualized care packages, based on professional assessments of need. It has to involve enabling people to participate in decision making processes about services, and in social, economic, and political life more broadly. (Aronson & Neysmith, 2001, p. 154).

Participants in this study reflected these same concerns regarding young adults with disabilities lacking social inclusion, meaningful engagement and a sense of purpose. Boyle, Buchman and Bennett (2010) conducted a study in Chicago that examined whether purpose in life was associated with reduced risk of disability. They found that among community-based older adults with dementia, greater purpose in life was associated with an ability to maintain functional status and reduce risk of losing abilities basic IADLs and mobility related issues. Our

participants felt that integrating health and social care would aid in being able to provide a dignified quality of life for young adults with disabilities and would promote social inclusion.

In this paper, we shared international examples of how integrating health and social care has demonstrated improved health status as well as cost-savings to the health care systems. Integration has demonstrated benefits for both the young and older adult population (Thistlewaite, 2011). Success has been seen in countries like England, which have developed legislation to support this approach, through the Health and Social Care Act 2012 (Thistlewaite, 2011). The government worked alongside social care organizations to establish a policy framework for integrating these services, which was supported by central and local governments, regulators and national representatives from the health and social care organizations. By doing so, goals and strategies were developed to focus on the whole person. Integrating health and social care is necessary at the community, hospital and long-term care level. In order to support this, it is essential that inter-ministerial collaboration occurs with the objective of promoting health and social care models for individuals with disabilities. Our study participants want Ontario ministries to show leadership in this regard by encouraging service user and service provider collaboration when engaging in policy reform. The Ministry of Health and Long-term Care, Ministry of Municipal Housing and Affairs and the Ministry of Community and Social Services continue to work in silos. Unfortunately, this results in barriers to a shared approach to supporting those in need. Harris & Scarfone (2014) recommended the development of a province wide strategy to provide an integrated model of care for persons with disabilities, and the results of this study support this as well. Golden (2019) articulated this concept well:

In order to achieve better and more equitable health outcomes, addressing social factors such as housing, healthy food options, education, safety and employment in health care

delivery — the economic and social conditions that influence differences in health outcomes — is essential to help address inequities in health and wellbeing. (p. 1)

3. Collaboration with private developers: It is recommended that community-based providers consider collaborating with private developers in the community to seek opportunities to provide appropriate housing for young adults with disabilities. Leveraging and transforming existing buildings and housing into supportive housing options reduces the need for significant funding from the government. Hub and spoke models that use mobile supports should be considered more widely as they have shown positive results in supporting individuals with high needs to live as independently as possible in community settings (Williams, 2017). These services can also be extended to provide support to those residing in rural settings with the main hub being a supportive housing building, adult day program or a long-term care home. These types of creative and collaborate approaches may prove to be particularly relevant in Northern communities where services and funding resources are limited. Collaboration should also be extended to inter-agency support for shared care plans. Some individuals will require “lighter touch” assistance while others will require more extensive and long-term support. Service planning that reflects the individuality of each person, includes social workers as key players in providing case management, advocacy, navigation and counselling support to those with high needs.

4. Enhance caregiver respite support: We heard from participants that caregivers are struggling with limited availability and options for respite services. The literature demonstrates that this is true for both young older adults. As evidenced within this research paper, there is a lack of practical, social, emotional and financial support for unpaid caregivers. According to Sinha (2014), it is estimated that the unpaid caregivers in Canada generate the equivalent of \$25

billion dollars each year in economic value. Unfortunately, this contribution continues to go unacknowledged by governments and our health care system. With our rapidly aging population and increasing needs of young adults with disabilities, the urgency to create better support options, including respite relief, is significant. If these concerns are not taken seriously, it will have significant economic consequences. According to Wilson et al. (2011),

Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming ‘collateral casualties’ of the illness, compromising their health, reducing their efficacy to help and increases costs to the health and social service systems (p. 4).

Respite services allow caregivers and their families the opportunity to sustain their role as caregivers and improve their quality of life. Respite and day program interventions have been found to reduce caregiver depression and increase well-being.

Recommendations for long-term care homes

Participants spoke specifically about the barriers that are encountered by young adults in long-term care, and suggestions were made to make this a more inclusive home environment. Assuming that long-term care remains a part of the continuum of services available for young adults with disabilities, the following is a list of recommendations that Long-term Care Homes and the Ministry of Health and Long-Term Care should consider when planning for the needs of young adults. It’s important to identify that many of these suggestions would enhance quality of life for older adults residing in these homes as well. These recommendations have been made with the report titled "Disability and Dignity Enabling Home Environments: A Key Message from an Ontario Study" (Gibson et al., 2011) in mind.

1. Increased funding for more staff in long-term care homes: Limited staff, with limited time was a theme that emerged in this study and it requires attention. The Ontario Health Coalition

(2019) identified that the lack of staff in long-term care homes as critical, resulting in basic physical and social needs going unmet. As the Ontario Health Coalition (2019) stated;

Not enough care means residents are fed too quickly, cannot get enough food down, and lose weight, becoming frail and risking dehydration or starvation. It means no time for bathing or repositioning to prevent bed sores. It means no friendly visits or socialization for lonely or depressed residents (p. 26).

Canadian armed forces were deployed to several long-term care homes in light of the struggles they were experiencing with the spread of COVID-19. The armed forces released a report that highlighted the horrific work and living conditions of staff and residents at several long-term care homes in Ontario (Sinha & Nicin, 2020). However, in order to retain staff, nurses and personal support workers must be adequately paid for the work that they are providing and appropriate staff to resident ratios are imperative. Inadequate training in managing responsive behaviours and mental health issues was cited by participants as being a significant concern for front line staff. Quality of life for residents residing in these homes would certainly benefit from increased funding for staff, a minimum staff to resident ratio and incorporation of comprehensive mental health and behavioural-based intervention training for front line workers.

2. Specialized units in long-term care: Increasing staff levels in long-term care homes is essential for young adults with disabilities as well as for older adults residing in these homes. Designated young adult units within the long-term care homes may be beneficial, however, increasing staff levels would be imperative. Simply creating these units without increasing support levels would be ineffective. It is recommended that long-term care homes and community agencies collaborate with their local Ontario Health Team to explore financial support required to create designated young adult units where the population warrants this.

Young adult units would require increased staff levels in order to truly promote independence and to meet the rehabilitative and social needs of this population. The Ministry of Health and Long-term Care funding could remain the same but the LHIN (soon to be Ontario Health Teams) could provide a top up to increase staffing to ensure the individuals' safety and needs are met from a holistic perspective, ensuring that the clients' rehabilitative goals are met. In addition, opportunities to improve the design of long-term homes to provide privacy for young adults with partners and children are important to assist them in maintaining these relationships. Promoting social connection with others their own age, age appropriate activities that facilitate inclusion into wider society would be imperative to enhancing quality of life amongst this population. Participants in this study also noted the benefits of "friendly visiting" programs in some long-term care homes and the benefit of having volunteers who can go on outings with residents. Unfortunately, many Northern communities do not have the population to warrant designated units. In these instances, hub and spoke models should be considered as explored in the above recommendations.

3. Collaborating with community partners for capacity building: Long-term care homes should seek to develop collaborative relationships with independent living and not-for-profit organizations in the community who have the staff, training and expertise required to care for specific populations of individuals. Long-term care home staff would benefit from education on the independent living philosophy, which emphasizes choice, control, and autonomy in daily living for individuals with disabilities. Independent living service providers such as; developmental services, March of Dimes, MS Society, and the Huntington's Society could provide this training to long-term care staff. Building these collaborations could also result in community-based service providers coming on site to offer day programming and to provide

opportunity for residents to engage in community-based activities. Participants indicated that finances can be a barrier to participating in community-based activities. It is recommended that long-term care homes seeks out opportunities to advocate for the financial needs of those residing in these homes and engage in fundraising opportunities where possible to support these programs. Some of the independent living service providers also having funding allocated for including participants in programs at no cost as well. Building these relationships with independent living service providers is imperative to finding ways to overcome the social exclusion that this population experiences.

4. Make Social Worker required position in homes for long-term care: The medical approach to care continues to dominate in the long-term care sector, as evidenced by the lack of social work staff in long-term care homes. Social workers can employ and advocate for psychosocial interventions including engaging residents in meaningful activities and providing cognitive-behavioural therapy approaches to reduce severity of mental health symptoms. In addition, participants felt that young adults in long-term care often have complex family dynamics and minimal family support. Social workers are equipped to provide psychoeducational interventions with family members and provide them with support to help maintain relationships with their loved ones in the long-term care setting. Young adults in long-term care are coping with significant loss in their independence and accompanying mental health and addiction related issues. Participants felt that a social worker would be beneficial to help advocate for clients to engage with community-based services, working to overcome barriers that hinder social inclusion.

Accountability

A particularly important feature of this sector, that must not go ignored, is the difference in governance and ownership of long-term care homes in Ontario (Berta et al., 2014). Most privately owned homes have board oversight among publicly-traded and investor-owned companies (Berta et al., 2014). It's important to acknowledge that a key component of neo-liberalism is the encouragement of seeking out market-based solutions, resulting in a divestment of government involvement. In a significantly underfunded system, long-term care homes find money in reduction of staff levels and lower wages and of course, in private facilities, the consideration of profit margins worsens the situation. Participants echoed what has been identified in numerous reports, which is the need for increased funding in the long-term care sector. Increased funding is not intended to mean increased profits for those in the private sector. The Ontario Health Coalition has argued that it would be beneficial for the long-term care sector to be enshrined in the Canada Health Act, to offer protection against further privatization. In light of COVID-19, we have seen the Canadian Armed Forces (CAF) sent to long-term care homes in Ontario to assist staff who were struggling to cope with the COVID-19 outbreaks. Four out of five of these homes were privately owned, and the CAF released a report that revealed the deeply disturbing conditions for workers and residents (Declerq, 2020; Canadian Military Family Magazine, 2020). Premier Ford indicated that he was not aware of the “full extent of what these homes, what these residents were dealing with”(para. 11), despite numerous reports being released over the last couple of decades highlighting the staffing crisis and quality of care issues in these homes (Declerq, 2020). Service Employees International Union President Sharleen Stewart pointed to decisions made by Premier Ford, which have directly impacted long-term care homes including, capping wages of the lowest-paid employees in long-term care homes,

eliminating sick days for these essential workers and reducing resident quality indicator inspections in the long-term care sector (Declerq, 2020). In light of the CAF report, Ford has now called for an independent commission into long-term care homes (Declerq, 2020). As the Ontario Health Coalition (2020) has articulated, this commission should be done under the “public inquiries act and fully independent of for-profit long-term care operators.”

Accountability is paramount and the government is reminded of the consequences associated with neglecting to address the underfunding of our long-term care homes and the lack of accountability in regards to the standards of care being provided in these various homes. Lister (1997) explained that privatization of formerly public services, results in a “consumerist, market-oriented conception of rights in which the citizen is transformed into a customer” (p.206). There have been recent discussions about the need for national standards in long-term care homes in Ontario. History and the experience in long-term care homes in light of COVID-19, demonstrate a system that is in desperate need for change and this change must include increased funding and enhanced government oversight and accountability measures. The Ford government indicates that they weren’t aware of how bad the conditions were in these long-term care homes, which indicates that there needs to be more direct consultation with individuals living in and at risk of entering long-term care in order to be truly responsive to creating policy changes that meets there needs (DeClerq, 2020). Reforms will not be successful if the government does not engage in in-depth and meaningful discussions with service-users themselves about their needs.

Future Research

Future research in this area should include interviews with young adults with disabilities in long-term care in order to gain a true picture of how the current policy discourses affect service users. Furthermore, research from long-term care homes that have incorporated a young adult unit into the home would be beneficial as it would provide an opportunity to better understand what works and what doesn't work, in order for other long-term care homes to adopt or adapt new approaches and service delivery models. In addition, research on the roles of social workers who work within long-term care would be beneficial to gain a better understanding of how this role benefits residents and family members. Further, it may create opportunity for social workers to be more readily recognized as key players in a multidisciplinary team within long-term care.

Conclusion

The systemic exclusion of individuals with disabilities from mainstream society is the result of historical underlying societal assumptions that discriminate and devalue their lives (Barnes & Mercer, 2003). Throughout history, individuals with disabilities have encountered significant barriers to living full, independent and productive lives in a society where they have been regarded as being functionally limited and as requiring medical intervention (Hiranandani, 2019). When we fast forward to 2020, it seems that many of these same concerns continue to exist in our present delivery systems. Despite Ontario's adoption of the Accessibility for Ontarians with Disabilities Act 2005 (AODA), it continues to fall behind the standards achieved in a number of other countries including Japan, Sweden, Germany, Australia, and parts of the United States when it comes to the inclusion of people with disabilities. This study reinforces the literature indicating that this is most obvious when examining the intersections of health care and housing policies that directly affect individuals with disabilities. There continues to be minimal

consideration to how a person's home environment directly impacts one's psychological well-being and social inclusion (Gibson et al., 2011). Young adults with disabilities are increasingly forced to give up living in the community to reside in long-term care homes in order to receive the physical care that they require, but in so doing, must sacrifice access to social and civic participation, as well as emotional connection that all humans desire and enable us to thrive.

The research garnered from this study has brought attention to the ways in which young adults being placed in long-term care homes in Northern Ontario is problematic. Changes have not been made to better meet their needs, as these settings continue to be primarily focussed on the needs of the geriatric population and, heavily focused on a medical model of care. Participants in this study spoke about the unmet social needs of young adults in long-term care, as they are often physically and psychologically complex, with significant social, physical, emotional, behavioural, and financial issues. The study demonstrated that there were significant barriers within the long-term care setting which make the current environment problematic, as it is unable to truly promote a dignified quality of life. As Kaplan (1991) highlighted, the "the less actual and perceived social support made available to young disabled adults, the more likely the incidence of client emotional problems and rehabilitation failure" (p. 78). This essentially results in increased pressure on the health care system as health-related issues are generated from physical and emotional deterioration, which negatively impacts the individual's quality of life.

There has been increased pressure and thus some response from the government to increase services and community-based supports for the geriatric population as the baby boomers are aging; however, unacknowledged are the unique needs of young adults with disabilities who are left with little to no options (Harris & Scarfone, 2014). The research has shown that where community-based supportive housing options are available, the waitlists are very long (Harris &

Scarfone, 2014). Participants in this study strongly advocated for increased community supports to prevent unnecessary and inappropriate admissions to homes for long-term care. As Joffe (2010) put it:

However we define it, surely meaningful inclusion must entail a range of living options that realistically is not currently available to most people who require daily living supports due to limitations in the capacity of supported living services; paternalistic attitudes that endure despite a rhetoric of inclusion and choice. (p. 8)

Participants in this study also noted that our current health care system is complex, difficult to navigate and under significant pressure with a rapidly aging population and increase in young adults with disabilities requiring chronic care and long-term support. With the growing needs and the looming healthcare crisis that our system now faces, the effectiveness, quality, and financial feasibility of maintaining it will surely result in significant negative consequences for all. As the province moves towards rolling out Ontario Health Teams with the stated objective of developing an integrated health care model, it is imperative that young adults with disabilities become a priority and that care models for young and older adults embrace a socially responsive approach by integrating health and social care. Integrated social and health care models in Torbay, England demonstrated a decrease in the number of occupied hospital beds and delayed transfers from hospital were reduced. We are at a time right now where “hallway medicine” has become a significant concern for Canadian society and a new service delivery model is imperative. Given the complexity of this population, simply deinstitutionalizing individuals or creating a specific “unit” in a long-term care home would not create for better circumstances that promote quality of life. Instead, service provision must acknowledge and address the health and social care needs of these individuals simultaneously, and this cannot be adequately achieved

without increasing staffing levels in these homes. As seen in the media and in a variety of reports, the long-term care home sector is struggling to meet the needs of even the geriatric population and the growing complexity of individuals entering long-term care as a result of limited training, lack of specialized mental health supports and a shortage of staff. The COVID-19 pandemic has accentuated the lack of funding and the consequences of having poorly staffed long-term care homes. It has exposed the significant gaps that have long been present and ignored by policy makers (Ontario Health Coalition, 2020). It has also brought attention to the consequences that can be associated with the privatization of long-term care homes, as research has continually demonstrated that for-profit long-term care homes typically have lower staff levels, lower wages for workers and ultimately lower quality of care.

It is critical that young adults with disabilities are not lost when it comes to policy provision by virtue of their small number. As we become increasingly focused on the needs of the geriatric population, it is essential that we do not forget about the other 10% of individuals who are being inappropriately placed in long-term care homes to spend the remaining decades of their lives. Participants believed that collaborative opportunities between community-based partners and independent living providers could be developed to promote capacity building and to further support community integration for residents in long-term care. Participants also saw a benefit to having social workers as part of the long-term care team, to advocate for the needs of clients', to help support connections with family and referring to community resources that promote social inclusion.

Disability activists must continue disseminate information that is reflective of the discrimination present within our society and advocate for services that recognize the innate dignity and worth of those with disabilities. The government needs to be reminded of the

discrepancy between their stated goals and the current reality in community-based services and long-term care homes. With the roll out of Ontario Health Teams, it is imperative that disability advocates and service users operate from a critical perspective on disability when promoting policy reform. Recognition of the importance of social inclusion and the social and physical benefits associated with having a purposeful and meaningful life is integral to improving the quality of care in this sector. As Prince indicated,

Critical perspectives on disability tend to express liberal individualism in at least two respects: one is that each person is a moral whole with equal ethical worth; and, the second is a belief in the value of community and that the individual is part of a larger social whole - a common humanity. These beliefs contain the ideas of inherent dignity and expected interdependence as well as that self determination and justice depend on consent, forgiveness, healing, inclusion and participation in communities (Prince, 2009, p. 26).

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Appendix A

Research Ethics board Application



Project Title: Young Adults in Long Term Care

Student Researcher: Chantelle Taylor, MSW candidate, Laurentian University.
E-mail: cx1_taylor@laurentian.ca

Faculty Supervisors:

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Part I:

Introduction: My name is Chantelle Taylor and I am currently completing my Master's in Social Work at Laurentian University. I am inviting you to participate in a study that I am conducting about young adults in long-term care. I encourage you to take time to reflect on whether you would like to participate in this study. I assure you that if you have any questions at anytime, I am happy to take time to elaborate and explain further.

Purpose:

Researchers have identified young adults with disabilities being admitted to long-term care homes as an issue in many developed countries; however, there is very limited research available on this phenomena that is Canadian based. Advancement of medical technology in combination with limited community based housing options has resulted in many young adults, with a wide range of disabilities being admitted into long-term care homes as they have no other housing options available to them. The current research available, although limited, demonstrates that the population of individuals that our society usually associates with long-term care homes in Ontario is

seniors, but the reality is that there are many young adults living in long-term care homes as well, both nationally and provincially. Therefore, the purpose of this research study would be to answer the following research questions:

1. What are the implications associated with young adults residing in long-term care in Ontario?
2. What are the most appropriate housing option(s) for young adults with complex care needs in Ontario?

Research Participation:

Interviews will be conducted in a semi-structured format, consisting of a series of questions in a general form of an interview schedule. These interviews can be conducted face-to-face or over the telephone depending on what works best for you, the participant. If you agree, the interview will be recorded using a voice recorder which will assist me in accurately transcribing your responses at a later time. The interview should take no longer than 1 hour.

Participant Selection:

You have been selected to participate in this research study because you have experience working with young adults with disabilities and you likely have an informed perspective on the growing phenomena of young adults entering long-term care. Your experience in the disability field can contribute significantly to our understanding and knowledge of this growing issue.

Voluntary Participation:

Your participation in this study is entirely voluntary and you are free to withdraw at any time. Your signature below indicates that you understand that your participation is voluntary and that you are free to withdraw at any time without fear of reprisal. Withdrawal or participation in the study will not affect your career or future in anyway. Please notify me if you would like to withdraw from the study at anytime.

Procedures:

We are asking you to help us learn more about the experiences of young adults in long-term care. We are inviting you to take part in this research project. If you accept to participate, you will be asked to complete in a semi-structured interview with this interviewer. During the interview, I will sit down with you in person at a location of your choice or I will conduct the interview over the telephone should you wish. If you

do not wish to answer any of the questions during the interview, you may say so and the interview will move on to the next question. No one else but myself will be present during the interview. The information will be recorded using a voice recorder, should you consent to this. The interview will then be transcribed verbatim at a later time. The information recorded is confidential. Your name will not be identified on the voice recorder and the voice recorder will be kept in a locked safe. The locked safe and the computer used will be kept in my locked home office. The voice recordings will be deleted when the study has been completed. The transcribed data will be stored on a password-protected computer and will be destroyed at the end of the study.

Risks:

There may be a risk that the questions that are asked during the interview may be an emotional trigger. Participants will be offered counselling resources should it be required. Below is a list of some local resources that are available should you require support:

Sudbury Mental Health & Addictions Centre & 24-hour crisis line: 705-675-4760

Canadian Mental Health Association: 705-675-7252

Manitoulin Health Centre/Family Health Team: 705-368-2300

In addition, when meeting face to face with this interviewer, depending on location, there is the possibility that you may be seen by others. If you prefer to complete the interview over the telephone, this option will be made available to you. Please be aware that you can discontinue your participation in the study at anytime as your participation is completely voluntary. Again, please note that you are not obliged to answer any questions that you find objectionable or which make you feel uncomfortable. No identifying information will be collected. Also, the interview will require approximately 1 hour of your time. As a result, this will likely take place during your own personal time outside of work hours. I am very flexible and would be willing to meet with you at a time that is most convenient for you.

Benefits:

Participation in this study may not provide any personal benefit to you; however, as a professional working with young adults at risk of entering long-term or that have entered long-term care, the research would allow you to contribute to a very under researched topic. Your participation in this study could lead to positive recommendations for addressing this issue moving forward and may lead to the development of proposed policy changes that affect this population.

Confidentiality:

The information that you share will be kept confidential. Each participant will be provided with a pseudonym; therefore, no identifying information will be used in my thesis or any presentations or publications based on this research.

All transcribed transcripts will be saved on this interviewers' PC computer in a word document. The word document will be encrypted and password protected. In addition to the document being password protected, this interviewer will also use a separate user account that is specifically designated for this study which will also be password protected. This will be done on a personal lap top that is used by myself only. The voice recordings that are used during the interviews will be locked in a safe that will only be accessible to myself only. The voice recorded interviews will be stored in a locked safe for the duration of the study. The transcripts will be saved on my PC until the end of the study as well. At the end of the study, they will be digitally shredded. The voice recordings from the interviews will be locked in a safe that will be accessible to myself only. The voice recordings that have been saved on the recorder will be deleted using the delete option on the recorder at the end of this study.

Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a Laurentian University Research Ethics Committee (ORE#6009956). If you have questions or possible ethical issues or complaints about the research itself, please contact the Research Ethics officer, Office of Research Services at 705-675-1151 ext. 3681 or 2436. You can also call toll free at 1-800-461-4030 or e-mail ethics@laurentian.ca

Certificate of Consent

By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

Title of the study:

Young Adults In Long Term Care

I have read the information about the study being conducted by Chantelle Taylor, under the supervision of Karen McCauley and Duncan Matheson at Laurentian University. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details. I was informed that participation in the study is voluntary and that I can withdraw this

consent at any time by informing the researcher and I am aware that this will not affect my future in anyway.

This study has been reviewed and received ethics clearance through Laurentian University Research Ethics Committee (ORE#6009956). If you have questions or possible ethical issues or complaints about the research itself, please contact the Research Ethics officer, Office of Research Services at 705-675-1151 ext 3681 or 2436. You can also call toll free at 1-800-461-4030 or e-mail ethics@laurentian.ca.

For all other questions please contact Chantelle Taylor at cx1_taylor@laurentian.ca.

___ - I agree to have the interview audio recorded.

___ - I do not agree to have the interview audio recorded.

___ - I give permission for the use of anonymous quotations in any thesis or publication that comes from this research.

I am voluntarily signing this form. I agree on my own free will to participate in the study. By signing this consent form, I am indicating that I agree to participate in this study.

Name of participant: _____

Signature of participant: _____ Date: _____

Appendix B

Interview Questions

1. Demographics

I would like to begin by choosing your pseudonym and by going through some demographic questions. Please be aware that none of this information will be used in ways that break confidentiality protocols:

Field/Industry of organization (i.e. disability field, geriatrics):

Years working in the field:

2. Interview Questions

1. Please describe your current or previous role working with individuals with disabilities?
2. Please describe the experiences you have had with young adults who reside in long-term care?
3. Could you describe some factors that you feel result in young adults moving into long-term care?
4. How do you feel about long-term care being a form of housing accommodation for young adults with disabilities?
- 5.. In your opinion, do young adults with disabilities encounter barriers when seeking appropriate accommodation? Please elaborate.
- 6.. Do you feel that the needs of young adults with disabilities differ from older adults with disabilities?
7. In your experience, does long-term care meet the mental, emotional, physical, social and spiritual needs of young adults in long-term care? Please elaborate.
8. Can you identify any implications associated with young adults residing in long-term care?
9. Can you suggest any possible housing alternatives for young adults with disabilities?

Appendix C

Description of Participants

Mary: has been working in the disability field since 1970. She has worked with all ages of individuals with disabilities. She spent many years working front line in the developmental services sector and with individuals in need of respite care. She is now in a managerial role with a community-based organization that supports young adults with acquired brain injuries.

Janet: has been working in the mental health field for the past 16.5 years. This has mainly been with individuals over 60 years old who require assessment and treatment for cognitive and mental health issues. She works in the community and provides services to those in long-term care homes as well. She also has over 16 years in a general hospital setting and has worked in the developmental services sector as well.

Betty: was a manager in the recreation department in a long-term care home between the year of 2005-2018 in Northern Ontario.

John: works with individuals' and their families who have a specific type of neurological disease. Her current role includes providing case management, linking clients to supports and providing education to individuals affected by the disease, their family members and staff members in long-term care. John has been working with this specific population of individuals since 2015 and spent over 13 years in the mental health field prior to that. She is now in a managerial position with the community-based organization that she works for.

Simon: works front line in the recreation department in a long-term care home. She previously worked in community home care, assisting both young and older adults with disabilities.

Sally: has worked with individuals with disabilities at different points in her career and has been with a specific community-based organization providing supports to those with a specific type of disability. In her current position she works at a system level to provide support and navigation to those in need. She also provides advocacy at a systems level to help improve services for this population. She has sat on human service coordinating committees, neurological health charity committees.

Please note that all participants work in Northern Ontario.

