Setting the Balance of Care for Sexually Diverse Seniors: The Social Exclusion of LGBT Seniors in Home and Community Care

By

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A thesis submitted in conformity with the requirements for the degree of Master of Science

Institute of Health Policy, Management and Evaluation

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Abstract
The central aim of this dissertation is: to identify how past experiences of social exclusion have influenced the current cohort of lesbian, gay, bisexual, and transgender (LGBT) seniors and health care providers in Toronto, Ontario regarding accessing and using home and community care (H&CC) services, and to consider what can be done. To do this, I conducted a case study on LGBT seniors’ use of H&CC services in Toronto, Ontario. My findings suggest that past experiences of social exclusion impact on LGBT seniors’ access and use of H&CC services. H&CC providers acknowledge an overall lack of H&CC for LGBT seniors, but differ in their approaches to providing culturally appropriate H&CC. I conclude with recommendations regarding remedies to the social exclusion of LGBT seniors within H&CC, and policy options for reducing social exclusion more broadly.
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Chapter 1: Introduction

Seniors who identify as lesbian, gay, bisexual and transgender (LGBT) were born, raised, and have aged during a time when discrimination due to sexual orientation was commonplace and widespread. The central aim of this thesis is: to identify how past experiences of social exclusion have influenced the current cohort of LGBT seniors and health care providers in Toronto, Ontario regarding accessing and using home and community care (H&CC) services, and to consider what can be done.

The growth of the population of seniors (aged 65 and over) presents significant challenges and opportunities for policy-makers and health care providers and has implications for seniors, their families, and caregivers. Over the next 20 years the population of seniors in Canada will reach roughly 10 million, almost a quarter of the total population (Library of Parliament, 2012). At the same time, population aging is occurring during a period of rapid social and cultural change; the population of ethno-cultural Canadians continues to grow, the nuclear family is no longer the norm, and growing numbers of LGBT individuals and families are living openly (Employment and Social Development Canada, 2013; Statistics Canada 2011). The health care of the aging population has emerged as a priority at all levels of government, policy-makers are tasked with developing policies which meet the changing health care needs of our increasingly diverse society.
In this introductory chapter I present my conceptual framework (1.1), the current state of knowledge surrounding LGBT seniors (1.2), the home and community care policy context (1.3), followed by my study design (1.4), and the organization of subsequent chapters (1.5). I conclude with a brief summary which highlights the contributions of this thesis to the literature and to future policy.

1.1 Conceptual Framework

Discrimination against individuals because of their sexual orientation has been classified as homophobia (fear or hatred) and heterosexism (heterosexuality is normal, all other forms of sexuality are deviant). Much has been written about the discrimination of LGBT seniors prior to the era of gay liberation which started in the late 1960’s in Canada. During this time, individuals who were outed (meaning their sexual orientation was made public) were at risk of physical harm, being ostracized by their family and friends, losing their job, being jailed, and being treated by means of electroshock or aversion therapy (Daley, 1998). Following the gay liberation of the late 1960’s (homosexuality was decriminalized in Canada in 1969), attitudes towards homosexuality slowly began to shift, however LGBT individuals continued to live at risk of discrimination in their social and public life (Brotman, Ryan & Cormier, 2003). Discrimination against LGBT people in health care settings was frequent, LGBT individuals were often subjected to attempts to heal their same-sex attractions, and even after homosexuality was removed from the classification of mental disorders by the American Psychiatric Association in 1973, many health care providers continued to consider homosexuality a mental disease (Jones
& Gabriel, 1999). Despite decades of progress and changing social attitudes towards LGBT people, fear of discrimination is still salient among many members of this generation of LGBT seniors.

In this thesis I question how the social exclusion of LGBT seniors has impacted on their current use and access to H&CC services. The concept of social exclusion includes a multi-dimensional focus on inequities and power imbalances. The World Health Organization (WHO) Social Exclusion Knowledge Network (SEKN) uses the following definition to describe social exclusion:

“Exclusion consists of dynamic, multi-dimensional processes driven by unequal power relationships. These operate along and interact across four dimensions - cultural, economic, political and social – and at different levels including individuals, groups, households, communities, countries and global regions” (Popay, Escorel, Hernández, Johnston, Mathieson, Rispel, p. 36, 2008).

This definition is consistent with the majority of the literature on social exclusion in that it emphasizes the multi-dimensionality of the concept.

Social exclusion occurs when individuals are excluded from rights, resources, or opportunities that are normally available to members of society (Popay et al., 2008). Although the history of discrimination against LGBT individuals in Canada has been well documented, there has been no previous Canadian research which uses the conceptual framework of social exclusion to examine the impact of discrimination on LGBT seniors. I use a combination of literature on the
history of LGBT rights, and accounts from LGBT seniors who lived before and after the gay liberation era, to identify how this group experienced social exclusion, according to a matrix of indicators of social exclusion (Levitas, Pantazis, Fahmy, Gordon, Llyod & Patsios, 2007) and based on extensive review of the concept.

1.2 Background and Rationale: Challenges for LGBT Individuals and Researchers

Conducting research on the population of LGBT seniors in Toronto, Ontario presents a number of challenges. First, it is difficult to estimate the population size of LGBT seniors, for reasons including stigma, variability in definitions and labelling of sexual orientation, and because very few surveys of our population include indicators for sexual orientation. Statistics Canada does not collect any information specifically about the population size of LGBT seniors; the most recent data available from Statistics Canada about same sex couples comes from the 2011 census, and the most recent population data about sexual orientation comes from the 2012 Canadian Community Health Survey (CCHS) (Statistics Canada, 2012). A total of 64,575 same-sex couple families were reported in the 2011 Census (according to Statistics Canada 2011 this may be a slight overestimation due to reporting errors), and in the 2012 CCHS 2.4% of individuals self-identified as homosexual or bisexual (Statistics Canada, 2014), however the CCHS only includes individuals between the ages of 18 and 59. We do not therefore have any statistics about the population size of LGBT individuals 65 years and older.
One challenge in undertaking research on LGBT seniors derives from the variability of terms used among this population to self-describe their sexual orientation. For example, a study based in the United States (US) including 1300 LGBT individuals aged 18 – 92 found that men who have sex with men (MSM) who are age 65 and over are significantly more likely to use the term “homosexual” compared to MSM in other age groups who are more likely to use the term “gay” when describing their sexual orientation (Adelman, Gurevitch, de Vries, and Blando, 2006). The same study found that while overall women who have sex with women (WSW) are most likely to self-identify using the term “lesbian”, WSW who are over age 65 are ten times more likely to use the term “gay” than women in younger age groups. The lack of demographic information is problematic because it prevents researchers, policy-makers and health care providers from understanding the population’s status and needs, and from identifying health disparities that may exist. Alper, Feit, & Sanders (2013) describe some of the barriers to collecting demographic information about LGBT individuals, including: reluctance on the part of health care providers to ask questions about sexual orientation and gender identity, a lack of knowledge by providers about how to elicit this information, hesitancy on the part of patients to disclose this information for fear of being “outed” (sexual orientation made public), and privacy concerns.

The difficulties measuring the size of the population of LGBT seniors is further complicated by the lack of efforts on the part of the healthcare system to collect information about the health and health care use of LGBT seniors across Ontario. The population of LGBT seniors is largely
unrecognised in research about Ontario health care services in part due to difficulties identifying LGBT seniors; sexual orientation is not identified on common health care assessments including the Resident Assessment Instrument for Home Care (RAI-HC) which is used by all Community Care Access Centres (CCAC’s) in Ontario. This presents ongoing difficulties for both policy makers and care providers interested in promoting the visibility of LGBT seniors and in resource planning for this population. In this thesis I present data from extensive personal interviews with a small group of LGBT seniors and H&CC providers; this window into the experiences of this group provides valuable insights regarding the design of H&CC and the needs of LGBT seniors.

1.3 The Home and Community Care Policy Context

The Ontario government has, in recent years, initiated a number of policy initiatives and reports examining the current state of the health care system (Baker, 2011; Walker, 2011; Drummond, 2012; Sinha, 2012). These initiatives have consistently highlighted the important role of home and community care as a means of providing more appropriate, cost effective care. Additionally, research studies have identified H&CC as an effective way to respond to persistent problems such as inappropriate acute care admissions and wait lists for long-term care (LTC) (Hollander & Chappell, 2002; Williams et al., 2009). Further, H&CC has the potential to improve the personal experiences of seniors who consistently state they prefer to remain at home as long as possible (Anderson & Parent, 2004; Knapp, Chisholm, Astin, Lelliot, & Audini, 1997; Pedlar & Walker, 2004).
Nevertheless, there remains an overall lack of best practices regarding how services should be implemented for different ethno-cultural groups (Shaw, 2005; Williams, 2009b). The rapid growth of the H&CC sector necessitates an understanding of these differences, especially when considering populations which are at a higher risk of not accessing services or not receiving appropriate services due to cultural diversity, language, or sexual orientation. In their research on in-home nursing in Australia, Hall and McWilliams (2006) note the differences in client perceptions of nursing in the context of in-home versus out-of-home services, “homes represent and familiarize others intimately with personal and family functioning, possessions representing material wealth, hygiene and cleanliness practices, relationships, and personal habits, their lifestyles were exposed” (p. 80). This issue has particular relevance for LGBT seniors, many of whom spent years of their life hiding their sexual orientation, and some of whom still don’t publicly acknowledge that they identify as LGBT. For these seniors, allowing a stranger into their home, where it may be obvious that they are LGBT (perhaps due to images on their walls, photos with their same sex partner, a single bed for two adults of the same sex etc.) may be an especially fearful or nerve-wracking experience.

Among the plethora of recent policy initiatives and reports on Ontario’s health care system, including the Commission on the Reform of Ontario’s Public Services (Drummond, 2012), Enhancing the Continuum of Care: Report of the Avoidable Hospitalization Advisory Panel (Baker, 2011), Caring for our Aging Population and Addressing Alternative Level of Care (Walker 2011), Ontario Government Action Plan for Health (MOHLTC, 2012), and Living Longer, Living
Well (Sinha, 2012), only the Sinha report (2012) made any mention of accommodating ethnocultural and sexual orientation differences in designing care for seniors. Sexual orientation is not currently mentioned in the literature from the Ontario Community Care Access Centre, and only one Community Support Agency in Toronto currently has a diversity initiative which includes LGBT seniors as a targeted population. The lack of attention to how H&CC should be delivered to our increasingly diverse population of seniors in Ontario raises concerns about the potential of H&CC to achieve improvements.

In this thesis I use the conceptual framework of social exclusion to examine the personal experiences of LGBT seniors who have accessed H&CC services and of H&CC providers who have provided care to LGBT seniors. I also examine previous research on best practices and cultural appropriateness in H&CC. In doing this I identify whether and how the current design of H&CC is meeting the needs of LGBT seniors according to their own personal accounts and the opinions of those providing care. I also address the question of how to remedy gaps in our current understanding of how to provide culturally appropriate care to LGBT seniors and what actions at the policy level may remedy the impact of social exclusion on LGBT seniors.

1.4 Study Design and Research Questions

To review, the central aim of this dissertation is: to identify how past experiences of social exclusion have influenced the current cohort of LGBT seniors and health care providers in
Toronto, Ontario regarding accessing and using home and community care (H&CC) services, and to consider what can be done.

To do this, I conducted a case study on the experiences of LGBT seniors and H&CC in Toronto, Ontario. The case study involved multiple components including extensive review of two sets of literature as well as interviews with LGBT seniors and H&CC providers. The first set of literature is on the state of knowledge of LGBT seniors, including the history of discrimination in Canada, as well as current health and social care needs. The second set of literature is on the conceptual framework of social exclusion, including measurement of social exclusion and international efforts to remedy the social exclusion of various groups. I also employ qualitative methods, conducting interviews with both LGBT seniors as well as providers of home and community care. These interviews focus on historical experiences of discrimination, current experiences of H&CC (including access, use, provision, and recommendations) and future considerations for accommodating the needs of LGBT seniors in H&CC.

My case study includes the following research questions:

Q1) How do previous experiences of social exclusion impact on LGBT seniors’ access and use of home and community care services?

Q2) Moving forward, how can the H&CC sector respond to the needs of LGBT seniors?
1.5 Organisation of Thesis

This thesis is divided into eight chapters (including this introductory chapter). In Chapter 2 I present the conceptual framework which explores the concept of social exclusion, how social exclusion is identified and measured, and what remedies to exclusion of specific populations have been previously identified. In Chapter 3 I provide an overview of the literature on the health of LGBT seniors, informal support patterns among LGBT seniors, and the provision of formal health care to LGBT seniors. Chapter 4 outlines the methods and methodology used to collect and analyze the data. I present the findings and discussion in the three subsequent chapters. In Chapter 5 I focus on the classification of the historical social exclusion according to personal accounts. In Chapter 6 I explore the findings related to the impact of historical social exclusion on the access and use of home and community care services by LGBT seniors. In Chapter 7 I focus on responses to the impact of historical social exclusion in the H&CC sector. I present my final conclusions in Chapter 8.

1.6 Summary and Contributions

The context of this thesis is grounded in the significant role that H&CC services play in the current political context and the preference among seniors to age at home, rather than in long-term care (CIHI, 2011). H&CC has been increasingly considered by decision makers and politicians as a cost-effective measure to reduce health system expenditures in the face of public and political concerns about sustainability and access to care. H&CC is of particular
concern when considering the needs of LGBT seniors who may experience a heightened vulnerability in home and community settings as compared to institutional settings. This thesis contributes to our understanding of how the history of discrimination of LGBT individuals impacts on LGBT seniors today. I hypothesize that the current cohort of LGBT seniors experienced social exclusion, having lived through years of difficult social change in regards to legal rights and public attitudes regarding homosexuality, and that these experiences have shaped their approach to accessing and using home and community care services. The results of this research will contribute to our understanding of how social exclusion impacts on H&CC use and delivery for marginalised populations. It is my hope that this knowledge will inform future decision making regarding the design of culturally appropriate care to diverse populations in Ontario, including but not limited to LGBT seniors.
Chapter 2: Conceptual Framework: Social Exclusion

As I stated in the introductory chapter, there has been no Canadian research which uses the conceptual framework of social exclusion to examine the impact of discrimination on LGBT seniors. This gap reflects the overall dearth of research in the field of LGBT seniors in Canada and perhaps also reflects a widespread lack of discourse regarding policies addressing the H&CC of LGBT seniors in Toronto, Ontario. I have elected to frame my research around the concept of social exclusion because it suggests that there is a government responsibility to address discrimination (and its impacts) when discrimination results in power imbalances between a subset of the population (in this case LGBT seniors) and the rest of society. The concept of social exclusion further suggests that efforts to redress these power imbalances may result in not only individual benefits (among individual LGBT seniors) but improvements for society as a whole.

In this chapter I begin by introducing the history of social exclusion (2.1), and clarifying the difference between social exclusion and social cohesion, two concepts which are frequently used interchangeably but have related yet separate meanings (2.2). I next discuss the various elements included in definitions of social exclusion (2.3). Next, I explore how the experiences of social exclusion impact on access and use of H&CC services for LGBT seniors in Toronto (2.4), Ontario. I then discuss remedies to the impact of social exclusion on H&CC for LGBT seniors (2.5).
2.1 A Brief History of Social Exclusion

Discourse on the topic of social exclusion originated in France in the 1970’s (Silver, 1994; Peace, 2001). *Les exclus* described the condition of groups of people on the margins of society, who were cut off from regular sources of income, from the welfare state, and who did not have the same rights as most citizens. These individuals were victims of discrimination, often people with disabilities or asylum seekers, who did not have connections or a voice in society (Pierson, 2010). The term social exclusion became prominent in English speaking Europe during the 1990’s as an important policy concept responding to the growing social divides resulting from new labour market conditions and the inadequacy of existing social welfare provisions to meet the changing needs of more diverse populations (Silver, 1994). In the United Kingdom (UK) the Labour Government established the Social Exclusion Unit (SEU) (later rebranded the Social Exclusion Task Force) in 1997 with the goal of reducing disparities for individuals suffering from multiple problems such as poor housing, low income, bad health and family breakdown. The Social Exclusion Task Force was abolished in 2010 under the Coalition Government and its functions were absorbed into the Office for Civil Society (Barret, 2010). Interest in social exclusion has continued in academic literature both in the UK and in other regions, in 2006 the World Health Organization (WHO) Commission on the Social Determinants of Health established the Social Exclusion Knowledge Network (SEKN) with the goal of understanding meanings of social exclusion around the world in the context of health inequities (Popay, Escorel, Hernández, Johnston, Mathieson, Rispel, 2008).
2.2 Social Exclusion vs. Social Cohesion: Clarifying the Difference

As noted in the final report of the SEKN (Popay, 2008), use of the concept of social exclusion, while increasing, has not achieved prominence outside of Western Europe. During the same time period as the UK was establishing the SEU, discourse on the concept of social cohesion was emerging at the federal level in Canada. In introducing the concept, Judith Maxwell (Beauvais and Jenson, 2002) likens social cohesion in social policy discourse to ‘big picture concepts’ such as competitiveness and globalization in social economics discourse. Maxwell suggests that social cohesion serves as a ‘macro’ picture for social policy discussion, while acknowledging that the concept means different things to different people. While definitions of social cohesion abound, Maxwell maintains that this ambiguity is not a weakness, and that the concept of social cohesion has great utility, “[it contributes] to framing conversations, to helping to make sense of complex relationships, and to setting goals”. Interest in social cohesion on the part of the Canadian government was spurred by similar concerns in Europe related to social exclusion. In particular, the Canadian government was concerned that a lack of social cohesion, from any number of causes, would result in negative outcomes such as income inequities and poorer health outcomes for Canadians. These concerns reached new heights during the late 1990’s in North America and Europe due to rising concerns about national financial instability.
The dimensions of social cohesion closely align with dimensions of social exclusion. In her 1998 review of the literature on social cohesion Jenson outlines five dimensions common to research on social cohesion:

- belonging / isolation
- inclusion / exclusion
- participation / non-involvement
- recognition / rejection
- legitimacy / illegitimacy.

The first dimension, belonging/isolation refers to the extent to which individuals share values and therefore feel a part of the same community. Feelings of isolation from the community form a threat to social cohesiveness. The second dimension, inclusion/exclusion assumes that social cohesion exists when institutions provide equal opportunities to each member of society. This dimension is often related to economic institutions, specifically market economies. However researchers have also made explicit connections between social cohesion and healthcare institutions (Armstrong, 2001, Chan, 2006), suggesting that where equal opportunity (inclusion) is available in healthcare, social cohesion is fostered, where equal opportunity in healthcare is not included (exclusion), social cohesion deteriorates (Jenson, 2002). The third dimension, participation/non-involvement refers to the extent of involvement within the community. Participation may take place through the volunteer sector or by direct or indirect involvement with public or private institutions. The fourth dimension, recognition/rejection refers to the practice of recognising differences, this dimension primarily refers to the extent to which institutions contribute to the recognition of value differences as opposed to rejecting
differences and fostering intolerance. Finally the fifth dimension, legitimacy/illegitimacy
suggests that social cohesion is maintained when institutions mediate conflicts, and therefore
the legitimacy of these institutions must be upheld in order that specific interests do not
attempt to quell the voice of less powerful interest groups or individuals.

Beauvais and Jenson (2002) discuss at length the different ways of defining social cohesion, and
the subsequent approaches to measuring social cohesion. In their 2002 discussion paper, they
suggest that while each definition may be linked, they may also be free standing. Choosing one
or another definition of social cohesion will affect the frame from which any analysis of social
cohesion takes place. This is very similar to discussions around the definition of social exclusion
which I elaborate on in the next section.

The concept of social cohesion is highly correlated with the concept of social exclusion; both
concepts are multi-dimensional, indeed Jenson’s dimensions of social cohesion overlap
significantly with the dimensions of social exclusion (explored further in this chapter) and in fact
social exclusion is listed as one of the dimensions of social cohesion. The concept of social
cohesion includes a definition of which members of society are “in” and which are not. The
social exclusion of certain members of society is considered a reflection of a lack of social
cohesion within that society (Jenson 2002). Social cohesion however, while evidently a
desirable objective, may or may not emerge from the elimination of social exclusion. Feudal
societies may have been in equilibrium, but they were certainly exclusive. Measures to reduce
social exclusion may or may not increase the capacity of people to live together in harmony. Even though it would definitely be useful to examine the potential synergies and potential tensions between social cohesion and social exclusion in broader terms, for the purpose of this thesis, a focus on social exclusion alone provides sufficient material for consideration.

2.3 Defining Social Exclusion

The World Health Organization (WHO) Social Exclusion Knowledge Network (SEKN) uses the following definition to describe social exclusion:

“Exclusion consists of dynamic, multi-dimensional processes driven by unequal power relationships. These operate along and interact across four dimensions - cultural, economic, political and social – and at different levels including individuals, groups, households, communities, countries and global regions” (Popay, Escorel, Hernández, Johnston, Mathieson, Rispel, p. 36, 2008).”

This definition is consistent with the majority of the literature on social exclusion in that it emphasizes the multi-dimensionality of the concept of social exclusion. It is important to note here that most definitions of social exclusion avoid listing characteristics of individuals, but rather focus on the areas where exclusion takes place (e.g. economic, social, cultural and/or political arenas).
Another key point, in discussions of social exclusion, is that much of the initial attention to this concept was associated with anti-poverty measures. The SEU focused on excluded groups, including (but not limited to) teenage mothers, low income households, ex-prisoners and other groups primarily associated with poverty (Social Exclusion Unit, 2001). Indeed much of the early literature on social exclusion focuses primarily on poverty as the primary factor driving social exclusion (Sen, 2000). Increasingly however the understanding of social exclusion has been expanded to encompass forms of exclusion that go beyond poverty, acknowledging that individuals who do not live in poverty may also be excluded from participating in society, and can also be considered as living in the margins of society, due to factors other than poverty (Silver, 1994; Takacs, 2006; Moffat & Glasgow, 2009).

The assumption that social exclusion is normatively bad is supported in the extensive literature on social exclusion, much of which has come out of Europe, where governments have made concerted efforts to reduce the exclusion of certain populations (Peace, 2001). Definitions of social exclusion abound, however they have in common the underlying tenet that social exclusion leads to negative outcomes including but not limited to: poverty, poor mental and physical health, lack of education, and lack of political participation (Popay et al., 2008). Efforts to promote social inclusion, such as anti-poverty measures and targeted health initiatives, are therefore normatively good. Discussions of social exclusion become far more complicated however when we begin to question whether or not individuals (as opposed to groups) are socially excluded. Can an individual, for example, choose to be socially excluded? If they do,
does it remain the responsibility of the state to address their social exclusion? Barry (2002) suggests that social exclusion cannot occur by choice, and that individuals who select to live in ways that would otherwise be considered socially excluded (such as choosing to live in poverty) are in fact not socially excluded, but socially isolated (Dowding, Goodin & Pateman, 2004). The question remains however as to whether some individuals who are members of a socially excluded group are in fact not socially excluded. Orr (2005) suggests that this is entirely possible, she describes the example of an individual who has not worked for a long period of time. This individual ostensibly is a member of a group of individuals considered socially excluded because they are long-term unemployed, however if that individual does not work because they are wealthy, then it stands to reason that the label of socially excluded does not fit that particular individual. What Orr’s logic suggests is that while membership in a socially excluded group may very likely suggest that an individual is socially excluded, it is not sufficient. This logic is supported by most definitions of social exclusion, which emphasize the multidimensionality of the concept of social exclusion. As an example, Levitas et al. (2007) focus on the process, as opposed to the outcomes of exclusion in their description of social exclusion:

“Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.”
2.4 Identification of Social Exclusion

Much of the literature of social exclusion focusses on children and youth, who are consistently considered at high risk for social exclusion. However, as the understanding of social exclusion expands past considerations of income only, so too has the concept been increasingly applied to populations beyond children and youth, particularly to older adults. Traditionally the focus of social exclusion measurements included labour force participation and other metrics that do not apply to older people. Scharf (2001) has argued however that social exclusion is a valuable way of examining the disadvantages that older people experience in later life, especially related to “participation in civic society and access to services and amenities” (p. 83).

Concannon (2009) furthers these arguments by pointing out that while health and social services literature includes a deep understanding of the needs of older seniors, and while the needs of older people are increasingly included in discussions of social exclusion/inclusion, very little discussion includes seniors who identify as LGBT. Concannon (2009) highlights the history of older LGBT seniors in Britain, in particular the ways in which they have historically been excluded from society. He discusses the fact that the current generation of LGBT seniors were at one point considered criminals, mentally ill, and assumed to be physically ill during the AIDS crisis.
Although LGBT people are not frequently included in discussions about social exclusion, there is acknowledgement that LGBT individuals who fall into the generation labelled “the parents of the baby boomers” (born between 1919 and 1940) (Statistics Canada, 2011) lacked many of the legal rights now afforded to LGBT people. This cohort of LGBT individuals, also referred to as “pre-liberation” (Brotman, 2003), who are now seniors, were largely invisible in social and political spheres in Canada for much of their lives due to widespread discrimination (Smith, 2008).

2.5 Impact of Social Exclusion

Takacs (2006) discusses the implications of social exclusion for LGBT individuals. She argues that the lack of recognition of their identity in social and political spheres prevents full participation in society, including socio-economic and cultural injustices. Whether the source of exclusion is poverty, discrimination, or fear of differences, the consequences are similar and may include: a lack of recognition and acceptance; powerlessness; voicelessness; economic vulnerability; diminished life experiences; limited life prospects. These consequences have profound effects both at the individual level and more broadly, the social exclusion of individuals and groups is a major threat to social cohesion and economic prosperity (Silver, 1994).

There are many reasons that social exclusion is a cause for concern, it has been linked to a wide range of issues including: poverty, poor mental and physical health, lack of education, and lack
of political participation (Popay et al., 2008). While these issues are undoubtedly of grave concern for individuals experiencing social exclusion, they are also concerning for policy-makers. The UN report *Analysing and Measuring Social Inclusion in a Global Context* outlines some of the international motivations for reducing social exclusion, “Exclusion from the exercise of political and economic power fuels armed rebellion and undermines peaceful transition under democracy. In a less extreme form, social exclusion lies behind urban rioting and the disaffection of young people. In many countries, there are various powerless groups (including ethnic communities, minorities, etc.) that suffer poverty and social exclusion; there are regions that have been left behind by economic progress; and there are barriers to social mobility” (Atkinson & Marlier, 2010, p.3).

One of the major issues associated with social exclusion is the cost to public systems. While the general cost to society of social exclusion is well acknowledged (especially in discussions of social cohesion), there is little research which has attempted to quantify the costs of social exclusion. This is likely due to the multi-dimensional nature of social exclusion (recall the dimensions of social exclusion outlined by Levitas et al. (2007), used in my analysis, including lack of resources, lack of participation, and lower quality of life) and associated difficulties with measuring the direct impacts of this complex construct. Scott, Knapp, Henderson & Maughan (2001) in the UK are one of the few groups that have attempted to measure the cost of social exclusion. They focused on children with antisocial behaviours, and conducted a longitudinal study including 142 individuals, following them from age 10 to 28. They examined the costs of
public services used over and above basic (or typical) provision, including the costs of crime, special education, and foster and residential care, controlling for most variables associated with anti-social disorders. The researchers found that the high cost of supporting these socially excluded individuals fell on a wide variety of agencies, most of which did not participate in prevention efforts directed at this group.

A significant amount of attention at the international level is focused on the costs of social exclusion to health systems. A recent report by the World Health Organization (2010) concludes that poverty and social exclusion are the driving forces behind health inequities across Europe, and subsequent health system costs.

Attempts to measure the impact of social exclusion are complicated by the multiple dimensions of the concept. In attempting to measure the impact of social exclusion, researchers have considered the lack of resources, the inability to participate in relationships and activities, and the quality of life of individuals in terms of economic, social, cultural and political arenas (Levitas et al., 2007). When attempting to measure the impact of social exclusion, it is important to consider that many dimensions of the concept can be considered both risk factors and outcomes of social exclusion (for example, low income could cause social exclusion, or could be a result of social exclusion). There is currently no agreement in the literature regarding which dimensions are risk factors, outcomes or both. Similarly there is no agreement regarding the relative strength of each dimension. As Levitas (2007) asserts, it would be unwise
to attempt to assign more importance to one dimension over another, or to attempt to count
the number of dimensions in order to measure overall levels of social exclusion, because that
would suggest thresholds or binary divisions of dimensions that are not yet established.

In an attempt to capture the full range of dimensions of social exclusion, Levitas et al. (2007)
developed the Bristol Social Exclusion Matrix (B-SEM) which contains 10 dimensions important
to social exclusion. The dimensions were developed conceptually (as opposed to based on the
availability of data) after consulting multiple measures of social exclusion and related concepts
including: The drivers of social exclusion (Bradshaw, 2004); the Audit Commission’s local quality
of life indicators (Audit Commission, 2005), the Atkinson indicators (Atkinson, T., Cantillon, B.,
Marlier, E. and Nolan, B, 2002), the Opportunity for All series (DSS, 1999), Monitoring Poverty
and Social Exclusion (Howarth, C., Kenway, P., Palmer, G. and Street, C. , 1998), and the PSE
Survey (Barnes, M., Blom, A., Cox, K., Lessof, C. and Walker, A., 2006).

The dimensions are organised under three main categories:

- **Resources**
  - Material/economic resources
  - Access to public and private services
  - Social Resources
- **Participation**
  - Economic participation
  - Social participation
  - Culture, education and skills
  - Political and civic participation
- **Quality of life**
  - Health and wellbeing
An individual or group may be considered socially excluded under multiple dimensions, to varying extents. In this thesis I use these dimensions (described in more detail below) as a means to understand how the social exclusion of LGBT seniors impacts their experiences of H&CC.

B-SEM Dimensions:

Resources

Domain 1: Material/economic resources
This domain refers primarily to income levels, whether from employment, social assistance, pension or another source. These resources could also include home ownership, savings and possession of necessities. Subjective poverty (whether one considers themselves in poverty) is also included in this domain.

Domain 2: Access to public and private services
This domain recognises the importance of access to public and private services. The authors explicitly list access to home care services as an example of services considered under this domain.

Domain 3: Social resources
This domain refers to support available from friends and family on a day-to-day basis. It recognises the importance of social networks. This domain overlaps in a number of ways with
Putnam’s concept of social capital (Putnam, 1995) however the authors state that they prefer to use the term social resources as it more broadly includes both individuals and communities.

**Participation**

**Domain 4: Economic participation**

This domain refers to access to employment. It is considered separately from domain #1 (access to material resources) because some people who are not employed may still have access to material resources, and some people who are employed may not be paid well. This domain may apply to people of all ages, however the authors suggest it is important to recognise that a lack of access to employment is different from choosing not to engage in employment, and therefore the domain may not apply to some groups of people such as older persons who no longer are able to work due to age or health reasons.

**Domain 5: Social participation**

This domain refers to participation in common social activities and the extent to which these activities are carried out within meaningful relationships and roles. The authors note that participation in social activities may be limited by material resources.

**Domain 6: Culture, education and skills**

This domain refers to the various manifestations of cultural participation, including institutionalized cultural capital (education), objectified cultural capacity (art), and embodied cultural capital (tacit knowledge, behaviours, dispositions) all of which impact on one’s ability to participate in society.

**Domain 7: Political and civic participation**
This domain refers generally to opportunities to participate and feel included in decision making and to have influence over decisions. It also includes citizenship status and other reasons for exclusion from the political process.

Quality of life

All of the domains can be seen as aspects of quality of life. Consequently, many of the issues covered above are themselves incorporated into the quality of life indicators. The domains below are not captured by the domains already listed.

Domain 8: Health and well-being

Health is treated as a risk factor for social exclusion consistently across the literature on social exclusion. This domain refers to health at the individual level, including physical and mental health and disability. It also includes life satisfaction, personal development, self-esteem, vulnerability to stigma and self-harm (e.g. substance abuse).

Domain 9: Living environment

This domain refers to homelessness and housing quality. It also includes neighbourhood quality, safety and/or satisfaction. Access to open space is also an indicator under this domain.

Domain 10: Crime, harm and criminalisation

This final domain refers to both victims and perpetrators of crime. It also refers to community safety and community cohesion. Indicators include feelings of safety, and experiences of crimes or abuse.
Levitas et al. (2007) recommend that in addition to secondary analysis of existing datasets, the above dimensions be used to inform qualitative research which delves into the causes and consequences of social exclusion. Specifically they suggest that in-depth interviews be undertaken with groups at-risk of social exclusion in order to explore the experience of social exclusion and the nature and sequence of precipitating events and interventions that reduce or prevent exclusion. The authors emphasize however that the above domains serve as a heuristic device for examining available data, and that further knowledge is necessary to understand how these domains interact and which elements apply to which populations.

2.6 Application of the B-SEM

The bulk of research aiming to identify social exclusion is based on survey and census research using quantitative indicators of social exclusion. Researchers acknowledge however that these types of measures are not always possible, especially in populations that are hard to reach, such as is the case for LGBT seniors in Canada. Fish (2010) conceptualises the social exclusion of LGBT people based on previously established “schools of thought” in the literature on social exclusion. This approach uses existing literature to establish links between dimensions or categories of social exclusion and population specific research (in this case research on LGBT seniors). Fish’s approach responds to the difficulties associated with conducting research on social exclusion with populations for which there is little or no quantitative data.
Following the approach adopted by Fish (2010), I use the domains suggested by Levitas et al. (2007) (described above) to describe how LGBT seniors in Canada were historically socially excluded.

2.6.1 Resources

The first three domains included in the composite definition of social exclusion (Levitas et al., 2007) fall under the category of resources, which they refer to as “access to all resources, rights, and goods” (p.86). The authors acknowledge that resources include more than income, and recognize that social networks and family members are a resource in both practical and emotional terms. Research on the lives of older LGBT people indicates that many members of this population experienced denial of the resource of public and private services due to their sexual orientation (Brotman, Ryan, & Cormier, 2003; Fredriksen-Goldsen et al., 2011). For many, sexual orientation was a barrier to access to health (including mental health) services, LGBT individuals did not access these services due to experiences of discrimination from professionals offering these services (Dentato, Orwat, Spira, & Walker, 2014).

Social resources are an important element in preventing social exclusion, however many studies on LGBT seniors indicate that this population is less likely than heterosexual individuals to have access to social resources (Cohen & Murray, 2006). Heaphy, Yip & Thompson (2004) conducted research on the aging process for LGBT individuals, they surveyed 266 lesbian, gay and bisexual individuals, conducted focus groups with 30 gay and lesbian individuals and interviewed 20 gay and lesbian individuals, all over the age of 50. Among their multiple
findings, they found that 34% of women and 22% of men were estranged from their families of origin (a term used to describe families we are raised with, as opposed to families we choose). There are no available statistics indicating how common estrangement from families of origin among LGBT seniors in Canada was, however Brotman, Collins, Chamberland, Cormier, Julien, Meyer, Peterkin & Richard (2007) conducted interviews with 17 LGBT caregivers and found that many LGBT individuals receive supportive care from their “chosen family”. The authors also emphasize the difficulties faced by gay and lesbian seniors who have been rejected from their families.

2.6.2 Participation

Participation in economic, social, cultural, and political life is frequently a key element included in definitions of social exclusion. LGBT individuals in Canada endured a historic lack of social protections in employment which may have impacted their economic participation. The addition of sexual orientation as a prohibited ground of discrimination under the Canada Human Rights Act took place in 1996 (Nierobisz, Searl, & Theroux, 2008). Prior to this change, LGBT individuals were at risk of losing their jobs if they were “outed”, and some LGBT individuals would change jobs more frequently than their heterosexual colleagues in order to avoid being discovered as a homosexual, thus limiting their chances for job advancement (Smith, 2008). Although there is no Canadian data to demonstrate income differences over time among LGBT individuals versus heterosexual individuals, the lack of employment protection for LGBT individuals and concerns about discrimination, has led some authors to
suggest that LGBT individuals were less likely to have successful careers, and thus acquired less economic resources than their heterosexual counterparts (deVries, 2005).

Participation as a political domain of social exclusion refers to people’s ability to engage in decision making which impacts their lives, whether through involvement with local government, or through community groups in public forums (Percy-Smith, 2000). Throughout much of their lives, the current cohort of LGBT seniors had no opportunity to participate in public decision making about their own lives. To the contrary, they lived in hiding, unable to publicly advocate for their rights because prior to 1969 they were considered criminals due to their sexual orientation, and for years afterwards because they were heavily discriminated against (Warner, 2002).

2.6.3 Quality of Life
Certainly all of the domains of social exclusion can be considered related to quality of life, however Levitas et al. outline domains associated with quality of life that are not captured with the dimensions of resources and participation. These dimensions include: health and well-being; living environment; and crime, harm and criminalisation. Historical measures of the health and well-being of the current cohort of LGBT seniors (for example illness, mental health, obesity) do not exist, this population was largely invisible and health information about this group was not collected. More recent research which examines the mental health of the
current cohort of LGBT seniors suggests that LGBT seniors may have higher rates of mental health issues such as depression and anxiety (Cochrane, 2001) which may be attributed to lifetime experiences of discrimination. Indeed, it has been well documented that this cohort of LGBT individuals were pathologized and in some cases subjected to arcane treatment methods such as electro-shock therapy aimed at curing their sexual orientation (Fish, 2009). LGBT individuals, in particular gay men and transgender individuals, were also frequently targeted by police. Although homosexuality was decriminalised in Canada in 1969, police continued to target bars and other locations (such as bath houses) where gay men congregated (Smith, 2008).

2.7 Solutions to Social Exclusion

As I describe above, social exclusion is a complex concept, involving multiple dimensions and affecting multiple disadvantaged groups. The literature on social exclusion suggests that solutions (also referred to as social inclusion efforts) are dependent on actions from government aimed at reducing power imbalances across disadvantaged groups (Louis, 2007). Given the complex nature of the concept, it is perhaps unsurprising that there are differing opinions in the literature on how governmental bodies can best enact policies aimed at reducing/eliminating social exclusion and remedying the impacts of social exclusion.

Some researchers question the long-term efficacy of solutions to social exclusion which target specific groups (Popay et al., 2008). The Teenage Pregnancy Strategy implemented in the UK
to prevent the social exclusion of teenage mothers is an example of a targeted social inclusion effort. This program included targeted neighbourhood education programs (in low income neighbourhoods) and child care services for teenage mothers (Wiggins, Oakley, Sawtell, Austerberry, Clemens, & Elbourne, 2005). Rose (1992) suggests that it is problematic to view marginalized groups as separate from the rest of society, and that instead of targeted initiatives, there should be population-wide strategies for reducing social exclusion. Watt (2001) agrees with this notion, and suggests that while policies to address the problems of target groups are welcome, they essentially provide micro solutions for a macro problem, “the solution to social exclusion lies not in myriad attempts to repair society at points of breakdown, but in persuading relatively affluent groups that social inclusion is worth paying for” (Watt, 2001, p. 176). Watt cautions that targeted initiatives risk missing individuals at the threshold of exclusion, who may not meet arbitrary divisions between groups. Watt specifically refers to educational programs as a broad approach to improving social exclusion as it relates to poverty, encouraging national programs of education, as opposed to neighbourhood (or population) specific programs. Popay et al. (2008) recommend limiting targeting (a focus on one specific socially excluded group) and conditionality (membership in a specific group is a condition for participation), arguing that these types of social inclusion efforts can be stigmatising and disempowering, and risk reproducing exclusionary processes and exacerbating inequities. Popay et al. (2008) recommend that conditionality and targeting should only be incorporated into social inclusion policies and actions where there is convincing evidence that they are necessary to achieve the intended outcome.
In this thesis I focus specifically on the social exclusion of LGBT seniors, a relatively small subset of the Canadian population. The literature suggests that remedies to social exclusion, and to the impacts of social exclusion, may lie in direct efforts aimed at the LGBT population, or may be approached from a broader perspective. Here we grapple with concerns related to recognition of social exclusion, and whether it is sufficient to address social exclusion of marginalized groups broadly (in the context of this thesis this might look like diversity initiatives in H&CC aimed at multiple types of diversity such as race, language, sexual orientation).

2.8 Summary of Conceptual Framework

In this chapter I reviewed the history of social exclusion which emerged in France during the 1970’s and has since reached prominence internationally, becoming a key feature of the World Health Organization’s efforts to reduce health inequities. I also clarified the difference between social exclusion and social cohesion, two concepts which are frequently used interchangeably but have related yet separate meanings. I presented definitions of social exclusion, which focus on the multi-dimensionality of the concept, and which emphasize social exclusion as a process (as opposed to merely a fixed state). I subsequently discussed the three sections of my conceptual framework, including the identification of social exclusion among disadvantaged groups, the impact of social exclusion, and solutions to social exclusion.
Chapter 3: Background Literature

LGBT seniors are often described as an invisible or hidden segment of the population (Brotman, Ryan, & Cormier, 2003; Butler, 2004; Grigorovich, 2013). Brotman et al. (2003) attribute this invisibility to a defense mechanism used to prevent further discrimination due to sexual orientation and old age. A consequence of this invisibility is a general disregard among many researchers, policy makers, and health professionals for the needs of LGBT seniors (Cahill, 2002; Fredriksen-Goldsen, Hoy-Ellis, Goldsen, Emlet, & Hooyman, 2014). In this chapter I present literature which illuminates our understanding of the needs of LGBT seniors. I focus on their health needs, informal support patterns, and the availability and appropriateness of formal healthcare services. This background chapter establishes our understanding of the current cohort of LGBT seniors and serves to demonstrate the limitations in our current knowledge of this population.

3.1 Health and Mental Health of LGBT Seniors

There is a growing interest in better understanding the H&CC needs of LGBT seniors. Although there are no inherent health differences between LGBT individuals and heterosexual individuals, researchers have consistently identified disparities on a number of different indicators related to the both the physical and mental health of LGBT individuals. These differences are frequently attributed to limited use of needed health care, unhealthy or risky behaviours, experiences of stress, and other factors which are all considered reactions to experiences of discrimination (Banks, 2003; Brotman et al., 2003; Cochran, 2001).
A prevailing theme in research on the health of LGBT seniors is the negative impact of a lifetime of discrimination. Researchers have documented that LGBT seniors, many of whom lived their youth and adult lives in environments that were hostile to LGBT individuals, experienced stress related to coping with homophobic and heterosexist discrimination in numerous areas including family and social settings, the workplace, education, the legal system, and in healthcare. These stressors can lead to an increased risk of unhealthy aging among LGBT seniors (Brotman, S. & Ryan, 2008; Cahill, South, & Spade, 2000). Researchers interested in the long-term impact of discrimination due to sexual orientation on mental health have found higher rates of poor mental health among homosexual individuals compared to heterosexual individuals. In their review of the literature on depression rates among homosexuals, Corboz et al. (2008) found that gay men have significantly higher rates of depression than heterosexual men. Results from Cochran et al. (2003) indicated that gay and bisexual men had higher rates of panic attacks and psychological distress than heterosexual men, while lesbian and bisexual women showed greater prevalence of generalised anxiety disorder than heterosexual women.

The results are even more alarming when considering the mental health of individuals who are transgender. Researchers from the Trans Pulse project, a research initiative started in 2009 to study the social exclusion of transgender individuals, found that among the 433 Ontarian transgender survey respondents, 36% had experienced suicidal thoughts and 10% had attempted suicide in the previous year (Scheim & Bauer, 2014).
In their review of the literature on the health, social care and housing needs of LGBT older people, Addis, Davies, Green, MacBríde-Steward & Shepherd (2009) concluded that the predominant theme arising from the literature relates to discrimination experienced by LGBT older people and the effect of this discrimination on patterns of accessing services. Brotman et al. (2003) suggest that LGBT seniors’ reluctance to use health care services is linked to the fact that gay and lesbian seniors are often still very suspicious of lingering discrimination, prejudice, or abuse from “networks and social institutions that have traditionally been known to be intolerant of them” (Brotman, Ryan, & Cormier, 2003, p. 197). Although the research is now somewhat dated, Brotman and Ryan (2003) were the first to draw attention to the health care needs of Canadian LGBT seniors, in particular the risk that LGBT seniors avoid and delay accessing needed health care services.

As demonstrated above, despite challenges with research on this population, studies have consistently identified the negative impacts of discrimination on the health of LGBT individuals. Furthermore, they have demonstrated that discrimination impacts on LGBT individuals’ decision to access health care. In this thesis I focus specifically on LGBT seniors and their access and use of H&CC. Research on the H&CC needs of LGBT seniors in Toronto, Ontario is extremely scarce and there are significant gaps in our understanding of the experiences of this group in H&CC settings. In the next sections I emphasize the importance of focussing on how we design care in the H&CC context given the increase in attention at the policy level.
**3.2 Informal Care for LGBT Seniors**

An important point to consider when discussing the health care of LGBT seniors is the higher likelihood that LGBT seniors will live alone or live with non-traditional support networks. Research emphasises differences in social support patterns for LGBT seniors due to family structure differences. Literature on LGBT families uses the term “family of choice” (Neville & Henrickson, 2008) to refer to the diverse family structures found in the LGBT community. The current cohort of LGBT seniors are less likely to have support from their “family of origin” because they are less likely to have children and tend to have closer relationships with partners, friends and neighbours (Cantor, Brennan, & Shippy, 2004; Cronin, Ward, Pugh, King, & Price, 2011). Survey research conducted in the US indicates that LGBT seniors report inadequate social support at double the rate of their heterosexual peers (Cantor et al., 2004).

In cases where caregivers are present, research examining the experiences of gay and lesbian caregivers (often caring for LGBT family members) indicates that they frequently fear discrimination from health care providers because of their sexual orientation, and are thus less likely than heterosexual caregivers to access needed caregivers supports such as counselling and respite services (Hash, 2001,2006; Hash & Cramer, 2003).

**3.3 Formal Healthcare for LGBT Seniors**

The current cohort of LGBT seniors is more likely than heterosexual seniors to avoid accessing health care services. In their cross-Canada research focussed on gay and lesbian seniors
Brotman, Ryan and Cormier (2003) conducted a series of focus groups with self-identified LGBT community activists working within the community (senior’s groups, health care providers, policy makers in the public health system). The results of their research indicated that LGBT seniors may avoid accessing health care services and “arrive at the doors of the health care system and long-term care network in a more advanced state of risk than their heterosexual counterparts” (Brotman et al., 2003, p. 199). Research in the UK by Heaphy, Yip and Thompson (2003) suggests that avoidance of the health system relates to the fact that gay and lesbian seniors doubt the system’s ability to meet their particular needs.

Research which examines use of health care services by LGBT individuals has consistently noted that LGBT patients fear disclosing their sexual orientation to their health care provider (Beehler, 2001; Eliason & Schope, 2001; Stein & Bonuk, 2001; Kimmel, 2014). Studies internationally indicate that LGBT seniors have a preference for health care services which are targeted towards LGBT seniors. Survey research by River (2006) in the UK found that lesbian seniors generally avoid senior services because they are unsure whether they would be accepted. Grigorovich (2013) highlights the current gays in both research and policy with respect to the long-term care needs of older lesbian and bisexual women, noting that current policies can disadvantage lesbian and bisexual women. Not surprisingly, researchers consistently report that fears about long-term care are a chief concern among LGBT seniors (Almack, Seymour, & Bellamy, 2010). Johnson, Jackson, Arnette, & Koffman (2005) administered questionnaires about perceptions of retirement facilities to 131 gay, lesbian, bisexual and transgender adults in
Washington, US. The findings of their research indicated that 73% of respondents believed discrimination exists in retirement settings, and 60% believed they do not have equal access to social and health services. A subsequent study conducted by Jackson, Johnson & Roberts (2008) found that LGBT individuals fear and suspect discrimination in retirement facilities more than heterosexual individuals.

3.4 Background Literature Summary

In this chapter I reviewed the health, informal support and formal healthcare of LGBT seniors. The literature on the health of LGBT seniors indicates that many of the health disparities between heterosexual seniors and LGBT seniors may stem from historical experiences of discrimination. These negative experiences impact on both the physical and mental health of LGBT individuals over time. I also reviewed issues surrounding informal care options for LGBT seniors. This population is more likely than heterosexual seniors to live alone, in part due to differences in family and relationship structures. In the final section of this chapter I reviewed research which focuses on the provision of health care to LGBT seniors, in particular Canadian research by Brotman et al. which indicates that LGBT seniors may avoid accessing care due to previous experiences of discrimination in health care settings.
Chapter 4: Methods & Methodology

In this chapter I introduce the methodology and methods employed in this study, discuss procedural details and provide justification for my choices and the overall approach. This chapter is divided into the following sections: 4.1. methodology; 4.2, study context; 3.3, reflexivity and positionality; 4.4, ethical considerations and approval; 4.5, study design; 4.6, criteria for study participants; 4.7, analysis; 4.8, rigour and trustworthiness; and 4.9, summary.

4.1 Methodology: Case Study

A case study design was utilised in this study. Case studies involve the systematic gathering of information about a particular person, social setting, event or group in order to permit the researcher to effectively understand how the subject operates or functions (Berg, 2007). In this study the primary focus was a group, LGBT seniors, and I sought to understand their experiences with H&CC. Case studies are particularly useful in situations where the researcher seeks a deep understanding of causal processes but where it is not possible to assign subjects to different groups or manipulate independent variables (Johnson & Joslyn, 2005). A case study’s questions are generally focussed on ‘how’ and ‘why’ considerations (Berg, 2007), and they are ideal when investigating complex processes in contemporary contexts (Yin, 2008).

The case study design was particularly useful in this study for a number of reasons. First, the participants in this study were a very specific and difficult to access group which could not be manipulated by the researcher. Second, my research question asks how the experiences of
social exclusion have influenced LGBT seniors. In order to explore this question an in-depth understanding of the experiences of LGBT seniors was required which included discussions with both LGBT seniors and H&CC care providers as well as an exploration of the historical and political background of this cohort of LGBT seniors.

4.2 Study Context

One of the inherent difficulties in engaging in this study was the difficulty in accessing LGBT seniors with experiences receiving H&CC. This population is more likely to be home-bound (by nature of having required home care at some point) and therefore less likely to participate in community activities, essentially making this group of seniors difficult to find (Miller, McKeever & Coyte, 2003). In addition, seniors who identify as LGBT are less likely to be “out” and willing to discuss their sexual identity than younger generations of LGBT individuals (Jacobs, Rasmussen & Hohman, 1999). Anticipating these challenges, I decided to locate this study in the City of Toronto. Toronto has a high proportion of LGBT individuals who live in the city, although population statistics do not exist for LGBT seniors, as of 2006, 55% of all same sex couples in Ontario lived in the City of Toronto (Statistics Canada, 2011). For this reason Toronto was considered ideal due to the higher likelihood of recruiting LGBT seniors willing to participate in the research.

A second consideration was the likelihood of finding H&CC providers with experience and knowledge of the population of LGBT seniors. Care providers in the long-term care and H&CC
sector are typically unaware of the realities and needs of seniors in relation to sexuality and sexual orientation (Daley & MacDonnell, 2015). In Toronto, the Senior Pride Network consists of H&CC providers who share information and provide education about LGBT seniors, this network provided an ideal source of H&CC organisations more likely to have an in-depth understanding of the care experiences of LGBT seniors.

### 4.3 Reflexivity and Positionality

Positionality requires that a researcher acknowledges their values, views, and beliefs in relation to the research they are undertaking. Self-reflection is therefore an important aspect of positionality. A reflexive approach to research requires that a researcher both acknowledges and discloses their own selves, and their influence on the research they are engaged in (Berger, 2015). In this section, I briefly reflect on my positionality and reflexivity in relation to the subject of H&CC, and the subjects of this research, LGBT seniors.

First, I have a background working in the H&CC sector, having worked part-time as a personal support worker at a supportive housing program during my undergraduate years. I therefore have knowledge of the H&CC sector not just as a researcher, but as a provider. This background knowledge of H&CC meant that I had personal experiences with some of the examples and stories discussed by the H&CC providers during their interviews, such as
experiences with training programs and an understanding of the limited budget and over-worked employees in the H&CC sector.

Second, my interest in exploring the experiences of LGBT seniors in H&CC was motivated by my sexual orientation. I identify as a lesbian and have a personal interest in the history of LGBT rights. I also have an undergraduate degree in Gerontology, and was thus motivated to conduct research on LGBT seniors. My approach to this research was thus influenced by my values, including the belief that LGBT individuals should have equal rights under the law, and equal opportunities for health care. In addition, my rapport with the LGBT seniors who participated in this research was aided by our shared sexual orientation, and my ability to empathize with their experiences of heteronormativity.

4.4 Ethical Considerations and Approval

4.4.1 Ethical Considerations

In designing this study I anticipated one potential ethical challenge related to the research participants: vulnerability. Vulnerability of the participants was a consideration given that the population under study is senior, likely to have required home care services at some point (and therefore potentially home-bound) and may or may not be comfortable “outing” themselves as an LGBT person. To address these concerns I included a number of considerations in the design of the research. First, I did not seek out any specific individuals to participate in the study (despite personal knowledge of some seniors who met the study criteria) in order to ensure
that no individuals felt pressured to participate. All recruitment was conducted through information sharing (verbally to groups of seniors, electronically, and via posters) and participants were asked to contact the researcher directly if they were interested in participating. Second, I conducted the interviews at a location chosen by the participant and provided a number of options (private space at the University of Toronto, public spaces such as coffee shops, or in their own home), understanding that some participants would be burdened by having to leave their homes to participate while others may feel more comfortable in a public space.

4.4.2 Ethics Approval

Prior to recruitment, ethics approval was received from the University of Toronto Ethics Review Board on February 22, 2010. A copy of the approval letter can be found in Appendix A. Informed consent to participate in the study and permission to audiotape the participants in the semi-structured interview was sought and provided prior each interview. All individuals were assured of complete anonymity.

A separate ethics approval was obtained from one of the community care organizations in order to get permission to recruit participants from a bi-weekly LGBT community group. This social-recreational group included seniors who receive services in Toronto and who identify as LGBT, making them an ideal group to recruit from for the study.
4.5 Study Design

A qualitative approach was adopted for this study. Creswell (2005) outlines a series of questions or reasons which assist researchers in determining whether they have a strong rationale for engaging in qualitative research. These reasons include the type of research question under study; qualitative questions typically seek to answer how or what, in order that topics can be explored in detail (as opposed to why questions which require comparisons groups and relationships between variables). In addition, Creswell (2005) suggests that a qualitative approach be undertaken when researchers are aiming to provide a detailed view of a topic which includes participants in their natural settings. In accordance with Creswell’s rationale, qualitative methods were useful in engaging in this study because I sought to understand how the social exclusion of LGBT seniors may impact on their access and use of H&CC services; I aimed to explore the experiences of LGBT seniors at a deep level of understanding and in great detail. Other methods such as surveys would not have provided sufficient detail or depth to answer my research questions. Additionally, qualitative methods were chosen for practical reasons; LGBT seniors are not identified on most common health assessments in Ontario and therefore secondary data sources about LGBT seniors were not available.

4.5.1 Data Collection

The primary sources of data used in this thesis were literature, interview recordings, interview transcripts, and field notes. I searched multiple online databases including MEDLINE, PsychInfo,
PubMed, Scholars Portal, Google Scholar, and Google. I also consulted literature reviews provided to me by other scholars in the field of LGBT health and health policy. My searches included various combinations of the following key words and their variants: “lesbian”, “gay”, “bisexual”, “transgender”, “queer”, “senior”, “aged”, “elderly”, “older persons”, “health”, “home and community care”, “long-term care”, “caregiver”, “social exclusion”, “social cohesion”, “discrimination”.

4.5.2 Interview Procedures

The interviews took place between January of 2010 and May of 2012. I used two separate interview guides for this study; one for the group of LGBT senior participants and one for the group of H&CC providers (additional details about the participants are found in section 5.1). Both interview guides used a semi-structured format. This type of interview includes a number of predetermined questions and topics, but provides the freedom for the interviewer to digress from the planned questions and probe beyond the answers provided (Berg, 2007).

Prior to engaging in interviews with the study participants, both interview guides were critically examined by two experts familiar with the study’s subject matter (LGBT seniors and H&CC services). These individuals represented local community organisations which work extensively with LGBT seniors. This process included identifying poorly worded questions (in particular questions which may be confusing for a senior participant), and questions that were considered “loaded” (suggesting a bias).
4.6 Criteria for Study Participants

4.6.1 LGBT Seniors

Anticipating the difficulties in recruiting participants for this study, in particular LGBT seniors, I conducted a series of consultations with prominent figures in the Toronto LGBT community representing health care organizations and LGBT advocacy groups in order to gain advice around recruitment approaches. Representatives from the following organizations gave advice and assistance with recruitment: Rainbow Health Ontario, Sherbourne Health Centre, 519 Church Street Community Centre, Toronto Senior Pride Network, City of Toronto Long-Term Care Homes and Services, the Aids Committee of Toronto, Toronto Bisexual Network, and Mt. Sinai Hospital. The advice provided included identifying organizations and community settings where I was likely to access LGBT seniors who would be interested in participating as well as suggestions for H&CC organizations that were likely to have staff experienced at providing care to LGBT seniors.

The sampling strategy employed was purposive (non-probability) sampling, this type of sampling allows for the selection of information-rich cases and in-depth study (Kempar, Stringfield, & Teddie, 2003). I chose to use a purposive sampling strategy because my goal was not to increase the quantity and/or generalizability of my data, but instead to increase the quality of the data I was collecting (Kemper, Stingfield & Tedley, 2003). Participant recruitment was conducted using posters advertising the study at health care organisations and community
centres across Toronto. Electronic recruitment was conducted using key LGBT networks including: the Rainbow Health Network listserv, the Toronto Senior Pride Network listserv, the Toronto Bisexual Network listserv, the Canadian Association for Retired Persons newsletter, and via personal contacts from staff at Sherbourne Health Centre, the 519 Church Street Community Centre and members of community groups. In addition two presentations about the research study were conducted at key centres where LGBT seniors are active participants: the 519 Older Persons Drop-In and the Metropolitan Community Church (MCC) Toronto. These locations were chosen based on the expert advice from representatives of local LGBT community organizations.

When selecting LGBT senior participants for this study I was reliant on LGBT seniors contacting me directly by email or phone. I listed the eligibility criteria on advertisements in print and email in order to inform potential participants about the type of individuals I was hoping to interview. When participants contacted me about participating in the study I verbally confirmed that they met the eligibility criteria prior to moving forward with arranging an interview. The following criteria were listed on the study advertisements:

- Over age 65
- Identify as lesbian, gay, bisexual or transgender
- Have ever received home and community care OR have acted as an informal caregiver to someone receiving home and community care
Although adults of all ages may require H&CC, I chose to interview individuals over the age of 65 because I wanted to ensure that all participants in the study were a part of the cohort of seniors who lived through extensive social change in regards to legal rights and social acceptance of homosexuality in Canada. While including all seniors over the age of 65 results in a wide age range for the study, I chose to keep a wide age range in order to increase the pool of potential participants, keeping in mind the anticipated difficulties in recruitment.

The second criteria was that the participants identify as either lesbian, gay, bisexual or transgender. The use of this terminology is consistent with Rainbow Health Ontario (RHO, 2013). Participants were not asked to provide any further details about their sexual orientation in order to meet the eligibility criteria for the study other than to confirm that they self-identify as LGBT (although further details, such as relationship status, were provided in the interview process).

The final criterion for the LGBT senior participants was stating that they had received H&CC either directly, or acting as a caregiver to someone (friend or family) receiving H&CC. This criterion was established in order to ensure that all participants had actual experiences with H&CC. Previous research on LGBT seniors and H&CC in Canada has explored the perceptions of LGBT seniors related to H&CC, but interview participants were LGBT advocates and did not necessarily have actual experiences of H&CC (Brotman, 2003).
Participants were given the option of conducting the interview either at their own home, at an office at the University of Toronto, or in a coffee-shop. Two participants elected to conduct the interview in a coffee-shop. In both cases the interview was conducted in the middle of the day, when the coffee-shop was not overly busy. We sat at a table that was not near any other people so as to ensure we had privacy for our discussion and so that the tape recording would be clear. The participants were aware of the topics we were discussing in advance of the interview, and were comfortable discussing the topics in a semi-public place, in fact the participants elected to conduct the interview in a coffee-shop instead of a private office out of their own personal preference. For these reasons I was not concerned about the location of the interview impacting on the quality of the discussion or the comfort level of the participants.

4.6.2 H&CC Providers

When selecting criteria for the H&CC provider participants the overarching goal was to ensure that participants were well informed about the needs of LGBT seniors and their care experiences. Previous research suggests that health care providers for seniors are not aware of the needs of LGBT seniors. Research conducted in long-term care settings suggests that care providers are often unaware of sexuality and are not prepared to address the needs and desires of LGBT seniors (River et al., 2006). With this in mind I attempted to assess the knowledge and comfort level of potential participants prior to engaging in an interview. I advertised about the research in print and email using the following criteria:

- Represent a home and community care organisation
- Position at minimum of care manager or equivalent
• Experience providing front line home and community care
• Knowledge about home and community care for LGBT seniors

Participants from the H&CC provider group either contacted me directly after viewing the research advertisements, or responded to my request for an interview. I contacted individuals at H&CC organisations based on the recommendations of experts in the field. In order to ensure that participants met the criteria set out above, I verbally questioned them prior to arranging for an interview.

Participants were considered to represent a H&CC organization if they were employed at an organization which provided any of the following services to seniors: home care services (e.g. home-making, personal support), professional in-home health care services (e.g. nursing, occupational therapy), or community services (e.g. day program, recreational program). It was crucial to engage with representatives from H&CC organizations as opposed to representatives from other health settings such as long-term care in order to ensure that the participants understood the experiences of LGBT seniors receiving care in their own home and community (as opposed to other health care settings).

I stipulated that participants should be employed at the level of case manager or above in order to ensure that participants could comment broadly on the status of the H&CC sector. While the insights of front-line providers such as personal support workers would also be valuable, I aimed to solicit the opinions of H&CC providers who had an understanding of the system level
barriers to implementing care for LGBT populations and therefore decided to interview participants with a more senior position at their organization.

While it was important that participants have an over-arching understanding of the H&CC sector, I did not choose to interview organizational heads such as executive directors. I sought to discuss the experiences of LGBT seniors in their homes, and for this reason it was important that the participants had some recent experience with actual seniors “on the front lines”. I therefore stipulated that participants have some level of experience providing H&CC.

The final criterion was that participants have some knowledge of H&CC for LGBT populations. This criterion was purposefully vague, understanding the varied experiences of H&CC providers. I did not administer a check list or knowledge test, but rather asked potential participants about whether they have any direct experience providing H&CC to LGBT seniors, or whether they felt comfortable discussing the needs and experiences of LGBT seniors. I did not ask the H&CC participants to disclose their sexual orientation. I chose not to ask participants their sexual orientation because I was interested in their experiences and understanding of LGBT seniors, based on their professional interactions. I acknowledge that the H&CC providers who identified as LGBT may have had more insight or understanding of LGBT seniors, however my research goal was not to compare how LGBT versus non-LGBT providers perceive H&CC for LGBT seniors.
Interviews were conducted in person (n=23) and over the phone (n=1). The interview which was conducted over the phone was conducted with an individual (an LGBT senior) who had recently moved outside of Toronto. The interview location was determined by the participant. In-person interviews with LGBT senior participants took place at the University of Toronto (3), at public settings (2) and at individuals’ homes (6). All interviews with H&CC provider participants took place at the H&CC provider organisations with the exception of one interview which took place in a coffee shop adjacent to the H&CC office. All interviews were audio-recorded.

Each group (LGBT seniors and H&CC providers) was questioned using a separate interview guide (see Appendix B). Interview questions for Group 1 focused on their personal experiences with healthcare services generally and home and community care specifically, their perceptions of what constitutes culturally appropriate H&CC as well as their perceptions of the experiences of other LGBT seniors in their cohort. Group 1 was also asked a series of questions about how their H&CC experiences relate to the 5 dimensions of social cohesion as described in the Chapter 2 (Beauvais & Jenson, 2002).

Interview questions for Group 2 examined the personal experiences of the H&CC providers with clients who identified as LGBT as well as their understanding of the strategies for providing culturally appropriate H&CC for LGBT seniors and what it means to provide culturally appropriate H&CC. They were also asked about their perceptions of how sexual orientation
impacts on access and use of H&CC services, specifically whether (and how) they believe LGBT seniors avoid accessing H&CC, whether there are differences in the provider-consumer relationship when the consumer is LGBT, and whether there are any differences in the type of care and services that LGBT seniors may require.

Field notes were written during and following each interview. Field notes consisted of jotted notes and observations taken during the course of the interview. These notes highlighted key observations or insights that were elaborated on following the interview. Where possible, following each interview I filled in observations and comments in order to increase the clarity and thoroughness of the notes.

4.7 Analysis

The analysis of the interview transcripts and field notes was conducted using the content analysis approach as outlined by Berg (2007). The research used both an inductive and deductive content analysis approach. Initial analysis was structured with a particular concept in mind, namely the concept of social exclusion (Levitas, 2007), with the aim to better understand how social exclusion impacts on the H&CC experiences of LGBT seniors (Hsieh & Shannon, 2005; Elo & Kyngäs, 2007). While this concept were used as a guide for coding and analysis this does not mean that all categories were anticipated prior to analysis. The benefit of this approach was the ability to revise the concepts as data emerged that were not easily classified creating concepts that are well defined (Downe-Wamboldt, 1992).
The data collection and analysis were concurrent. The content analysis consisted of coding using the constant comparative method (Creswell, 2005). The analysis was dependent on making comparisons both within data sources and between data sources and asking questions of the data in order to search for both similarities and differences. Initially conceptual themes, ideas or assumptions located in the data were identified. NVivo software was used to assist in the coding process. The process included the following steps:

- **Step 1:** In the first stage of the analysis I used my (hand written) field notes to reflect on the content of the interviews and to generate initial themes.

- **Step 2:** I personally transcribed each interview verbatim, I chose to transcribe the interviews myself because I wanted to become more familiar with the content of the interviews. During this process I added to my field notes and continued the process of generating initial themes.

- **Step 3:** The coding process consisted of close reading of each interview transcript as well as re-listening to the interviews. The selection of categories during the open coding process was guided by the conceptual framework and the research questions related to the experiences of H&CC for LGBT seniors, their conceptualization of culturally appropriate H&CC, and how sexual orientation impacts on access and use of H&CC.

- **Step 4:** Once the first phase of coding was completed I reviewed the codes to look for patterns and differences. Using an inter-relational process I examined how (or if) the themes related to each other. This process was conducted within groups (LGBT seniors
and H&CC providers) and between groups to look for similarities and differences among LGBT seniors, among H&CC providers, and between these two groups overall. These themes were subsequently refined.

4.8 Rigour and Trustworthiness

Traditionally, assessment of the rigour and trustworthiness of research findings is established by exploring the reliability and validity of the research methods (Seale & Silverman, 1997). Reliability refers to “the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure” (Polit & Hunger, 1997, p. 651 in Long & Johnson, 1997). Validity, is defined as “the determination of whether a measurement instrument actually measures what it is purported to measure” (LoBiondo-Wood & Haber 1998, p. 561, in Long & Johnson, 1997).

Reliability is a difficult concept to demonstrate in qualitative research. In fact, Long & Johnson (2000) go so far as to state “although efforts may be made to enhance a study’s reliability, in most cases the nature of the data and the sample make this practically hopeless” (p. 31). My efforts to ensure reliability in my research included the consistent use of a semi-structured interview guide. As described in section 4.5.2, I used two separate guides, one for the LGBT seniors and one for the H&CC providers. Within each group I used the exact same guide for each interview, and I asked every question on the guide of each participant. In addition, I
ended each interview by asking the participant if there was anything additional they would like to add, or if there were any questions they expected but were not asked. The use of a semi-structured guide allowed for probing questions when responses were unclear, or if the participant did not at first understand the question, thus ensuring that each question or topic was fully addressed.

Long and Johnson (2000) describe a number of different measures of validity which may be applied to qualitative research depending on the methods being used. Two measures which they propose can be applied to this research, the establishment of content validity through professional consultation, and peer debriefing. First, as described in section 4.5.2, I consulted with experts in the field regarding my interview guide, to establish the content of the questions and make revisions where necessary. I also engaged in peer debriefing, first by reviewing my findings with my thesis supervisor, and second my presenting emerging findings at three national research conferences: The Canadian Association for Health and Policy Research, The Canadian Gerontology Association, and Rainbow Health Ontario’s National Annual Conference. These opportunities allowed me to discuss the emerging findings with knowledgeable colleagues, allowing for the exploration of new perspectives at various stages in the data collection and analysis process.
4.9 Summary

In summary, this research used a case study design and qualitative methods. The key data sources were interview transcripts and field notes from interviews conducted with 12 LGBT seniors and 12 H&CC providers using two separate semi-structured interview guides.

Interviews were audio-recorded and transcribed. Analysis of the interview transcripts and field notes was conducted using a content analysis approach with the assistance of NVivo Software.
Chapter 5: Findings and Discussion on the Impact of Historical Experiences of Social Exclusion among LGBT Seniors

In this chapter I present and discuss findings which respond to my first research question, “How do previous experiences of social exclusion impact on LGBT seniors’ access and use of home and community care services?” I begin this chapter by listing the characteristics of the LGBT seniors and H&CC providers who participated in qualitative interviews. My analysis of the interview transcripts and field notes resulted in two key themes in response to this question. First, some LGBT seniors may avoid accessing H&CC due to previous negative experiences in the health care system. Second, in response to negative experiences in the health care system, some LGBT seniors self-advocate for H&CC services which are free from discrimination. I present a series of different examples of self-advocacy and draw linkages between these examples and previous literature on resiliency among LGBT seniors.

5.1 Study Participants

Interviews were conducted with 12 seniors who were over age 65, identified as LGBT and who had personal experiences with H&CC services either for their own care or when they were acting as a caregiver. The following chart describes the LGBT senior participants:
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Identity</th>
<th>Consumer/Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew</td>
<td>74</td>
<td>Male</td>
<td>Gay</td>
<td>Caregiver</td>
</tr>
<tr>
<td>Brian</td>
<td>71</td>
<td>Male</td>
<td>Gay</td>
<td>Consumer &amp; Caregiver</td>
</tr>
<tr>
<td>Corry</td>
<td>79</td>
<td>Male</td>
<td>Bisexual</td>
<td>Consumer &amp; Caregiver</td>
</tr>
<tr>
<td>Daniel</td>
<td>73</td>
<td>Male</td>
<td>Gay</td>
<td>Consumer &amp; Caregiver</td>
</tr>
<tr>
<td>Ellen</td>
<td>66</td>
<td>Female</td>
<td>Lesbian</td>
<td>Caregiver</td>
</tr>
<tr>
<td>Frank</td>
<td>70</td>
<td>Male</td>
<td>Bisexual</td>
<td>Consumer</td>
</tr>
<tr>
<td>Gemma</td>
<td>88</td>
<td>Female</td>
<td>Lesbian</td>
<td>Caregiver</td>
</tr>
<tr>
<td>Henry</td>
<td>81</td>
<td>Male</td>
<td>Gay</td>
<td>Consumer</td>
</tr>
<tr>
<td>Isaac</td>
<td>74</td>
<td>Male</td>
<td>Gay</td>
<td>Consumer</td>
</tr>
<tr>
<td>Jessica</td>
<td>79</td>
<td>Female</td>
<td>Lesbian</td>
<td>Consumer</td>
</tr>
<tr>
<td>Kelly</td>
<td>67</td>
<td>Female</td>
<td>Trans Woman</td>
<td>Caregiver</td>
</tr>
<tr>
<td>Larry</td>
<td>81</td>
<td>Male</td>
<td>Gay</td>
<td>Caregiver</td>
</tr>
</tbody>
</table>

LGBT Senior participants consisted of 8 men and 4 women, 6 of the men identified as gay, 3 women identified as lesbians and 1 women identified as a trans woman. The average age of the participants was 75. Three of the participants had experiences with H&CC as both a caregiver and a consumer, 5 of the participants had acted only as a caregiver, and 4 had received H&CC only as a consumer.
Interviews were also conducted with 12 representatives from 11 H&CC organisations in Toronto, Ontario. The following chart describes the H&CC Provider participants:

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Job Description</th>
<th>Type of H&amp;CC Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angela</td>
<td>Female</td>
<td>Case Manager/Supervisor</td>
<td>Personal Care and In-Home Professional Services</td>
</tr>
<tr>
<td>Betty</td>
<td>Female</td>
<td>Outreach Supervisor</td>
<td>Personal Care and Outreach Services</td>
</tr>
<tr>
<td>Callie</td>
<td>Female</td>
<td>Recreation Coordinator</td>
<td>Day Program</td>
</tr>
<tr>
<td>David</td>
<td>Male</td>
<td>Case Manager</td>
<td>Day Program</td>
</tr>
<tr>
<td>Evelyn</td>
<td>Female</td>
<td>Supervisor</td>
<td>Meal Delivery and Outreach</td>
</tr>
<tr>
<td>Felix</td>
<td>Male</td>
<td>Case Manager</td>
<td>Personal Care and Day Program</td>
</tr>
<tr>
<td>Ginny</td>
<td>Female</td>
<td>Director</td>
<td>Day Program and Meal Delivery</td>
</tr>
<tr>
<td>Helen</td>
<td>Female</td>
<td>Case Manager</td>
<td>Personal Care and Transportation</td>
</tr>
<tr>
<td>Isobel</td>
<td>Female</td>
<td>Case Manager</td>
<td>Recreation and Outreach</td>
</tr>
<tr>
<td>Jennifer</td>
<td>Female</td>
<td>Case Manager</td>
<td>Supportive Housing</td>
</tr>
<tr>
<td>Kevin</td>
<td>Male</td>
<td>Case Manager</td>
<td>Counselling and Outreach</td>
</tr>
<tr>
<td>Leslie</td>
<td>Female</td>
<td>Program Director</td>
<td>Day Program</td>
</tr>
</tbody>
</table>

The majority of the H&CC Provider participants were female, with the exception of three male participants. The H&CC agencies served individuals across the city of Toronto, including North Toronto, Etobicoke, and Scarborough. All participants had experience providing direct care to seniors, and all stated they were comfortable discussing the needs of LGBT individuals.
5.2 Personal Historical Experiences of Social Exclusion among LGBT Seniors

In the interviews with LGBT seniors, I asked the participants about their experiences in the health care system over time. I wanted to learn about whether they had experienced any forms of discrimination because of their sexual orientation prior to the time when they needed to seek out H&CC services. Many of the LGBT senior participants did articulate that they had memories of negative experiences with accessing health care at some point in their life which they attributed to their sexual orientation. The severity of these experiences varied among participants. Examples included: refusals by health professionals to provide services, refusals by health professionals to acknowledge same-sex relationships or families of choice, discriminatory attitudes of health professionals, and discriminatory policies of health institutions.

Among the participants, it was the three seniors who are HIV positive, all of whom contracted HIV during the 1980’s, who shared some of the most extreme examples of negative experiences in healthcare settings. Most of these experiences occurred during the early stages of their disease when many health care professionals lacked an understanding of the transmission of HIV/AIDS and discrimination against individuals with HIV/AIDS was commonplace. The
following three quotes from individuals with HIV/AIDS illustrate past negative experiences directly related to refusals to treat individuals with HIV with respect:

“A lot of doctors and nurses wouldn’t touch me unless they put not one but two sets of gloves on, and I just felt like I had leprosy and I was treated very poorly and um it was very frustrating”. (Henry, Senior Participant)

“And a very shocking experience at [name removed] hospital, I was rushed by ambulance there and I was in the emergency room, it was completely full and standing room only... and in a very very loud voice the doctor approached my bed and he said ‘you’re HIV’ he says, ‘what the hell are you doing in this hospital? You belong at the Wellesley’, loud loud voice and 3 or 4 doctors around them and the shock in their faces”. (Brian, Senior Participant)

“Over the years I’ve had many many bad experiences dealing with HIV especially in the early 80’s. I’ve had 2 doctors telling me that they couldn’t see me anymore because their wives didn’t want them dealing with people with HIV” (Isaac, Senior Participant)

Seniors who are HIV+ and their partners constitute a significant portion of LGBT seniors who require H&CC, whether that care occurred when they were initially diagnosed, whether they require care now due to complications related to their HIV status, or whether they acted as caregivers to family and friends who suffered from HIV or AIDS and required in-home help.

Among this group, AIDS Service Organizations (ASOs) commonly assist in referrals for H&CC and offer community-based support groups. The seniors who had accessed services through ASOs tended to have positive experiences with the services and staff at these organizations, however in-home care provision, even when referred through ASOs was still a concern for this group. This finding is consistent with research conducted by Fritsch (2005) who interviewed 34 HIV+ individuals in a study examining the experiences of HIV+ individuals when accessing medical
and social services. Fritsch found that among the individuals over age 50, experiences with social services were largely positive. These findings were attributed to knowledge among these individuals about their disease, available services, and the support found within the gay community.

While the seniors I interviewed stated that they didn’t really consider not accessing care, simply because they were too sick to avoid it, they expressed that they experienced stress, nervous feelings, and in some cases fear about the idea of having workers who were aware of their sexual orientation and disease status entering their home to provide care. The seniors expressed that these feelings stemmed from their negative experiences in health care settings and with health care professionals, but also from a lifetime of discrimination in everyday social situations.

The AIDS crisis during the 1980’s and early 1990’s, prior to the development of successful medications, devastated a generation of gay men, many of whom are now members of our aging population. Data about LGBT seniors who are HIV+ is scarce, however we do know that the largest proportion of people over age 50 who are HIV+ are men who have sex with men (MSM) (61.3%) (Public Health Agency of Canada 2010) and that the number of people over age 50 who are HIV+ has been increasing over the past decade (Canadian AIDS Society, 2011). Very little research exists which documents the experiences of LGBT seniors who have lived with HIV for years, and whether H&CC agencies are equipped to provide services to this group (Public
One area that has been researched fairly extensively is the capacity of LGBT caregivers to support people with HIV/AIDS (most often partners and friends). Among those men (while women were also impacted, the overwhelming majority of individuals infected with AIDS during the early years of the disease were gay men) who were impacted by the AIDS crisis and are still alive today, many have experiences with caregiving either because they were receiving or providing care (Grant, Vance, Keltner, White, & Raper 2013). Fredrikson et al.'s (1999, 2007) survey research on LGBT caregivers has demonstrated that this group frequently experiences distress due to stigma about HIV/AIDS and expresses fears about accessing services outside of HIV/AIDS specific organizations.

The historical social exclusion of LGBT seniors is evident in the stories of the LGBT seniors interviewed in this research. Individuals spoke of years of hiding their sexual orientation from families and friends, of rejection because of their sexual orientation, of moving away from their home towns because they could not live openly and remain safe. These findings support previous research which indicates that fear dominates the discourse around long-term care among LGBT seniors (Butler, 2004; Cohen & Murray, 2006).

The LGBT seniors I interviewed described years of struggle, not merely restricted to their own social networks, but more broadly when accessing public institutions. These findings are consistent with previous research by Stein, Beckerman & Sherman (2010) who conducted focus groups with 16 gay elderly people in New York and concluded that participants were
particularly fearful of being rejected by personal care aids in community settings. The historical experiences of the LGBT seniors interviewed for this research continue to influence their current attitudes and behaviour. LGBT seniors stated that their negative experiences in health care settings have led them to be fearful of accessing health care services such as H&CC, and they remain concerned about future health care services such as long-term care.

5.3 Accessing and Avoiding H&CC

Most of the H&CC providers who were interviewed agreed that LGBT seniors who have experienced discrimination in the past, especially discrimination in health care settings, are likely to be affected by these experiences. Moreover, they felt that LGBT seniors who have experienced discrimination in health care settings are more likely to refuse to accept health care services in the future. These thoughts were echoed by LGBT seniors who were concerned about their peers who they believe may not access help when they need to out of fear. The quote below from providers describe the concerns that providers have regarding LGBT seniors willingness to access services after experiencing discrimination,

“The problem is this, when you go out into this basket of services, the first time you receive discrimination, that ends the service, because people are not willing to try another service and go through a second level of discrimination and then trying a third service and go through another level of discrimination. The problem is you have a senior who is walking on egg shells, as soon as it cracks that first time, you basically have in my opinion, you’ve lost that senior to all other services. Because it’s the mentality of why should I bother if everywhere I go it’s going to be like this.” (Felix, Provider participant)
While the LGBT seniors I interviewed as a part of this study had all accessed H&CC at some point, they shared concerns about other LGBT seniors who they felt may not access services due to fears of discrimination. The two quotes below provide examples of the concerns expressed by the LGBT seniors interviewed regarding their LGBT peers,

“The stigma and a whole lot of other reasons and the possible cruelty by family which are the absolute worst, but by friends too or employers or anybody else, creates a situation where a person is highly sensitive and their feelings they wear, they literally wear their heart on their sleeve, is ultra-sensitive, when they’re treated poorly and with disrespect, and it goes far further, you know there are people that are attacked, and it breeds a kind of terror in an individual that does not want home service, doesn’t want the help. But then you place yourself in a horrible box, without any forward momentum nothing is going to change, and if you have only yourself as council, unfortunately me, myself and I are three ways of describing me but they may come to the wrong decision.” (Corry, Senior participant)

“It’s kind of like the word phobia, but this kind of phobia is a fear of taking any action that I might make a mistake, or do I have a right to even ask, and how do I get help. Some of them [LGBT people] don’t even go to doctors the way that they should which would get the ball rolling.” (Henry, Senior participant)

Further to this point, H&CC providers are concerned about the potential for LGBT seniors to avoid accessing services, and thus deteriorate to the point where they have no other option but to access health services. The two quotes below are examples of the concerns that H&CC providers described,

“I feel that most who do request for services will do one of two things. If it’s something as basic as transportation, transportation you can get anywhere so that’s something in which there is no need to identify a person’s sexuality because you’re just being driven around the city, the person’s not coming into their home. The second aspect to that would be once they need to come into their homes. Then, yes, then I would see most if not all, LGBT individuals waiting until it’s that dire moment. Where there is no family or
there is no friends, there’s no other supports and they really need it then they would turn to it.” (Corry, Provider participant)

“All I can say is I feel that if you’re not accepting services when you know you need services, the only time you’re going to accept is when you’re forced to. So that means being brought in through the ambulance, that means being forced into care or being put into long-term care because you’re no longer able to care for yourself. I’m painting a very extreme picture here but I also feel that it’s not wrong to say that because I feel that for those who don’t feel comfortable, they’re not going to ask for service.” (Daniel, Provider participant)

Some LGBT seniors also expressed concerns about their LGBT peers who may be avoiding H&CC services that they need due to fear of inviting strangers into their home. They acknowledged the risk that avoidance of H&CC presents to seniors, especially those who are living alone, “I know of many seniors who choose to live for example in filth or struggling to try to take care of themselves because they just refuse to have that help, they refuse to go through that whole stigma again. It’s not worth it sometimes” (Angela, Provider participant).

Demonstrating that LGBT seniors avoid accessing services is extremely difficult, we cannot know if an individual is avoiding a service, especially if they remain isolated from health professionals. We therefore rely on the opinions of H&CC providers to provide their expert opinion regarding the patterns of service use among LGBT seniors. LGBT seniors themselves are also a useful tool in this regard, as they may have insights into the behaviours of their peers. The findings from this research which suggest that some LGBT seniors are avoiding accessing H&CC are supported in previous Canadian research by Brotman et al. (2003) who reported that the LGBT individuals they interviewed had previously avoided accessing community based
services due to fears of discrimination and did not access services until they reached the point of crisis. This pattern is also evident in international research, Clover (2006) conducted in-depth qualitative interviews with 10 gay men in London, England and found that this group view health services with caution due to experiences and expectations of discrimination and poor treatment. Research conducted by Stein, Beckerman & Sherman (2010) in New York, United States also supports the finding that LGBT seniors may avoid H&CC. In this study researchers conducted two focus groups with 16 gay and lesbian seniors, they found that the seniors reported fear of being rejected or neglected by personal care aides. A more recent study conducted in California, United States surveyed 502 gay and lesbian adults over age 50, the survey results indicated that almost one third of respondents are uncomfortable using older adult social services which are not specifically catered to LGBT people (Gardner, de Vries, Mockus, 2014).

5.4 LGBT Seniors Rely on Self-Advocacy to Ensure Positive H&CC experiences

In response to previous negative experiences in health care settings, many of the LGBT senior participants described a variety of methods which they use to advocate on their own behalf to ensure that they have positive H&CC care experiences. These methods range from actively seeking out LGBT friendly care either by hiring care privately or requesting specifically trained workers to expressing dissatisfaction with workers in their home and demanding changes.
5.4.1 Refusal to Experience Discrimination

The following quotes illustrate individuals’ self-advocacy through refusal to accept services which are not provided free of prejudice:

“No I felt that these are serious matters and if I get the slightest indication that I’ve got somebody who’s prejudiced and so on I will immediately but politely make it absolutely clear in their minds that their services cannot be used. ‘I can see that this meeting is now concluded’. Period. I don’t yell and scream, I never do things like that, I’m a quite soft spoken fellow…” (Ellen, Senior Participant)

“I think it’s probably because I always beat everybody to it, you know if anybody come in I kind of let them know, you know my “partner” and I kind of just brought it out so like now if you have a problem with it let’s hear it, because then I would let you have it, so I kind of beat them to it, so at least to what I say they took it in stride, if they had any prejudice I beat them to it, I guess I was protecting him, with me I don’t care how you feel about me, with my loved one, ya I do care, nobody’s going to do anything to him. I kind of smoothed the way, I said I’m gay, my partner’s gay, and that way I avoided unpleasantness. I guess I took the fight out of everybody because before they could say anything I beat them to it.” (Isaac, Senior Participant)

In the two quotes below the seniors express their understanding that while they may encounter care providers who hold prejudices against them because of their sexuality, they are unwilling to remain quiet in such a scenario:

“I wouldn’t have done a formal check-up, I would have done my own personal check-up like I did with that lady... Let’s say I received someone who gave any indications of homophobia or discomfort, I would have immediately raised that with her or him and would just said are you uncomfortable with it, because if you are, I’m uncomfortable and you know we can easily make arrangements so someone more comfortable would come”. (Frank, Senior Participant)

“I wasn’t too concerned about whether the individual would be gay positive or not, to be quite honest, as I said um I’m happy with who I am you know? And I think if the other individual has a problem, it’s their problem, Ok? And if I uh found out I guess, I
don’t know whether that’s the right word, that they were gay negative, I would let them know and something would have to be done about it.” (Larry, Senior Participant)

5.4.2 Prevention of Discrimination

In the quotes above, the seniors approach to self-advocacy was slightly more reactive, while they anticipated the potential for a negative experience, they attempted to give the benefit of the doubt to the individual coming into their home. The seniors expressed that they felt ready to actively remove themselves from any negative situation that might arise. The two quotes below exemplify seniors who feel it is necessary to take preventative steps, to ensure that they do not encounter care experiences where they feel discriminated against:

“When speaking with the supervisor from that service, I have said ‘they have to be, not that I talk about it, but I have pictures of me with my lover and I just don’t want to have any negative inputs’... so at least she’s aware of it.” (Andrew, Senior participant)

“In terms of our experience the advantage for both of us was that we were both professionals, we were both familiar with the system and we were not intimidated by the system and I think that was where we differ from the average person. And therefore if anyone had been the slightest homophobic they would have known about it because I would have written letters to the top, and I wrote a lot of letters. But always in my letters I listed solutions, I didn’t just rant, but that was one way of me dealing with the anger” (Gemma, Senior participant)

It is important to note that the LGBT seniors I interviewed as a part of this research all self-identified as LGBT and all approached me about participating in my study, which places them among the group of LGBT seniors who are publicly out and comfortable discussing their experiences with strangers. They may therefore represent LGBT seniors who are more likely to self-advocate for themselves than LGBT seniors who were not interviewed for this study. The
pattern of self-advocacy is strongly associated with previous research which suggests that due to years of struggle in both social and political spheres, LGBT seniors have developed a unique resiliency to some of the barriers associated with aging (Butler, 2004; Butler and Hope, 1999; Barranti and Cohen, 2000; Healy, 2002; Price, 2005). For example, many older gay men have learned self-reliance, survival skills, stress management, and how to care for themselves earlier in life, so the aging process in this regard tends to be smoother for gay men than for many men identifying as heterosexual (Brown, Alley, Sarosy, Quarto, & Cook, 2001; Wight, LeBlanc, de Vries, & Detel, 2012). Similarly, many older lesbian women have developed strong social support networks and advocacy skills (Averett et al. 2011). In addition, many LGBT have experienced the loss of relationships (such as parents and siblings) in the process of coming out, and as a result have built strong, alternative support networks (Berger and Kelly 2001; Grossman, D'Augelli, & Dragowski, 2007). Often, older LGBT adults develop a great deal of resistance to and resilience around negative social constructions of homosexuality, contributing to their psychological and emotional health and positive adjustment. These strengths may include: coping skills developed through the process of accepting their sexual orientation; the stigma associated with aging is often experienced as less severe than the stigma of being LGBT that they have experienced throughout their life; and skills developed through the coming out process and the management of the perception of “difference” which may help prepare LGBT seniors for society’s perception of older people (Barranti and Cohen, 2000, p.32).
LGBT seniors who participated in interviews outlined a myriad of methods which they undertook to prevent further negative experiences in the H&CC context. These methods ranged from moving from rural areas to Toronto in hopes of receiving more “friendly” care, to “outing” themselves and demanding care workers who were non-discriminatory of sexual orientation prior to allowing workers to enter their home. The pattern of self-advocacy is also linked to the concept of “environmental mastery” which has previously been identified in senior LGBT populations. This concept suggests that in response to living in a society which suppresses their sexual orientation, LGBT seniors make effective use of surrounding opportunities (Cantor et al., 2004).

5.4.3 Generational Differences in Self-Advocacy

Some of the seniors interviewed suggested that willingness to self-advocate may differ among cohorts of current seniors, and that perhaps seniors who were engaged in activism during their earlier years may be more likely to advocate on their own behalf because of a history of advocating for personal and legal rights. These LGBT seniors suggested that empowering and educating seniors is an important way to help outreach to isolated seniors who are afraid of accessing care and who may be unable or unwilling to advocate on their own behalf. The following quote is an example of concerns regarding the capacity of other LGBT seniors to advocate on their own behalf:

“I was lucky, and I consider myself very lucky with respect to how things have progressed in my treatment and my care. Um I know where to go, you know? But a lot of other folks don’t know where to go. And I’m not sure if I can pinpoint what the reason is for that. Whether they’re apprehensive about discussing their condition, or
apprehensive about talking to somebody about their condition”. (Frank, Senior participant)

The quote below exemplifies the way that one senior who had experienced negativity in his past now makes efforts to assist other LGBT seniors who do not have people supporting them:

“Um but the reticence is a real factor. You know it’s almost like an intrusion that I can handle it myself, some people particularly I think LGBT types are very proud and often because they have to be private. You know there is stigma all over the place and they’re scared that they might have an incident. My attitude is I can’t walk around with that attitude because as a younger man there were times even as a boy that I was worried, I was aware of what the story was, what’s that expression, what the score was. Um and I didn’t quite know how to handle it so I stumbled around a lot, but that’s an awfully long time ago, you know I’ve seen a lot of things in my life and um you know just to turn one more sentence on. That is that’s one of the reasons that I’m working at the [location removed] as a volunteer because I want to reach, I know this sounds like the AT&T commercial, but by reaching out and touching someone, and taking their hand if that’s what it takes, and saying look, this is a shared experience I can bring to you the confidence of knowing this is the right thing to do and I’ll be there if you want me there and that kind of thing really helps”. (Larry, Senior participant)

Recent research by Dentato, Orwat, Spira & Walker (2014) supports the finding that there may be generational differences in responses to challenges accessing H&CC. The authors suggest that it is necessary to take into account the historical and social contexts that surrounded LGBT adults when they came of age in order to understand their lived experiences, and their actions in later life. Individuals who participated in protests and civil unrest during the era of change in the early 1970’s may be more likely to continue advocating for change in their later years.

While these patterns may be consistent across age-groups to a certain extent, age alone cannot predict an individual’s response to discrimination, especially given that some LGBT seniors may have not “come out” until recently and therefore may not have a history of self-advocacy.
5.4.4 Rural to Urban Migration

One method of self-advocacy involved making efforts to access better care by moving away from rural areas. Rural areas, or small towns, are often not considered safe and LGBT seniors perceive that their ability to access H&CC free of prejudice or discrimination would not be possible outside of major cities. The two quotes below illustrate the perceptions of rural areas and reasons for moving:

“So in 2011 indeed for most of the past 20 or 30 years I think this society, particularly in cities, I wouldn’t want to figure things out in [name removed] Ontario, not that I’m casting aspersions on [name removed] but there is a cliff you go over the minute you get into certain areas for other more powerful forces, perhaps the church, which is unalterably opposed to gays”. (Daniel, Senior participant)

“… [name of town removed] was a very close knit, conservative, blue collar community. You know? Anything concerning gays was all underground, ok? Toronto is much more is much more liberal uh much more open, much more accepting I find in that particular regard” (Isaac, Senior participant)

The finding that some LGBT individuals decide to leave rural areas in order to access care in urban centres is not surprising. Previous research has indicated that even without considering sexual orientation, access to H&CC services in rural parts of Ontario can be challenging, and in fact seniors in rural areas may be more likely to be prematurely admitted to long-term care due to a lack of available services (Kuluski, Williams, Laporte, Berta, 2012). This pattern appears to be even more salient among LGBT seniors who in addition to the overall lack of services, have concerns about the potential for discrimination among the services that do exist. Although
research on rural LGBT individuals is limited, King and Dabelko-Schoeny (2009) found that lesbian, gay, and bisexual adults living in rural communities in Ohio lacked a sense of belonging to community, isolation due to a lack of informal support, and generally encountered obstacles to aging in place.

**5.5 Summary**

In this first chapter of findings and discussion, I presented findings related to the past experiences of social exclusion among LGBT seniors, and how these experiences have influenced the current cohort of LGBT seniors and health care providers in Toronto, Ontario. The findings support the literature on this cohort of LGBT seniors which states that as a group, this population experienced social exclusion. This was particularly true for LGBT seniors who were diagnosed with HIV during the early years of the AIDS crisis. I presented themes from my analysis of interview transcripts and field notes with both LGBT seniors and H&CC providers. The first theme described the reluctance on the part of some LGBT seniors to access H&CC due to fears of discrimination, in many cases due to previous negative experiences with health care professionals. I discussed the fact that this pattern of avoidance of care due to fears of discrimination is fairly widespread in research on LGBT seniors. The second theme described the pattern of self-advocacy evident in many of the participants’ approach to accessing and using H&CC. Examples of self-advocacy included attempts to prevent discrimination, requests for changes to negative situations, and rural to urban migration in order to receive H&CC that is more likely to be LGBT friendly. I discussed the connections between the literature on
resiliency in older age among LGBT seniors and the patterns of self-advocacy among the participants in this study. While the themes of avoidance and advocacy may at first appear incongruent, some LGBT seniors avoid accessing care while some self-advocate for care, I suggested that the differences in responses to historical negative experiences in healthcare settings may be attributed to generational and experiential differences. Individual LGBT seniors experience the same historical events in different ways. In addition, many factors, such as the age at which they “came out of the closet” may impact on an individuals’ likelihood of avoiding or self-advocating for care.
Chapter 6: Findings and Discussion of the H&CC Response to the Needs of LGBT Seniors

In this chapter I respond to my second research question, “Moving forward, how can the H&CC sector respond to the needs of LGBT seniors?” I begin by describing how LGBT seniors and H&CC providers view what it would mean to provide culturally appropriate H&CC, whether the care should be approached differently when the person receiving care is LGBT, and if so what those differences should entail. I next discuss the perception that culturally appropriate care for LGBT seniors is severely lacking in the H&CC sector, and describe the challenges and difficulties associated with attempting to make changes in the H&CC sector related to care for LGBT seniors. I end this chapter with a discussion of how H&CC providers and LGBT seniors believe change can be instigated in the H&CC sector.

6.1 Defining culturally appropriate H&CC for LGBT seniors

I asked the LGBT senior participants about how they personally would define culturally appropriate care for seniors who identify as LGBT. When asked to discuss the concept of culture, the respondents emphasized the diversity within LGBT seniors and emphasized that for them, in the context of health care, culturally appropriate constitutes the many complicated elements that contribute to “friendly” care. Within this idea the seniors suggested that culturally appropriate care should include a number of elements (including the total absence of
discrimination, openness and acceptance of homosexuality, understanding of different (i.e. non-nuclear) family and caregiver models), but that there is no simple definition of what this type of care would look like.

The majority of LGBT seniors stated that the most important aspect of care is that it is received free of prejudice and discrimination. Many seniors have previous negative experiences in the health system and have no desire for this sort of experience to be repeated. In addition, seniors expressed that there are a number of important factors associated with good care experiences, including confidence that the care provider is knowledgeable about the care they are providing, feeling comfortable and safe being “out” to their care provider, and having the opportunity to develop personal relationships with the individuals coming into their home (feeling comfortable discussing aspects of their lives related to their sexual orientation). The importance of the provider being comfortable with the fact that the client is LGBT is illustrated in the following quote which represents the feelings of many of the participants, “I think the only thing that is basically required is that whoever comes into your home to give care be comfortable about stepping into the home of a gay person. That’s the basic”. (Corry, Senior participant)

Some seniors stated that they avoid personal conversations with their workers for fear of having to discuss their sexual orientation. Typical conversation topics related to children and family, vacations, pets, etc. are avoided because something as simple as a pronoun (he instead of she) may inadvertently “out” the senior to their worker. If seniors are not sure of the
response of their worker they would rather avoid the conversation altogether. This however prevents relationship opportunities with the individuals coming into their home, and could potentially lead to a less thorough understanding of the senior’s condition or situation. For example, one senior who felt his home care workers were professional but very stand-offish expressed the importance of developing a personal relationship because the care takes place in their home.

“I think that it should be... not only because of the type of treatment that you’re getting but because of the place it’s taking place in. You’re not in a doctor’s office for goodness sake. You’re not on one of those tables. You’re in your bedroom being taken care of in your home. And I guess you’re perfectly correct in assuming that one should be cognisant of that particular fact and should understand that you’re being allowed, well I don’t know whether allowed is the right word but... someone is coming to your home, it’s not like coming to dinner, sitting down for a cocktail or two, but certainly having someone coming into your home to take care of you under those particular circumstances should be acknowledged as a different type of procedure than one that takes place in a doctor’s office.” (Henry, Senior participant)

H&CC Provider participants unanimously agreed that all H&CC services should be provided to LGBT seniors free of discrimination. The following two quotes describe the shared opinion of H&CC providers regarding providing H&CC to LGBT seniors,

“I think first and foremost the most important thing is non-discrimination, right. So and our organization as a whole does not discriminate anybody in terms of race, religion, sexual preference, whatever, and we make that very very clear to all of the people that we provide services do.” (Helen, Provider participant)

“I would say the important thing is to have a willingness to be open to the prospect and an understanding that regardless if an agency is LGBT or not, you will always have clients if they choose to self-disclose or not, you will always have clients that are LGBT. I think the same respect we give to minority groups, the same respect we give to women, men, whatever it should be, we need to recognize that we need to give the same respect. We in this day and age we don’t discriminate against religion, we are slowly starting to
respect that. I see a person being gay or lesbian or whatever as being no different.” (Felix, Provider participant)

Previous research has shown that noticing discrimination and subsequently preventing it may be difficult. Jones, Peddie, Gilraine, King, and Grey (2013) suggest that diversity initiatives are likely to fail if they target easily recognizable and overt types of discrimination while overlooking subtle, interpersonal discrimination. Widespread organizational policies may be sufficient to quell overt forms of discrimination, however prevention of what the researchers call seemingly benign types of discrimination requires a shift in organizational climate that includes a closer examination of subtle discrimination. Jones et al. (2013) state that failure to recognize subtle forms of discrimination can result in just as substantial, if not more substantial consequences than overt discrimination for three reasons: 1) Targets of overt discrimination can externalize negative experiences to discrimination, whereas targets of subtle discrimination may be more likely to make internal attributions, 2) Subtle discrimination is more difficult to report than overt discrimination, and 3) Subtle discrimination is more likely to occur more frequently.

When asked to elaborate on how care for LGBT seniors should be implemented, providers differed in their responses, and two overall approaches were described. One approach was to suggest that all seniors should be treated equally, regardless of sexual orientation; this opinion was expressed by four of the care providers interviewed for this study. Providers who advocated for the same treatment of all seniors based this on ideas about fairness, and their
understanding that LGBT seniors do not wish to be singled out, or treated differently because of their sexual orientation. Providers who believed in this approach assumed that treating LGBT seniors differently than heterosexual seniors would be considered negatively by LGBT seniors. This view is illustrated by the following two quotes from care providers:

“But our clients if they identify that way at the intake then we’ll make note of that but again it wouldn’t hinder their experience, it wouldn’t prevent them from getting service, and if they do identify that way and we’re aware of it, it doesn’t change the way that we provide service to them”. (Ginny, Provider participant)

“I think if you can include it in your mandate somewhere, I think some agencies are putting rainbow stickers everywhere because they want to be gay positive, but I think you just want to be inclusive, maybe just put that in there as part of your organizational mandate, you know we serve people of all creeds, cultures and sexual orientations. I don’t think it needs to be a separate thing. Most people don’t want to be centred out, we just want to be who we are, but just to know we’re included – I don’t need a big rainbow coming out at me. Especially the older generation, they’re not used to being as out as we are.” (Jennifer, Provider participant)

The care providers who believed that all clients should be treated equally regardless of sexual orientation elaborated on their viewpoint by explaining that they do not believe that sexual orientation has any impact on the health needs of individuals, and therefore there is no need to cater their H&CC services. The following quotes from providers exemplify the opinion from some of the care providers that there is no need for specific services for LGBT clients,

“I think for the services, there really isn’t a lot of catering to do, for a lot of services we provide here. I look at the adult day program we have here, I think that’d be fine for gay or straight.”(Betty, Provider participant)

“I think that most PSWs are incredibly caring and accepting, the majority of people providing services are perfectly fine. I don’t think a lot of services do need to be tailored
to LGBT people, I think the community just needs to be accepted as a whole and then everything will just fall into place.” (Isobel, Provider participant)

In contrast, a second approach which was suggested by providers is to actively engage LGBT seniors and offer programming and support that is specific to their needs. These providers stated that they believe there is a need among LGBT seniors for services that are explicitly labelled as LGBT friendly, and are catered to the needs of LGBT seniors. These providers further elaborated on the need for organizational change that is pervasive, and includes training that touches all aspects of the organization. The following quote represents the responses of these providers when asked to describe what they think constitutes culturally appropriate care,

“Maybe that’s part of what it is, that it’s training staff to um understand their own biases, their perspectives, their own limitations and hang ups and then trying to understand the needs of the individual, right like so when somebody asks for someone, when somebody says I have two partners and they both need access to me, you don’t go ‘What?’; because you understand that you just need to be like how can we make this happen. And I know that it’s tricky from a policy perspective because you want to have like set limitations or you know what I mean, you want to have clear codes, but that’s not really possible.” (Callie, Provider participant)

There is no previous research which examines the provision of H&CC to LGBT seniors from the perspective of the H&CC providers, for this reason it is difficult to find support for either of the two approaches to providing culturally appropriate care as described above. There are however studies which explore the preferences of LGBT seniors in terms of social and community-based services. For example, Jacobs, Rasmussen & Hohman (1999) surveyed 71 gay, lesbian, and bisexual seniors from San Diego, aged 50 – 80, about their social service needs. The results of their survey indicated that participants would prefer to receive social
services such as community health services and counselling groups in a gay or lesbian environment. The reasons for this preference were related to concerns about a lack of common understanding among heterosexual and non-heterosexual participants in social groups, as well as fears of discrimination from other participants and staff. These results suggest that H&CC providers may be more likely to accommodate the needs of LGBT seniors if they target LGBT individuals specifically, as opposed to treating all participants the same regardless of sexual orientation.

6.2 Lack of culturally appropriate H&CC services for LGBT Seniors

Both LGBT seniors and H&CC providers shared the overall concern that there is a lack of culturally appropriate H&CC for LGBT seniors. None of the LGBT seniors interviewed were aware of a H&CC organization that they could go to and be assured they would receive LGBT friendly care. While the seniors interviewed for this study used various methods of self-advocacy to prevent negative experiences, some stated that they fear other LGBT seniors who don’t make these extra efforts may therefore have negative experiences, or experience distress because of the fear of negative experiences, even if they do not occur. H&CC providers shared the concern that as a sector, there are very few organizations prepared to serve LGBT seniors, and in fact most providers were not aware of any organizations that catered services specifically for LGBT seniors, or provided training to their staff on LGBT sensitivity. The quote
below exemplifies the desire among H&CC providers for more services that cater to LGBT seniors,

“I think there could be more – when we try to hook some of our lesbian and gay population up with community services there’s not a lot, in terms of maybe something specific for them, um ya there’s a lot of community based services out there right. Sometimes what we find though is that our gay clients are really looking for something a bit more specific... So I honestly think there could be more community resources, I honestly think that.” (Helen, Provider participant)

Providers also raised the concern that the overall lack of H&CC services for LGBT seniors contributes to their feelings of exclusion,

“This isolation that people feel, and like they’re so cut off from services and they’re so closeted, it’s totally indicative of the larger problem” (Corry, Provider participant)

When considering the organizational implications of the social exclusion of LGBT seniors in H&CC it is helpful to consider whether there is a direct role on the part of H&CC organizations in contributing to the continued social exclusion of LGBT seniors. More specifically, do organizations increase the social exclusion of LGBT seniors by failing to provide culturally appropriate H&CC for this group? Viet-Wilson (1998) introduces the concept of strong versus weak social inclusion efforts when discussing methods for reducing social exclusion, and these concepts are useful in responding to this question. Weak social inclusion efforts focus solely on inclusion methods that respond to an individual’s characteristics. Strong social inclusion efforts emphasize the role of the individual(s) who are doing the excluding and aim to reduce the power or influence of those perpetuating the exclusion (Macrea, Maguire, and Milbourne,
Macrea et al. discuss the problem of lack of access to services, they focus on access to education for low income children, but their argument is useful in understanding the lack of access to H&CC services for LGBT seniors. They argue that the lack of access to services for marginalised populations increases their social exclusion, and that inclusion efforts should concentrate not just on efforts to improve the individual characteristics of the excluded group, but rather challenge the prevailing attitudes and policies put in place by decision makers.

### 6.3 H&CC Organizational Change

Most providers acknowledged that efforts to provide LGBT welcoming care in the H&CC sector are challenging. LGBT seniors are for the most part not on the radar of provider agencies, providers are not aware of the number of LGBT seniors they provide care to, and very few have heard feedback from LGBT seniors currently using their services, “I honestly don’t think that most agencies are aware of their LGBT clients. When you look at you know other kind of minority groups or something it’s much more visible, I honestly don’t think that other organizations probably are aware – no.” (Kelly, Provider participant).

In this context, advocating to the government for resources towards LGBT sensitivity training, or for formal processes to be put in place is difficult. Providers suggested that individual providers who are LGBT themselves may feel pressure to make extra efforts towards change within their organizations, but that for the most part there is little time to push these efforts forward as the sector in general is underfunded and individuals are typically already working at
their maximum capacity. Providers also felt that efforts to make organizational change are a positive step forward only if sufficient time and effort are invested by the organization.

Concerns were raised about the risk of adopting overarching policies without adequate follow-through and implementation. The quote below from one provider highlights the belief among many of the providers that there is a risk in implementing LGBT friendly policies without a plan for enforcement of these policies,

“I think that’s what makes us a bit unique, you can have a policy right, but if it’s sitting on a piece of paper in a binder that’s pulled out once a year and reviewed by the staff, that’s not good enough. You really need to put that policy into practice... We, you need to um, for lack of better, you know put your money where your mouth is. So if you actually see discrimination going on, you can’t just pass that by, you need to deal with it then and there and appropriately, and that doesn’t just include staff it includes the other clients too right... I do find there’s a lot of great agencies out there who will say you know yes we’re welcoming and all that type of stuff because they have a policy that says that, but then you need to actually put it into practice.” (Helen, Provider participant)

Providers did not want to formally advertise that their organizations were LGBT friendly without a firm understanding that this was the case throughout the entire organization, from management through to workers on the ground. Providers felt that advertising they were LGBT friendly without a guarantee that all services were actually LGBT friendly could potentially be worse for LGBT seniors as they may “out” themselves under the assumption that it is “safe” to do so, and may receive a negative response from the providers “on the ground” who are providing care in their home. The following quote from a provider describes the concerns of most providers regarding introducing LGBT friendly policies to H&CC organizations,
“I think that they need to go after money, they need funding and they need to commit to a long term plan. It’s not just about running a one off program or putting up like a rainbow sticker in your lobby. Like you really need to do like an internal scan of what’s happening, who are you serving, what do you really need to do at all different levels, like staff level, like policy level, at a participant level. Because there’s resistance from all different areas right, like if you start running your programming and you start inviting queer people and then the people at your program are homophobic, how are you staff going to deal with it? It has to be a bigger project, taking it on in really small ways is kind of futile in some ways and it’s not really appropriate. It’s very tokenistic to think that that’s going to do it, just to run something that you’re not capable of doing. I think if people want to do something like that they need to bring in outside facilitators and be really clear that it’s just one part of the provision of care is it’s queer positive, and not think they can run it in house if they’re not capable of doing it. But yeah I think people need money, and they need time, and they need to do a bit of an overhaul and really commit to it and integrate it into what they’re offering.” (Callie, Provider participant)

Providers also discussed the long-term effort required to implement an LGBT friendly environment in their organizations. They discussed the many different elements involved in this process, including establishing organization-wide policies, implementing ongoing training, conducting outreach and reviewing progress on an ongoing basis. The following quotes from two separate providers describe why they believe it is important to ensure that policies regarding LGBT seniors be implemented across the entire organization:

“I would say it has to come bottom, well top to bottom. But it needs to make sure that when we get to the bottom, which is the drivers, which is the personal support workers, those individuals that are actually going out into the community, who are actually providing the services, those are the individuals that we need to target. Those are the individuals we need to teach, we need to educate, uh and we need to make sure that there is that respect. And if we find during that assessment phase that there are certain individuals that are going to do more harm than good, then I’m not saying we should get rid of them, but we should make sure that they’re not filtered to these clients.” (Evelyn, Provider participant)
“It has to come from everywhere, from the board, to its managers to its staff, even to the other clients that come into the agency, they need to be aware of that and they need to respect that listen you’re coming into an inclusive area, if you don’t like it then there are other options and you can surely discover that.” (Felix, Provider participant)

The following quotes demonstrate the efforts and challenges associated with attempting to implement an LGBT friendly environment:

“It’s a process that will not complete itself within a week, within a few days. It’s ongoing. We’ve started with the request to have it trickle down. So from our board, the board has been trained, from the managers they have been trained, and we’re slowly hoping to get the other staff around trained, but that’s a process that will take some months, some years, and even after the training I’m sure people will still hold firm to their beliefs regardless of what they are. You know if you go back to the human rights for the LGBT, it’s been roughly in the past 20 years a lot has happened, but it still took some time to fight for it, and I think this agency will be no different. You will have people right out saying I will refuse to work with that population, but I respect that, at least we know we will never send that person into this you know into an atmosphere in which the poor client is going to feel oppressed because of them”. (Felix, Provider participant)

“For example let’s do something as basic as a request for transportation. You’re starting at the intake worker here who is providing information and registering the client for services. Then you’re transferred into the transportation department who has its own staff. They could be great, or you know they could be bigots. Then you have the drivers who take these clients out. So you need to make sure that whatever happens filters from the intake all the way into the department. Because if at intake you have a great individual who is very nice and very friendly and there is a connection with the client and the intake worker, that’s great. But if it doesn’t filter in, these people will in a sense I would say regret having started the process in the first place.” (Evelyn, Provider participant)

The need for organization-wide training is evident in research which examines the LGBT cultural capacity of H&CC agencies. There is no Canadian data regarding the amount of LGBT friendly H&CC agencies or extent of training of H&CC providers, however a US nation-wide survey of
nursing home social service directors suggest that there is a significant lack of awareness about LGBT seniors among individuals working with older people. Bell, Bern-Klug, Kramer & Saunders (2010) found that among the 1071 directors surveyed, three-fourths of the sample had received less than one hour of homophobia training over the past 5 years. Recent research examining the potential for organizational change regarding attitudes, beliefs, and intentions of individuals who provide care to the elderly suggest that cultural competency training about sexual and gender minorities can have a positive impact. Porter and Krinsky (2014) studied 4 training events in Massachusetts which focused on lesbian, gay, bisexual and transgender aging for mainstream elder service providers. Their findings suggest that providers’ knowledge, attitudes, and behavioral intentions significantly improved following training sessions. Participants had an increased knowledge regarding LGBT resources, policy disparities, spousal benefits, and the impact of homophobic remarks.

Previous research also supports the assertion by H&CC providers that organization-wide culture shifts are necessary in order to effectuate change in H&CC organizations. Landers, Mimiaga & Krinsky (2010) describe the elements necessary to achieve successful implementation of LGBT friendly policies in agencies which provide health and social care to seniors. They evaluate the Open Door Project, an initiative aimed at assisting home care agencies in Massachusetts to become “LGBT friendly”. The results of their evaluation suggest that there are a series of elements necessary to successfully implement organization-wide change in home care agencies. These elements include knowledge among staff about LGBT issues including comfort
with terms used to describe different sexual minorities, participation from organizational leadership in training programs, and a plan for sustainability of the program.

6.4 The Role for Government in Achieving H&CC Sector Change

Care providers felt that there are a number of barriers to the widespread implementation of LGBT friendly care provision in the H&CC sector. These barriers include the lack of awareness among providers surrounding LGBT care recipients (many do not believe they have any LGBT clients) and the lack of understanding of how to go about implementing LGBT friendly environments. Most care providers were aware of resources, such as the Senior Pride Network at the 519 Church Street Community Centre in Toronto and Rainbow Health Ontario, where information and education about the needs of LGBT seniors is available. Despite this awareness, care providers stated that providing care to LGBT seniors is not considered a priority when weighed against all the other issues and needs that underfunded H&CC organisations are faced with.

Care providers suggested that in order for real and lasting changes to occur it may be necessary for agencies to either be required to implement change or for incentives to be provided. The following quote demonstrates the perception that leadership from government agencies is critical to encourage H&CC organizations to begin the process of implementing LGBT friendly policies,

“I think it would need to come from the CEO, and be supported from the LHIN, like right now we have a falls initiative, it came from the LHIN and everything is about falls, we have to report on all falls, so something like that, like a common thread, I’m not saying
you have to make it a strategic aim, but some kind of focus, saying this here, this is what we’re focusing on. I think it’s going to take that long, that is what it will take, it involves a lot of retraining people, it’s a lot.” (David, Provider participant)

Some providers cautioned that agencies not be forced to implement LGBT friendly environments for fear that changes would be implemented only on the surface, which they felt may be worse than not making changes at all. Despite these cautions most providers did agree that in order to achieve real movement on these issues there may need to be funding provided, as organizations are underfunded across the board and this may be a way of getting sustainable LGBT friendly care on the agenda. The following quote is an example of a care provider who believes that funding from governmental agencies for H&CC organizations should require LGBT inclusiveness:

“Well my honest opinion is a lot of these organizations are dependent on funding. I think there needs to be a criterion which includes inclusiveness, not just for LGBT minorities, whatever it should be, and that has to be tied in, so if you’re not following this criteria we can pull our money back at any time. I think when we talk money, that’s when you’ll see reactions and you’ll see people do things”. (Isobel, Provider participant)

Governments around the world have used social exclusion to better understand how to reduce disparities among groups of individuals, under the assumption that a reduction in disparities will lead to positive outcomes such as improved overall health, education and decreased poverty (Peace, 2001). My findings from discussions with H&CC providers supported the notion that in order for the H&CC sector to make widespread change regarding the provision of care for LGBT seniors, there is a need for government intervention. This is challenging given that H&CC sector is under constant fiscal pressure to serve more individuals, with higher levels of
need (Drummond, 2011). In this climate, the needs of marginalized populations, including but not limited to LGBT seniors, are not likely to be addressed or even recognized. H&CC providers maintain that current standards are not sufficient to promote change. This is illustrated by, for example, The Toronto Central LHIN 2010 – 2013 Integrated Health Service Plan (IHSP) which did not include any priorities specifically targeted towards LGBT individuals.

There are a number of examples in the literature related to health promotion for LGBT individuals that include suggestions for inclusive policy development which could assist policy-makers interested in achieving system change. Mule, Ross, Deeprose, Jackson, Daley, Travers & Moore (2009) recommend targeted efforts at health promotion, aimed at the social determinants of health for LGBT individuals. They caution against an illness-based focus (such as HIV/AIDS) and suggest that “representation matters” when it comes to setting policies for diverse groups of individuals. Concannon (2009) furthers these arguments and suggests implications for social policy, service planning and professional practice. He recommends:

- Managers, practitioners and educators should become educated about the lives and concerns of LGBT people and understand areas that may affect their scope of practice
- Training be made available which includes the principles of respect, rights, fulfilment, independence, privacy and dignity
- Funding for LGBT advocacy groups
- Funding social groups which cater to the needs of older LGBT individuals who may have limited social opportunities in mainstream services for seniors
- Monitor and evaluate the needs of LGBT seniors
• Include reference to sexual orientation in equal opportunity policies

Finally, Cahill, South and Spade (2000) recommend a policy framework for LGBT seniors that includes research and needs assessment, access to services, training for care providers, recognition of LGBT families, LGBT housing options (such as LGBT friendly supportive housing and long-term care), accessible health care, and a non-discrimination and anti-poverty policy.

6.5 Summary

In this chapter I presented and discussed the findings related to my second research question which asks how the H&CC sector can respond to the needs of LGBT seniors. I first discussed how LGBT seniors and H&CC providers conceptualize the definition of culturally appropriate care. Next, I identified the overall lack of culturally appropriate care for LGBT seniors available in Toronto, Ontario. I also highlighted the fact that there were differences in the approaches to culturally appropriate care among the H&CC Providers, these differences related to a debate about whether LGBT seniors require programming that is specific to them in H&CC and whether LGBT seniors have equal opportunities as their heterosexual peers to access H&CC. I subsequently discussed opportunities and challenges associated with achieving cultural change in the H&CC sector, and the role for government in achieving such change.
Chapter 7: Conclusion

The central aim of this thesis was: *to identify how past experiences of social exclusion have influenced the current cohort of LGBT seniors and health care providers in Toronto, Ontario regarding accessing and using home and community care (H&CC) services, and to consider what can be done.*

To do this, I conducted a case study on LGBT seniors’ use of H&CC services in Toronto, Ontario. The case study involved multiple components including extensive review of two sets of literature as well as interviews with LGBT seniors and H&CC providers. The first set of literature was on the state of knowledge of LGBT seniors, including the history of discrimination in Canada, as well as current health and social care needs. The second set of literature was on the conceptual framework of social exclusion, including measurement of social exclusion and international efforts to remedy the social exclusion of various groups. I also employed qualitative methods, conducting interviews with both LGBT seniors as well as providers of H&CC. These interviews focused on historical experiences of discrimination, current experiences of H&CC (including access, use, provision, and recommendations) and future considerations for accommodating the needs of LGBT seniors in H&CC.

My case study includes the following research questions:

Q1) How do previous experiences of social exclusion impact on LGBT seniors’ access and use of home and community care services?
Q2) Moving forward, how can the H&CC sector respond to the needs of LGBT seniors?

7.1 Impact of Historical Social Exclusion on Access and Use of H&CC Services

A key finding that emerged from this thesis is that historical social exclusion impacts on how LGBT seniors access and use H&CC services. I found that many of the LGBT seniors interviewed who have accessed H&CC frequently make concerted efforts to advocate on their own behalf both prior to accessing services and in the process of accessing services. The LGBT seniors who participated in this study reported multiple examples of efforts they undertook to prevent negative experiences when using H&CC services. I have linked this finding to previous research which has indicated that due to years of struggles in response to discrimination, LGBT seniors develop resiliency which impacts on their ability to age well (Genke, 2004; Kushner, Neville & Adams, 2013). I have found that this resiliency may manifest as self-advocacy when LGBT seniors are accessing H&CC.

Researchers concentrated on the consequences of social exclusion have previously noted that there are individuals and families who appear to flourish despite extraordinarily tough experiences, this has led to discussions about the concept of resilience and its significance in the context of social exclusion (Burchardt & Huerta, 2009). Individuals who exhibit resilience have positive outcomes (or avoid negative ones), despite being exposed to adverse circumstances (Mohaupt, 2009). The patterns of resilience that I observed among the LGBT
seniors interviewed for this research included refusals to experience discrimination, efforts to prevent discrimination, and rural to urban migration.

The patterns of resilience do not however appear to apply to all individuals in the LGBT senior population; H&CC providers who were interviewed stated that they believe that there are many LGBT seniors who may require H&CC services but who do not use needed services because they fear discrimination. The literature on the concept of resiliency debates the question of whether it is an inherent psychological attribute, or whether it is generated by a range of characteristics and circumstances (Burchardt & Huerta, 2009). Both LGBT seniors as well as H&CC providers speculated that generational differences as well as differences in life experiences may be a factor in individuals’ responses to previous negative experiences (such as resilience versus avoidance). Burchardt & Huerta speculate that social exclusion qualifies as the kind of adverse circumstances in which someone might or might not exhibit resilience.

The finding that in response to experiences of social exclusion some LGBT seniors exhibit patterns of self-advocacy while others avoid accessing services, suggests that at the individual level, experiences of social exclusion and subsequent responses to social exclusion differ. The collective experience of social exclusion thus does not necessarily lead to a uniform response. This brings a new insight into our understanding of social exclusion, especially as it relates to the experiences of the current cohort of LGBT seniors.
7.2 Implications of Historical Social Exclusion for the H&CC Sector

An important and actionable finding from this research was the lack of culturally appropriate H&CC for LGBT seniors. This finding was somewhat surprising given the large population of LGBT individuals in Toronto, however H&CC providers shared the opinion that this sector is “behind the times” in regards to understanding sexuality in old age generally, and especially unaware of the fact that LGBT seniors are accessing services and have particular needs when accessing services. Even among H&CC providers with experiences providing H&CC to LGBT seniors, there was a lack of consistency in approaches to the provision of culturally appropriate H&CC to LGBT seniors.

The findings of this thesis also highlighted the challenges in the H&CC sector associated with initiating and sustaining efforts to implement culturally appropriate H&CC. H&CC providers had differing views on how to approach culturally appropriate care for LGBT seniors; some providers stated that all seniors should be treated equally, regardless of sexual orientation, while the other providers stated that there is a need for H&CC services designed specifically with the needs of LGBT seniors in mind. Previous research supports the idea that LGBT seniors are more likely to access H&CC if the approach to care provision is explicitly designed for LGBT seniors (River, 2006). This population has previously identified concerns about a lack of common understanding among heterosexual and non-heterosexual participants in social groups, as well as fears of discrimination from participants and staff (Almack et al., 2010). This
suggests that H&CC providers may be more likely to accommodate the needs of LGBT seniors if
they target services to LGBT seniors specifically, as opposed to treating all participants the same
regardless of their sexual orientation.

Even if there was widespread agreement regarding approaches to providing culturally
appropriate care, the subsequent challenge would be regarding shifting organizational culture
to adjust to this idea and successfully engaging in culturally appropriate care (Landers et al.,
2010). Ultimately, H&CC providers believed that government intervention including mandates,
attached to funding, were likely necessary in order to ensure real, consistent, and sustained
changes in the H&CC sector.

7.3 Implications for the Provision of H&CC to LGBT Seniors

The results of this thesis indicate that the shared experiences of social exclusion among LGBT
seniors influences their current access and use of home and community care services. These
findings have important implications for the design of H&CC for LGBT seniors, they provide
useful insight into the patterns of service use among this group, and they point to actions that
can be taken on the part of service providers towards ensuring LGBT seniors receive care that is
culturally sensitive.

There are a number of policy options open to decision-makers considering remedies to the
social exclusion of LGBT seniors within the H&CC sector. As I outlined in the conceptual
framework, there are debates within the literature on social exclusion as to how governments can best implement solutions to social exclusion. Some argue that broad, population-wide solutions such as education programs are more likely to have a long-term impact on the social exclusion of certain population groups (Watt, 2001). Others, argue that targeted interventions for socially excluded groups are necessary to reduce their exclusion (Louis, 2007). In the case of the social exclusion of LGBT seniors, both approaches appear to have merit, and I argue that solutions to the social exclusion of LGBT seniors in H&CC should include both wide-spread education as well as smaller-scale intervention programs. Government mandated education and training programs in the H&CC sector would ensure that over the long-term, there is continued awareness of the needs of LGBT seniors in the H&CC context. In future, this may prove sufficient to address the needs of LGBT seniors. Currently, programs of H&CC which focus on LGBT seniors specifically would be of great benefit to the cohort of LGBT seniors who are lacking the availability of culturally appropriate care.

Given the risk that social exclusion of any population group poses, the findings of this thesis suggest that targeted H&CC services for LGBT seniors may be preferable to the current status quo which my findings suggest includes a lack of culturally appropriate H&CC services for LGBT seniors. The fact that both H&CC providers as well as LGBT seniors stated that LGBT seniors are likely to avoid accessing H&CC due to the lack of culturally appropriate services emphasizes the point that targeting and/or setting conditions for H&CC services aimed at LGBT seniors may prevent avoidance of H&CC among this group. Targeted services, such as: programs where all
staff are trained in culturally appropriate care for LGBT seniors; intake forms and data collection including LGBT categories; visible signs of LGBT seniors present in organisational literature; and LGBT-specific programming, would seem to go a long way towards ensuring that LGBT seniors are not further impacted by the social exclusion they experienced in the past.

7.4 Looking Forward

For governments, the finding that a small group of seniors were socially excluded may not have significant impact at the policy level, especially considering the perception that due to changing social attitudes and the increasingly widespread acceptance of homosexuality, LGBT individuals are no longer as likely to face discrimination. Further, as Morales et al. (2014) and others have documented, the current cohort of LGBT seniors, labelled the parents of the baby boom generation, appear to be different than the subsequent generation, the baby boom. As the baby boom generation ages we can expect different patterns of health and health care use to emerge. It should be noted however that although the social exclusion of the LGBT population may be shifting at a collective level, this may or may not be true at the individual level.

Although there are changing social attitudes towards homosexuality, the extent to which the impact of social exclusion will persist over time is unclear. Individuals from rural and remote areas may not experience the same shift in societal attitudes towards homosexuality as individuals based in metropolitan areas. Additionally, newcomers to Canada, specifically individuals from countries that are not widely accepting of homosexuality (or areas where
homosexuality remains illegal and punishable), are likely to have recent experiences of social exclusion which may continue to impact on their use of H&CC in the future.

In this thesis I found that LGBT seniors who have experiences of social exclusion may avoid accessing H&CC due to previous negative experiences in health care settings. Previous researchers have suggested that when LGBT seniors do access needed health care they are in a worsened state than their heterosexual peers due to delays in seeking out care when they need it (Brotman at al., 2003). Avoidance of health care, whether it is H&CC or care in other settings, risks increasing the cost of care to the health care system. While this issue may not be of grave concern to decision-makers due to the relatively small size of the LGBT senior population, these patterns are likely to have a much larger impact when applied to other socially excluded populations.

LGBT seniors are among the minority when considering the social exclusion of groups across Canada. Researchers and policy-makers have identified numerous groups which are considered socially excluded, including but not limited to: racialized and ethno-cultural groups (Galabuzi, 2006; Hiebert & Ley, 2003), newcomers to Canada (Caidi & Allard, 2005), aboriginal groups (Reading & Wien, 2009), homeless and under-housed groups (Somerville, 1998), and people with disabilities (Shier, Graham & Jones, 2009). Furthermore, these groups are not homogenous, and individuals within these groups (including LGBT seniors) overlap.
When taking into account the large number of groups of Canadians who can be considered socially excluded, it becomes obvious that solutions to social exclusion which are applicable to multiple groups of people would be beneficial not just in terms of H&CC, but for health care services more generally.

7.5 Research Limitations

In conducting this research I encountered limitations which are worth noting. First, I was limited in my access to LGBT seniors who had experiences with H&CC. Despite my efforts, I only interviewed one individual who identified as transgender, and thus the voice of transgender seniors is not well represented in this research. Second, I was challenged by what I perceived to be a lack of awareness within the H&CC sector about LGBT individuals. Although there are specific H&CC organizations which engage with LGBT seniors, and specific individuals within H&CC organizations who advocate for LGBT seniors, across Toronto there are many organizations who do not appear to consider LGBT clients. This posed a difficulty when attempting to engage with H&CC providers on this topic.

7.6 Directions for Future Research

The lack of data collection about LGBT seniors (and more broadly LGBT individuals) is a research issue which can impede both policy and practice regarding H&CC. I note here that the Toronto Central LHIN, as a part of their “Measuring Health Equity in the Toronto Central LHIN” mandate, now requires hospitals and community health centres to collect demographic information
including sexual orientation (Toronto Health Equity, 2015). This is a positive step towards increasing our understanding of the LGBT population, and hopefully this will soon extend to the H&CC sector. At the system level, the collection of data about LGBT seniors who need and use H&CC may be an essential first step towards building inclusive policies. Within H&CC organizations, collection of data about LGBT participants using H&CC services would contribute to awareness about the existence of LGBT participants (many H&CC agencies are not aware of who their LGBT clients even are), and may lead to the development of services for LGBT seniors. Without data that represents LGBT seniors, agencies are limited in their ability to advocate for the resources to build LGBT positive environments. The field of research on LGBT aging would benefit from future research which identifies practical guidelines for the collection of data about LGBT individuals in a manner that is comfortable and feasible for both H&CC agencies as well as LGBT individuals.

7.7 In Conclusion: History Matters

As I stated at the outset, the context of this thesis is grounded in the significant role that H&CC services play in the current political climate, and in the understanding that care “closer to home” can enhance the independence, well-being, and quality of life of older persons. However, when compared to care in different locations in the health system, H&CC requires a different understanding of individuals’ personal contexts and circumstances. H&CC often takes place over a long period of time, and requires that care providers have an intimate understanding of the lives of care recipients, where and how they live, and who they live with.
For LGBT seniors, who share experiences of social exclusion, this understanding is crucial to ensuring that they access H&CC. While social attitudes towards LGBT individuals are shifting with each subsequent generation, for many, social exclusion is still a current consideration.
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Appendix A: Ethics Approval

University of Toronto
Office of the Vice-President, Research
Office of Research Ethics

PROTOCOL REFERENCE # 24713
February 22, 2010

Dr. A. Paul Williams
Health Policy, Management and Evaluation
Faculty of Medicine, University of Toronto
Health Sciences Building, 4th floor
155 College Street, Suite 425
Toronto, ON M5T 3M6

Dear Dr. Williams and Ms. Watkins:

Ms. Jillian Watkins
Health Policy, Management and Evaluation
Faculty of Medicine, University of Toronto
Health Sciences Building, 4th floor
155 College Street, Suite 425 Toronto, ON M5T 3M6

Re: Your research protocol entitled, “Setting the Balance of Care for Sexually Diverse Seniors”

ETHICS APPROVAL

Original Approval Date: February 22, 2010
Expiry Date: February 21, 2011
Continuing Review Level: 1
We are writing to advise you that the Health Sciences Research Ethics Board has granted approval to the above-named research study, for a period of **one year**. Ongoing projects must be renewed prior to the expiry date.

All your most recently submitted documents have been approved for use in this study.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your study. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry, as per federal and international policies.

If your research has funding attached, please contact the relevant Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your project.

Yours sincerely,

S. Lanthier
Research Ethics Coordinator
Appendix B: Semi-Structured Interview Questions

Group 1 Interview Questions

Thank-you for participating in the research for my graduate thesis entitled: Setting the Balance of Care for Sexually Diverse Seniors. The goal of this research is to explore home and community care for seniors who identify as lesbian, gay, bisexual, and transgender (LGBT). Home and community care services include any health care services which are provided in your own home or community such as meals on wheels, home making, nurse visits, occupational therapy visits, and visits to day programs etc.

Personal Experiences

1. Please describe your previous experiences in health care settings (such as clinics, doctor offices, hospitals)
   Probe:
   • Did you ever experience discrimination because of your sexual orientation?

LGBT Culturally Appropriate Care

2. How would you describe LGBT culture?
   Probe:
   • Do you think that LGBT culture matters when we’re discussing home and community care?
3. Do you think that home and community care should be different for LGBT people?
   Probe:
   • What sort of things do you think are important when home and community care is provided to an LGBT senior?
   • What home and community care services do you think are most important to LGBT seniors? Social programs, care coordination, caregiver counselling etc.?
   • What advice would you give to a healthcare provider coming into the home of an LGBT person? Are there specific actions they should take?
   • Are there differences in how care should be provided to lesbian, gay, bisexual and/or transgender seniors? Please explain.
   • What does it take for care to be LGBT culturally appropriate?

Access to Home and Community Care
4. Do you think that LGBT seniors fear using home and community care services?  
Probe:
- If yes, what specifically do you think LGBT seniors are fearful of?
- What do you think happens when LGBT seniors have negative experiences with home and community care?

5. Do you think that LGBT seniors avoid using home and community care services?  
Probe:
- If yes, why do you think they avoid using home and community care services?
- Do you believe that LGBT seniors make efforts to hide their sexual identity from home and community care service providers?

6. Can you suggest ways in which LGBT seniors could be made to feel more comfortable when looking to access home and community care? Are there things that organisations could do differently?

Personal Experiences with Home and Community Care

7. Please describe your experience either receiving home and community care services or acting as a caregiver to someone receiving home and community care services.
Probe:
- Overall how would you describe the experience?
- How did you or the person you know get connected to the home and community care services?
- What were some of the barriers and/or facilitators to receiving home and community care services?

8. Were you or the person you know ever reluctant to access home and community care services because you are LGBT?  
Probe:
- Please explain why or why not?
- Did you or the person you know feel comfortable receiving the home and community care services as an LGBT person?
- Can you describe why you did not feel comfortable and what could have been done differently to make you feel better?

The next few questions ask you to give a score on a scale of 1 – 5.
9. As an LGBT person, when you think about your experiences with home and community care, how would you describe your feelings on the following areas:

<table>
<thead>
<tr>
<th>Recognition vs Rejection</th>
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<tbody>
<tr>
<td>(This refers to respect for differences or tolerance for diversity from home and community care providers)</td>
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<tr>
<th>Legitimacy vs Illegitimacy</th>
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<tbody>
<tr>
<td>(This refers to whether home and community care organisations help to make sure your specific interests and needs and listened to)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Inclusion vs Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>(This refers to equal opportunities to access home and community care services)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Participation vs Non-Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>(This focuses on your participation in the care decisions about home and community care)</td>
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</table>

<table>
<thead>
<tr>
<th>Belonging vs Isolation</th>
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<tbody>
<tr>
<td>(This refers to the existence or absence of shared values between you and your home and community care provider in terms of how home and community care is provided)</td>
</tr>
</tbody>
</table>
Group 2 Interview Questions

Thank-you for participating in the research for my graduate thesis entitled: Setting the Balance of Care for Sexually Diverse Seniors. The goal of this research is to explore home and community care for seniors who identify as lesbian, gay, bisexual, and transgender (LGBT).

LGBT Culturally Appropriate Care

1. How would you describe LGBT culture?
   Probe:
   - Do you think that LGBT culture matters when we’re discussing home and community care?

2. Do you think that home and community care should be different for LGBT people?
   Probe:
   - What sort of things do you think are important when home and community care is provided to an LGBT senior?
   - What home and community care services do you think are most important to LGBT seniors? Social programs, care coordination, caregiver counselling etc.?
   - What advice would you give to a healthcare provider coming into the home of an LGBT person? Are there specific actions they should take?
   - Are there differences in how care should be provided to lesbian, gay, bisexual and/or transgender seniors? Please explain.
   - What does it take for care to be LGBT culturally appropriate?

Access to Home and Community Care

3. Do you think that LGBT seniors fear using home and community care services?
   Probe:
   - If yes, what specifically do you think LGBT seniors are fearful of?
• What do you think happens when LGBT seniors have negative experiences with home and community care?

4. Do you think that LGBT seniors avoid using home and community care services?
   Probe:
   • If yes, why do you think they avoid using home and community care services?
   • Do you believe that LGBT seniors make efforts to hide their sexual identity from home and community care service providers?

**Home and Community Care Organisations**

5. What changes would you suggest to organisations aiming to improve access to services for LGBT seniors?
   Probe:
   • Do you believe that the majority of home and community care service providers are aware of their LGBT senior clients?
   • Can you suggest ways in which LGBT seniors could be made to feel more comfortable when looking to access home and community care? Are there things that organisations could do differently?
   • Do you think the home and community care sector currently does enough to provide care that is culturally appropriate for LGBT seniors?
   • Are there broader changes necessary to the home and community care sector in order for organisations to improve services for LGBT seniors?
   • If yes, What changes are necessary? Human resources, funding, legislation changes?
   • How do you think organisations can prepare to provide home and community care services to LGBT seniors?

**Vignette/Care Package Examples**

- Provide an example

6. Do you think this care package is appropriate for an LGBT senior?
   Probe:
   • Are there services that you think are inappropriate?
   • If yes, What makes the service inappropriate for an LGBT senior?
• Are there alternative services that you would suggest?
• Are there specific providers that you would suggest?
• Overall, how would this care package change?
• What considerations are important in this care package if the client were an LGBT senior?
• What specifically is important if the client were lesbian, gay, bisexual, transgender?

**Costs**

7. Do you believe it costs more to provide home and community care services to LGBT seniors?
Probe:

- Where would the additional costs come from?
- Training, additional staff, service changes/additions?
- Can you provide examples of these costs from your organisation?

**I.Innis**

“I.Innis is not cognitively intact and requires assistance with all ADLs (totally dependent with locomotion in the home, eating, toilet use, personal hygiene and bathing). I. Innis also experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). I.Innis has a live-in caregiver.”

1) Cognition- Not Intact (short term memory problem, never/rarely makes decisions, ability is limited to making concrete requests).
2) ADL- Totally dependent on others to complete ADL (locomotion in the home, eating, toilet use, bathing and personal hygiene) - full performance of activities performed by others.
3) IADL- Great Difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation) - little or no involvement in activity is possible.
4) Caregiver (in home?)- Yes. Provides advice/emotional support and assistance with ADLs and IADLs
### Care Package for I. Innis

<table>
<thead>
<tr>
<th>Service</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-Home Support PSW (CCAC)</td>
<td>4 hours/day</td>
</tr>
<tr>
<td>Occupational Therapist (CCAC)</td>
<td>1 visit/week (total 2 visits)</td>
</tr>
<tr>
<td>Transportation</td>
<td>10 two-way trips per month</td>
</tr>
<tr>
<td>Meals on wheels</td>
<td>6 times per week</td>
</tr>
<tr>
<td>Caregiver Respite (Paid)</td>
<td>15 hours/week</td>
</tr>
<tr>
<td>Caregiver Support/Education Group</td>
<td>1 every two weeks</td>
</tr>
<tr>
<td>Home Help/Homemaking</td>
<td>4 hours every other week</td>
</tr>
<tr>
<td>Home Maintenance</td>
<td>1/month</td>
</tr>
<tr>
<td>Adult Day Service (Alzheimer's/Other Dementia)</td>
<td>2 days/week</td>
</tr>
<tr>
<td>CCAC Nursing – medications management</td>
<td>1 visit/week</td>
</tr>
<tr>
<td>Pharmacy Blister Pack Set-Up and Delivery</td>
<td>1/week</td>
</tr>
<tr>
<td>LTC short stay (1.5 weeks)</td>
<td>2/year</td>
</tr>
</tbody>
</table>