THE BC HOME AND COMMUNITY CARE SYSTEM AND OLDER ADULTS LIVING WITH HIV

An environmental scan of governance, policies, and funding of the home and community care system as they affect individuals aging with HIV.

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CENTRE *for* EXCELLENCE
in HIV/AIDS

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Preface

This environmental scan documents the policies, funding, and governance, as well as the ownership and operation, of home and community care services in British Columbia (BC), placing them in the context of our population's changing needs and political climate. It details the structure of home and community care in BC, including home support, assisted living, and residential care services. In particular, the environmental scan focuses on how these structures affect older adults living with HIV. In spite of the growing importance of this issue, there is a lack of adequate research and attention given to the experiences of older adults with HIV in home and community care.

The objectives of this environmental scan are to:

1. Review the evolution of home and community care in BC;
2. Identify home and community care service availability and gaps in care; and
3. Consider how the unique needs of people aging with HIV will contribute to the growing need for home and community care, and how these needs may be better met.

An environmental scan provides decision-makers with information about factors that are outside of their sphere of control, but will have an impact on the success of their programs (1). With this in mind, our team at the BC Centre for Excellence in HIV/AIDS wanted to lay a foundation for meaningful research and policy within the home and community care sector. While this environmental scan may be of use to policy-makers and decision-makers in health authorities and community-based organizations, we hope it will also be useful to service providers and older adults living with HIV. By providing more information on service availability and client rights, we hope that home and community care clients and their families will be able to more successfully navigate the system and advocate for meaningful change.

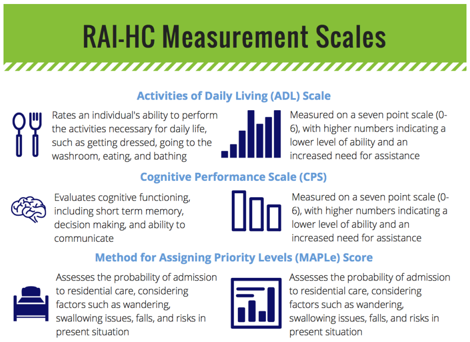
Partner Document

This environmental scan is intended to be read alongside its partner document: *A Provincial Overview of Community-Based Organizational Supports for Older Adults Living with HIV*. While the environmental scan documents formal support services through the home and community care system, the partner document details the community-based supports for older adults with HIV that may help fill in potential gaps left by the formal support system.

What will you see in this document?

In addition to written text, there are infographics summarizing information such as legislation and timelines of events. Information that is particularly pertinent for older adults living with HIV is featured in text boxes.

Infographics



RAI-HC Measurement Scales

Activities of Daily Living (ADL) Scale

Rates an individual's ability to perform the activities necessary for daily life, such as getting dressed, going to the washroom, eating, and bathing

Measured on a seven point scale (0-6), with higher numbers indicating a lower level of ability and an increased need for assistance

Cognitive Performance Scale (CPS)

Evaluates cognitive functioning, including short term memory, decision making, and ability to communicate

Measured on a seven point scale (0-6), with higher numbers indicating a lower level of ability and an increased need for assistance

Method for Assigning Priority Levels (MAPLe) Score

Assesses the probability of admission to residential care, considering factors such as wandering, swallowing issues, falls, and risks in present situation

Assesses the probability of admission to residential care, considering factors such as wandering, swallowing issues, falls, and risks in present situation

Acronyms Used in this Text

ADL - Activities of daily living
BC - British Columbia
CBO - Community-based organization
CHW - Community health worker
HCC - Home and community care
HIV - Human immunodeficiency virus
gbMSM - Gay/bisexual men who have sex with men
OALHIV - Older adults living with HIV
PLHIV - People living with HIV
PWID - People who inject drugs
PWUD - People who use drugs

These call-out bubbles contain **key messages** that summarize information applicable to OALHIV

Information Specific to OALHIV

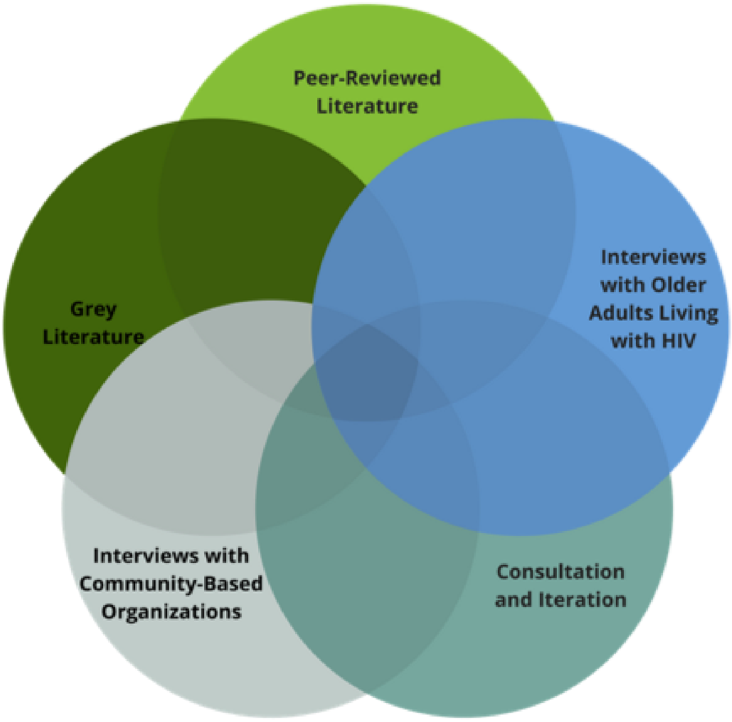
This type of box...
Will feature information from peer-reviewed and grey literature (reports and documents not published in academic journals) that relates specifically to HIV.

Living Experiences

This type of box...
Includes quotes or paraphrased messages from interviews with OALHIV who are currently or planning on accessing HCC, and interviews with case managers who work for HIV-related community-based organizations (CBOs) within the province.

Methods Used in the Creation of this Document

First, our team interviewed older adults living with HIV and HIV-related community-based organizations. After transcribing these interviews, we detected a number of main themes, which we used to guide our search of both peer-reviewed and grey literature. Finally, we hosted a community roundtable with service providers, older adults living with HIV, and local community-based organizations (CBOs), to receive feedback on an initial draft of the environmental scan. Main themes recorded from the community roundtable informed the final environmental scan.



Introduction

The baby boomer generation, born between 1946 and 1965, marked the greatest population increase of the past century (2). As of 2017, 1.9 million British Columbians were aged 50 or over, constituting approximately 39% of the total population. Home and community care (HCC) services are an integral part of the healthcare system in British Columbia (BC), particularly for individuals who are approaching older age. In 2017, approximately 14% of the current BC population accessed publicly subsidized HCC services (3–5). It is well-documented that healthcare services must adapt to support the baby boomer generation as they age and experience higher rates of illness (6,7). Baby boomers who are living with HIV, however, may fall through the cracks as they often represent the most marginalized group of older adults (8). Furthermore, the populations most affected by the HIV epidemic in BC (i.e. gay or bisexual men who have sex with men (gbMSM), people who use drugs (PWUD), and people of Indigenous ancestry) have unique healthcare needs. Many healthcare services developed for older adults were not originally established with their unique needs, experiences, or family and support structures in mind.

> Our province's HCC needs are changing as our population of older adults changes. The needs of communities most impacted by the HIV epidemic must also be reflected in HCC services.

HOME & COMMUNITY CARE SERVICES

HOME SUPPORT

Services provided to clients in their own homes. Community health workers provide assistance with activities of daily living (e.g. bathing, eating, going to the washroom, getting dressed, and taking medications). Specific nursing and rehabilitation tasks may also be provided by healthcare professionals. Intended for individuals who can still live safely in their own home but need assistance with minor tasks.

ASSISTED LIVING

Private units in apartment-style residences that also provide meals, housekeeping, assistance with taking medication, and other personal care services. Intended for individuals with low to moderate levels of disability who are able to live on their own with assistance.

RESIDENTIAL CARE SERVICES

24-hour nursing and supervision for individuals with complex care needs. Intended for individuals who can no longer live safely on their own.

Figure 1: Types of HCC Services (9)

Older adults living with HIV (OALHIV) are defined as people living with HIV (PLHIV) over the age of 50. While many disciplines define older adults as those over 65, among PLHIV, those over 50 have distinct physical and virological profiles that warrant specific focus (10). Further, OALHIV often face health-related consequences of the cumulative impacts of socio-structural marginalization over the life-course (11,12). In order to understand the current context of healthcare provision for OALHIV, a scoping review of the BC HCC system was conducted. This review helped identify the specific challenges and opportunities that are principal to supporting people living with HIV as they age.

The HCC system encompasses three main services, which will be the focus of this report: home support, assisted living, and residential care **(See Figure 1)**. In addition to these core services, services such as adult day programs, the Choice in Supports for Independent Living grant program, and palliative care fall within the larger framework of the HCC sector.

The Ministry of Health is the overall steward for HCC services in BC, and delegates funding and service delivery to the five regional health authorities: Fraser Health, Vancouver Coastal Health, Northern Health, Interior Health, and Vancouver Island Health **(See Figure 2)**. The First Nations Health authority can either fund care that is delivered through a health authority, or deliver the care directly, depending on the region where care is being provided. Finally, the *Home and Community Care Policy Manual*, published and updated by the BC Ministry of Health, is a comprehensive collection of policies that apply to public HCC services.

This report focuses on 3 main services in the HCC system:
1. Home Support
2. Assisted Living
3. Residential Care

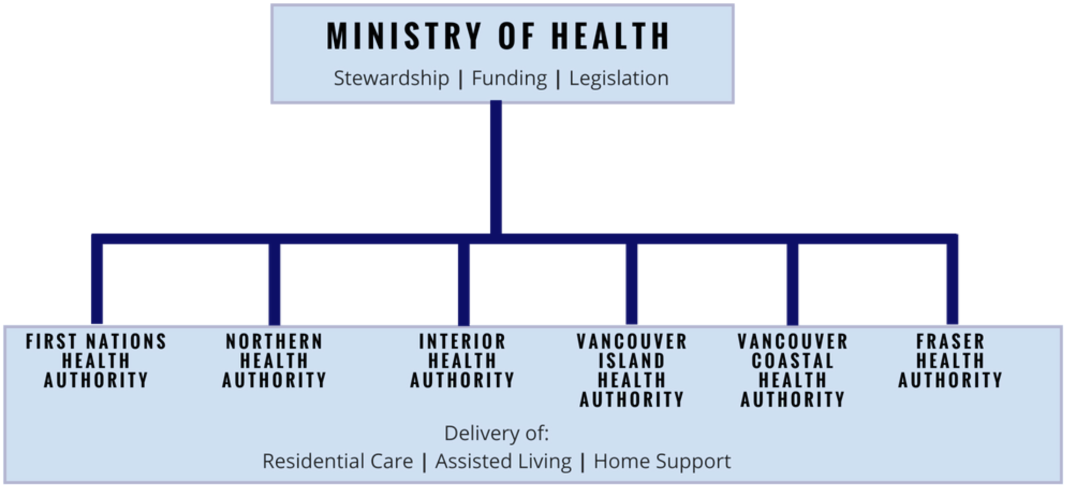


Figure 2: Governance Structure of HCC

Section 1

The Current Landscape of HIV, Aging, and Home and Community Care

1.1 Demographic Shift of People Living with HIV in BC

Advances in combination antiretroviral therapy have resulted in increased life expectancies for individuals living with HIV, who now have life expectancies comparable to those without HIV (10,13,14). Within the province of BC, these therapeutic advances, paired with a Treatment as Prevention® strategy, have contributed to a significant demographic shift, with an increasing proportion of PLHIV aged 50 or over. Data from the province's Drug Treatment Program at the BC Centre for Excellence in HIV/AIDS reveals that as of December 2016, nearly 56% of the 8,917 PLHIV living in BC engaged in HIV care were over the age of 50, compared to approximately 10% of PLHIV over the age of 50 two decades earlier **(See Figure 3)** (15). Among those aging with HIV, the transition into older age was unexpected for many, especially those diagnosed at the onset of the HIV epidemic.

Living Experiences of OALHIV

More than being unprepared to live into older age, long-term HIV survivors were told to prepare for an early death, and disposed of many assets. Living longer, which was unexpected for many, has put OALHIV in a precarious position later in life. In spending many years preparing to die, some older long-term survivors feel as though they missed out on life. Now that they are aging and once again thinking about the end of life, OALHIV may experience re-traumatization related to when they were first diagnosed with HIV.

BC has an aging population. The population of PLHIV is aging too: over half of PLHIV in BC are aged 50+.

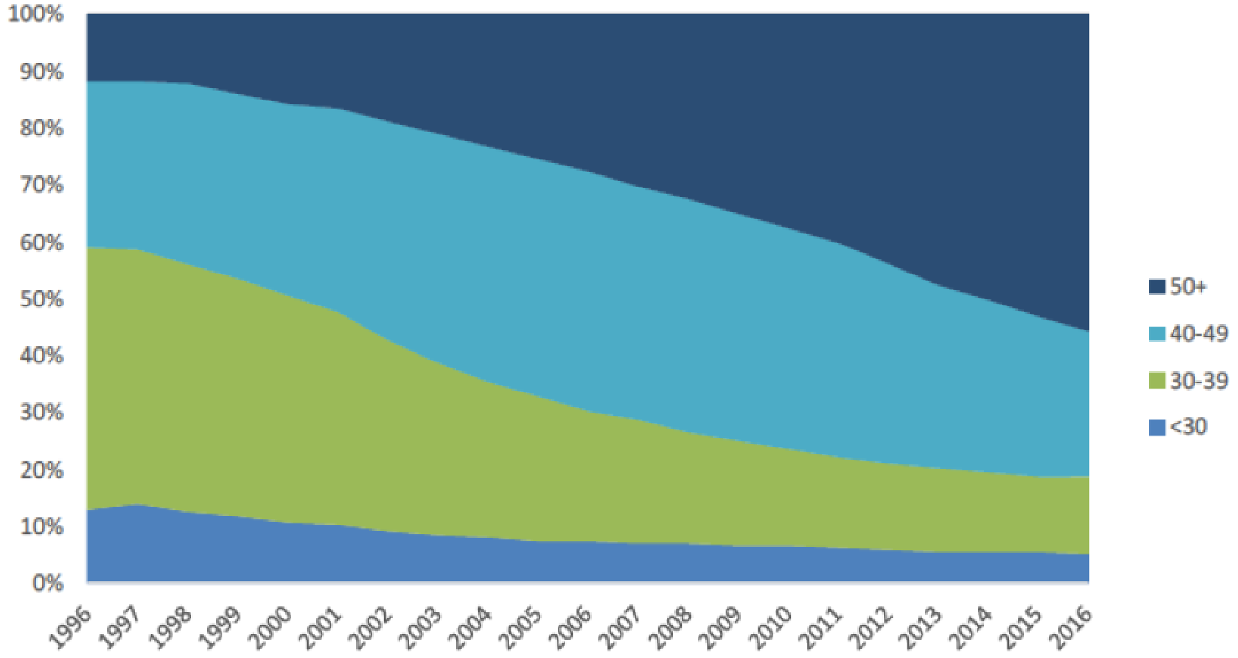


Figure 3: Annual age distribution of PLHIV engaged in care, 1996-2013 (15)

Among OALHIV in BC, 55% are between the ages of 50-59, 23.9% are between 60-69 years of age, 5.6% are between 70-79 years of age, and <1% are over 80 (15). Importantly, OALHIV in the province have been living with and managing their HIV for a median of 15 years (15). It should be noted, however, that these measures are an underestimate of OALHIV potentially requiring HCC, as they are limited to only OALHIV who are accessing treatment.

While the existing population of PLHIV is aging, the age at which people are being diagnosed with HIV is rising as well. Adults over 50 years accounted for only 7.9% of all new HIV diagnoses in Canada between 1985 and 2000; however, this number rose to 23.9% by 2015, representing a 300% increase (16,17). The experiences of older long-term survivors and newly diagnosed OALHIV vary greatly, in terms of both health status and social experiences (18).

It has become much more common for people to acquire HIV and be diagnosed after age 50.

1.2 Distinct Health Needs of Older Adults Living with HIV

The demographic shift occurring among PLHIV in BC has been accompanied by a subsequent rise in comorbid conditions and evolving healthcare needs. In regards to HIV care, OALHIV face multiple barriers to adhering to antiretroviral therapy, including medication complexity, side effects, and cognitive decline (19). In addition, management of multiple chronic conditions alongside HIV is now the rule, not the exception, among OALHIV (20). In a study of individuals aged 65 or over, seven times as many PLHIV had five or more co-occurring illnesses when compared to HIV negative individuals (21). These conditions may include co-infection with Hepatitis C, and non-infectious and HIV-associated-non-AIDS conditions such as cardiovascular disease, chronic kidney disease, non-infectious cancers, type 2 diabetes mellitus, and neurocognitive decline (21–24). Chronic conditions often have an earlier onset among OALHIV, and can be exacerbated by infectious comorbidities as a result of immune suppression, chronic inflammation, and long-term toxicities of combination antiretroviral therapy (22,25–28). Managing multiple conditions can result in potential medication interactions, pill burden, and related adverse health events (29–31). OALHIV are navigating complex and unprecedented terrain in managing their health that calls for enhanced coordination and integration of healthcare services.

OALHIV are navigating new, complex health concerns related to the long-term effects of HIV and HIV treatment. Initiatives to coordinate care, such as case management, may prevent OALHIV from falling through the cracks.

OALHIV are more likely to exhibit frailty at a younger age; frailty is a condition characterized by low levels of activity and increased susceptibility to injury (22,32,33). Frailty can lead to falls and resulting injury, and PLHIV over the age of 45 experience rates of falling similar to rates experienced by individuals without HIV over the age of 65 (34,35). Overall, OALHIV are at greater risk of falls and associated injuries, and would benefit from assistance with completing daily tasks that can lead to falls.

OALHIV experience distinct psychiatric and neurocognitive health challenges (18,36,37), in addition to the physical health challenges described above. Factors such as stigma, loneliness, declining health status, and financial distress place OALHIV at a higher risk for experiencing suicidal ideation, depression (28,38), and psychosocial stress (39). These challenges are often experienced alongside neurological changes, such as cognitive decline, which can further exacerbate mental health challenges (40). At the same time, OALHIV have shown high levels of resilience in coping with health and personal challenges (41–44). Early research in this field detected themes of contentment, patience, and a greater respect for life and death when asking OALHIV to reflect on living with HIV (45). More recent research has demonstrated how OALHIV draw strength from social supports, acceptance of the aging process, involvement in the community, and spirituality (44,46). In one study, time since HIV diagnosis was positively associated with self-efficacy among older gbMSM living with HIV (42). Strengths such as resilience and self-efficacy are known to improve both mental and physical health status among PLHIV (43,47,48).

Aging with HIV comes with distinct mental, emotional, and social experiences, including isolation, cognitive decline, and high rates of depression. While OALHIV show high levels of resilience, HCC must consider what care is appropriate for the person as a whole, rather than only their personal care needs.

1.3 Intersections of HIV-Related Stigma and Ageism

Experiences of stigma among OALHIV can be unique from the experiences of their younger counterparts (49–51). For OALHIV, HIV-related stigma often intersects with ageism, which can intensify feelings of loneliness, rejection, and low self-worth (49,50,52). In one study of OALHIV, 68% of participants reported previously experiencing both ageism and HIV-related stigma (53). In addition to exacerbating mental health challenges, such as depression and anxiety (12,50,54), experiences of stigma and discrimination can affect how OALHIV perceive and engage in formal and informal aging-related services (55,56).

Many older adults who experience challenges with everyday tasks rely on family and friends for assistance. However, studies have shown that OALHIV tend to have smaller and less robust social networks, in part because of HIV-related stigma and rejection (57–59). Further, anticipation of stigma may preclude OALHIV from engaging with senior-centred services in their community, such as faith-based or community centre programming (22). As a result, OALHIV may be less likely to have adequate community-based and informal supports, making them more reliant on formal HCC services (22,60,61).

Anticipation and experiences of stigma continue to persist among OALHIV accessing or planning to access HCC (56,62,63). In a qualitative study of OALHIV in Ontario, participants expressed concern about whether they would be accepted into residential care homes because of their HIV-status, and how they would be perceived by staff and other residents if they were to be accepted (56). In summary, the HCC setting poses a unique challenge to providing appropriate and inclusive care for OALHIV.

1.4 Diversity Among Older Adults Living with HIV

The population of OALHIV in BC is diverse, with individuals occupying multiple and intersecting positions in social, economic, and political structures. Diversity among OALHIV is important to acknowledge, as different groups of people may require different care to meet their individual health needs. Subpopulations of OALHIV who occupy socially marginalized positions in society (e.g. PWUD, gbMSM) are particularly vulnerable to negative health outcomes. This marginalization can also affect how OALHIV engage with healthcare services, such as HCC (49,64,65). Studies have documented how OALHIV who are part of gender and sexual minority groups, or who use illicit drugs, have concerns about moving into communal living environments, such as assisted living or residential care facilities (56,66–68). These environments can complicate an individual’s right to privacy related to HIV status, substance use behaviours, and sexual activity. The prevalence of substance use, as well as the increasingly common use of cannabis for medical and wellbeing purposes, highlights the need for harm reduction interventions and approaches in home and community care.

Data from the Drug Treatment Program at the BC Centre for Excellence in HIV/AIDS captures some of this diversity, but is limited to the 4,974 OALHIV who were accessing treatment as of 2016. This data reveals that most OALHIV live in the Vancouver Coastal and Fraser health authorities **(See Figure 4)** (15). It also demonstrates how the social demographics of OALHIV has changed over the past two decades. For example, the population of women living with HIV saw a 50% increase between 1996 and 2016 (15). As of 2016, females with HIV who are aged 50 or over made up almost 12% of the total population of OALHIV (15). A disproportionate number of OALHIV identify as Indigenous: 10.5% of OALHIV identify as Indigenous, while Indigenous Peoples constitute only 5% of the province’s total population (15,69). Other common ethnic backgrounds included White (69.9%), Hispanic (1.9%), Black (1.9%), and Asian (4.9%) (15). 30.3% of OALHIV in BC use injection drugs, and 7.8% reside in Vancouver’s Downtown Eastside neighbourhood (15). Different ethnic and cultural groups may have distinct needs with regards to aging well, HIV care, and HCC. This data, while limited to OALHIV receiving treatment in BC, highlights the need for personalized healthcare that considers the complex intersections of aging, HIV status, and socio-structural characteristics.

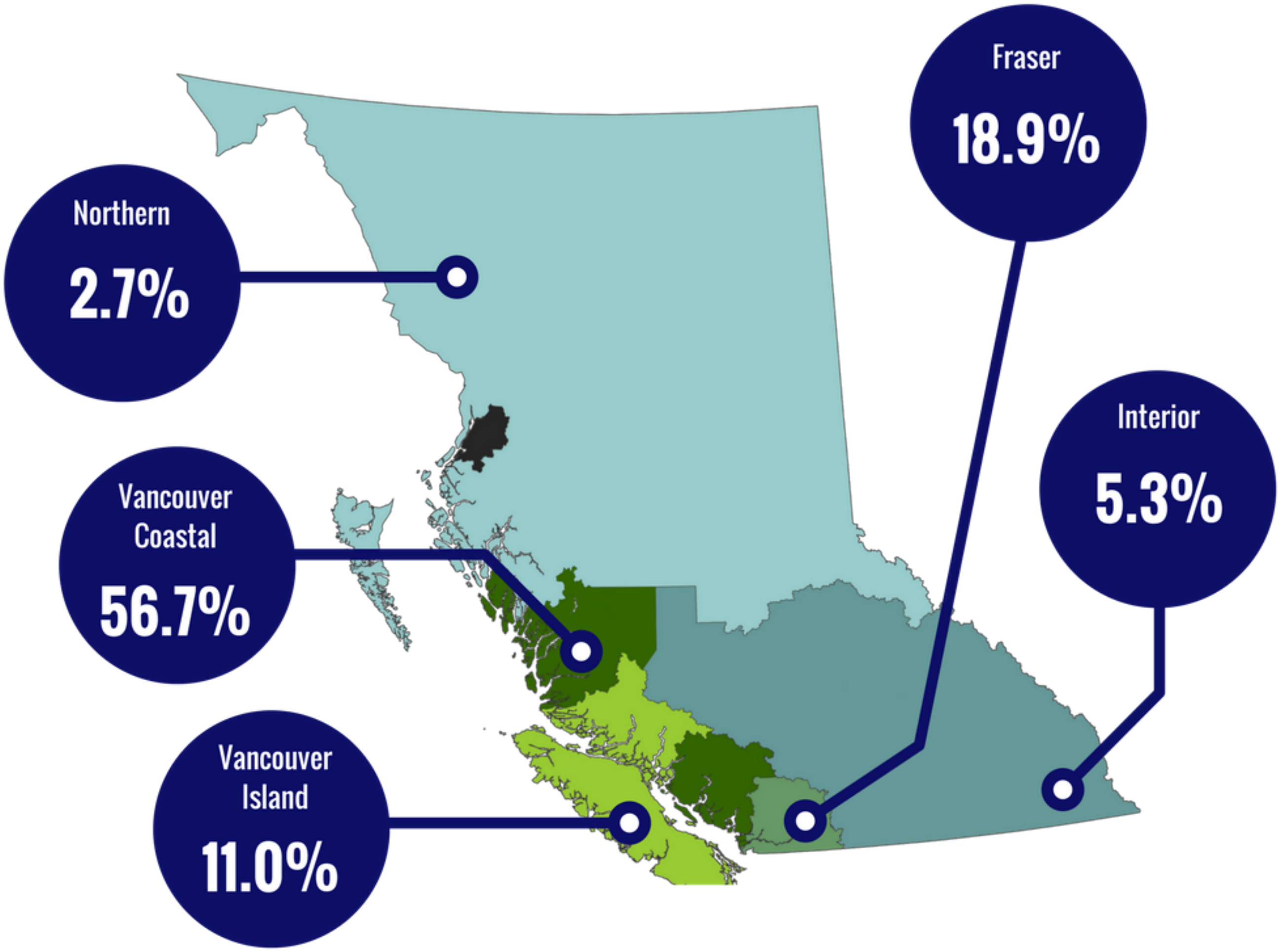


Figure 4: Proportion of OALHIV Accessing HIV Treatment in the 5 Health Authorities (15)

1.5 Historical Overview of the Home and Community Care System and the HIV Epidemic in BC

HCC was established under the Ministry of Health as a provincial program in 1978 (70). Initially known as Long-Term Care, this program was developed to support elderly adults with chronic disabilities. From 1978 to 1983, home support (then referred to as homemaking) services were scaled-up during an initial growth phase (71).

In 1991, the Royal Commission on Health Care and Costs (The Seaton Commission) called for the deinstitutionalization of healthcare, and a paralleled increase in care provided in the community (72). From this point up until the mid-1990s, home support continued to increase, while access to residential facilities decreased under funding constraints and the Seaton Commission's recommendation to bring care closer to home (71).

Up until the mid-1990s, BC was a leader among the provinces for prevention-based care, such as HCC (72). Following this time, however, the federal government imposed a period of funding cuts for social programming, which affected HCC (73). In line with the Seaton Commission, savings from cuts made to acute and institutional care services were to be reinvested into services closer to home. Cuts to residential care services resulted in an increased number of home support clients with complex healthcare needs (72,74). While these needs were intended to be met by reinvestment in home support, mounting pressures such as inflation, expensive new technology, and increases in the proportion of seniors prevented the savings from being transferred (74). As such, home support was restricted to individuals with urgent healthcare needs, and many day-to-day services, such as food preparation and housekeeping, were eliminated from the roster of home support provisions (72,75).

After the 1990s, residential care services were subjected to funding cuts. This created a shortage in residential care, and meant that clients receiving home support had more complex needs.

Living Experience of an OALHIV

"Whenever I needed anything extra, when I went through something, I would just call up [home] care and they'd OK for me to get an extra shift. I didn't abuse it; I didn't constantly say I needed more help. But that's when the cuts started happening [...] it was such a noticeable thing [...]."

Living Experience of an OALHIV

"The only thing I am actually assessed to get now, the way that home care is given out, is personal care. All of the cooking, cleaning errands [are] all cut out. I have certain workers that will do a little bit of it but they're getting in trouble now and looking at me and going "I just can't do it anymore." [...] Because of my skin infections, [...] my sheets used to get changed everyday. [Now], I buy more sheets."

By the time the campaign period for the 2001 provincial election began, media attention was directed towards the shortage of residential care in the province (75). More specifically, during the winter flu season of 1999-2000, many seniors awaiting placement in residential care were occupying acute care beds in hospitals. In response, the BC Liberals incorporated a promise for 5,000 new, non-profit intermediate and residential beds – to be built by 2006 – into their platform (76). Once elected, the BC Liberals instigated a series of systemic changes to the HCC sector.

Changes to HCC enacted by the BC Liberals began with the Continuing Care Renewal Plan, released in April 2002. One of the Plan's main goals was to develop the assisted living system and expand home support, in order to circumvent unnecessary institutionalization (77). With the same goal in mind, the Plan restricted residential care eligibility criteria, so that only individuals with complex medical needs could access residential care (78).

In effect, the initial promise of 5,000 new long-term care beds decreased to 1,500 long-term beds, with an additional supplement of 3,500 assisted living beds (71). Two years after the 2006 deadline, the government announced that it had created 3,677 beds, but did not specify if this was a net change, or whether these beds were residential or assisted living units (71). In more recent years, the BC Liberals have emphasized expanding home support and assisted living services, rather than residential care: reports released by the Ministry of Health in 2015 and 2017 stated the importance of having seniors stay at home for as long as possible (9,79).

Shifting demographics, along with the variety of indicators measuring access to HCC, present challenges in evaluating the success of the Liberals' Continuing Care Renewal Plan.

Living Experience of a Caseworker for OALHIV

We asked a CBO about how cuts to home support have affected OALHIV.

They responded by saying that there are now massive deficiencies within the system regarding what home support is willing to do versus what clients need. Before the cuts occurred – around 15 years ago – cooking, cleaning, and light housekeeping duties were available. Now, home support only helps with bathing once per week, getting dressed, and getting in and out of bed. When more supports were provided, people were able to stay independent. However, after the cuts, people were relegated to residential care facilities and many passed away soon after.

For example, the Canadian Centre for Policy Alternatives found that access to home support services for individuals aged 75 and over decreased by 30% between 2001/02 and 2009/10, after taking into account the 28% increase in the number of seniors during this time period (84). Another report published in 2017 indicates that a larger proportion of seniors were receiving home support services than in 2001, but each client received fewer visits with health professionals (80). Along the same lines, access to residential care declined by 20% between 2001 and 2016 (measured as beds relative to the population aged 75 and over) (80). The fractures in the HCC system are, in part, a result of financial pressure on this sector: since 2001, the number of seniors aged 75 or over has increased by 49%, while the increase in funding over this same period has been the lowest among the provinces, at 3.3% per capita (80). It remains unclear how successfully the Liberals' Plan expanded access in the community and closer to home.

Regardless of the ambiguous outcomes of the Continuing Care Renewal Plan, there have been other cost-effective and responsive actions taken by the Ministry in recent years. Since 2007, the Ministry of Health has provided Age-Friendly BC grants and other supports to help communities create more age-friendly environments (9). In 2014, the Ministry created the Office of the Seniors Advocate, which evaluates seniors' services and puts forward recommendations to the government, increasing transparency within the sector (80). One such recommendation was to increase funding to residential care facilities, in order to ensure that they have adequate resources to meet staffing guidelines.

A BRIEF HISTORY OF HOME & COMMUNITY CARE IN BC

1978
Program established under the Ministry of Health

1983
Completion of the initial **growth phase**, in which home care nursing and homemaker services (now referred to as home support) were scaled up

1991
The Seaton Commission (Royal Commission on Health Care and Costs) called for **deinstitutionalization,** with care provided closer to home

1993
Funding and capacity for residential care **diverted** towards homemaking and home care nursing sectors

1995
Impact of **federal funding cuts** reached home and community care. Services became more medically focused and were restricted to individuals with higher care needs

2001
BC Liberals won the provincial election. Their platform included a promise to build **5000** new long-term and intermediate care beds by 2006, as a result of increasing pressure on these services

2002
BC Liberals implement the **Continuing Care Renewal Plan**. Planned to expand assisted living and home care services in order to prevent unnecessary institutionalization

2006
BC Liberals did not meet their goal of 5000 intermediate and long term care beds

2008
The **BC Ombudsperson** launches an investigation of HCC services. **176 recommendations** are put forward

2010
Report by the **Canadian Centre for Policy Alternatives** finds that access to home support services have decreased by **30%** since 2001

2014
Ministry of Health creates the **Office of the Seniors Advocate**

2016
Report by the **Canadian Centre for Policy Alternatives** finds that access to assisted living and residential services have decreased by **20%** since 2001

2017
BC Liberals announced an additional **$500 million** over four years to increase staffing levels in residential care facilities

Both the BC Liberals and BC NDPs make statements about their potential contributions to HCC as part of their campaign platforms during the **provincial election**

Figure 5: Historical Overview of HCC Services (72, 80-83)

In response, in March 2017, the BC government announced an additional $500 million in funding over four years to improve staffing levels in residential care facilities (85).

During the campaign period for the May 2017 provincial election, both the BC NDP and the BC Liberals made statements about their potential contributions to HCC services (86). The BC Liberal platform included an addition of 500 publicly funded residential care beds by 2022, while the BC NDPs planned to invest $90 million by 2020 to improve home support and residential care.

With many changing factors, it is hard to know if access to home support is improving. Recently, several government initiatives have been put in place to help improve access.

1989
Establishment of BC's first needle exchange in Vancouver

1992
Establishment of the BC Centre for Excellence in HIV/AIDS

1996
The advent of Highly Active Retroviral Treatment (HAART). 1996-1999 marked the "HAART Era"

2001
Vancouver implements its Four Pillar Drug Strategy, including the pillar of harm reduction

2002
The Dr. Peter Centre provides supervised injection services to its clients

One-for-one needle exchange is replaced with unlimited needle distribution province-wide

2003
Insite, North America's first Supervised Injection Site, opens

2006
Treatment as Prevention, "TasP" is adopted by BC CfE HIV/AIDS

2012
TasP is expanded, due to its success in reducing transmissions

PRESENT DAY
BC is approaching its 90-90-90 goal: 90% of positive people diagnosed, 90% of those diagnosed on treatment, and 90% of those on treatment virally suppressed. As of 2013, BC had achieved 82-83-51

Figure 6: Historical Context of HIV in BC (90-92)

Historical Context of HIV

In Canada, HIV transmission has remained the highest among gay, bisexual, and men who have sex with men (gbMSM). New cases of HIV among gbMSM peaked between 1984 and 1986, and then continued to decline until 1999 (16). Cases of HIV transmission among people who inject drugs (PWID) peaked between 1986 and 1990, shortly after cases peaked among gbMSM (16). Injection drug use remained the second leading route of HIV transmission, and was exceeded only by transmission among gbMSM, until 2005 (16).

In BC, new diagnoses of HIV in all populations was highest in 1987 (87). Nationally, the HIV epidemic among PWID peaked between 1986 and 1990, but provincial rates peaked almost a decade later, from 1994 to 1997 (16,87). While gbMSM were the population with the highest HIV transmission rates throughout Canada, in BC, PWID and gbMSM had comparable transmission rates between 1995 and 2002 (16,87–89). HIV transmission among PWID has declined greatly since 2000 (16,87–89). At one point in time, as many as 300 people in BC acquired HIV every year by sharing injecting equipment; fewer than 50 infections a year resulted from injection drug use between 2011 and 2015 (16,87–89). This decline in HIV transmission among PWID is attributable to advances in HIV treatment and harm reduction policies.

Section 2

Cost of Receiving Care

2.1 Navigating Public Versus Private Sectors

Over the past two decades, BC has seen a changing landscape of ownership in the HCC system. Understanding ownership within the HCC realm can be complex: there are three types of ownership, three types of delivery, and two types of funding (93). For the purposes of this report, "public" ownership refers to services operated by the health authorities, "non-profit" ownership refers to religious or community organizations that redirect any revenues back towards client services, and "for-profit" ownership denotes services for which owners and shareholders retain revenues. Further, a distinction must be made between who owns the service, and who delivers or operates the service. Delivery may also be provided through "public," "non-profit," and "for-profit" providers, regardless of the type of ownership under which the organization falls. Finally, there are two types of potential funding that an organization may receive. "Public" funding is when the government provides some level of subsidization for the service, while "private" funding is when the client pays the full cost of the service. A service that is publicly funded is accessed through the health authority, while a service that is privately funded is accessed through the service provider directly (79). A service that is privately funded does not fall under the provincial legislature and regulations that are established for publicly funded services (74).

Many stakeholders within the HCC system have cited an increase in the proportion of for-profit and private services since 2001 **(See Figure 7, 8)** (80). In the context of BC, Bill 29 (the *Health and Social Services Delivery Improvement Act*) and Bill 94 (the *Health Sector Partnership Act*), along with a variety of changes in funding delegation have been cited as contributing factors to the growth of the for-profit and private sectors (80).

Living Experiences of an OALHIV

"Think of it this way. You all see the advertisements on TV for pay service. Those are the people that come in and say, 'Hi, how are you feeling today?' and actually build [relationships]. This is your friend. This is your little angel in waiting. That's the premise if you can afford it. But if you are government-assisted, if you can't afford it, we'll just put you in a hospital bed. It's not cost-effective. It doesn't have to be. It's not about money. It's about whether you die sooner."

There has been ample debate about the impact of privatization on the quality of HCC services. Advocates for the private sector argue that privatization can create a more sustainable and efficient market for HCC services without any reductions in the quality of care, which is urgently needed given the demographic shift towards an aging population (94). At the same time, research based in BC has shown that the number of complaints filed, as well as cases of pneumonia, anaemia, and dehydration, were higher in for-profit facilities than they were in non-profit facilities (95–97). Finally, many stakeholders are concerned that for-profit and private facilities choose to prioritize revenue over quality healthcare.

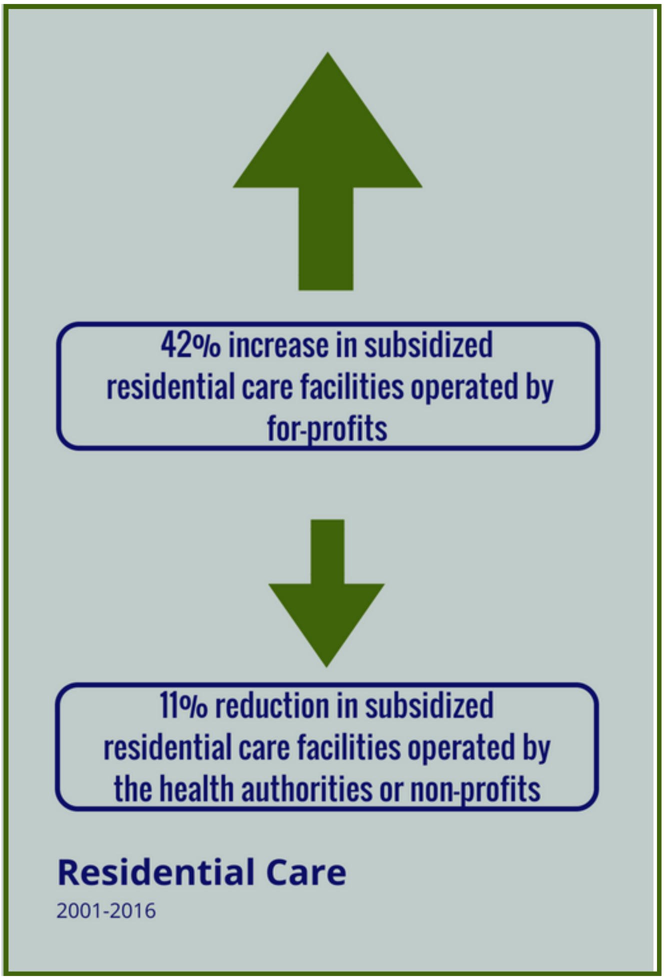
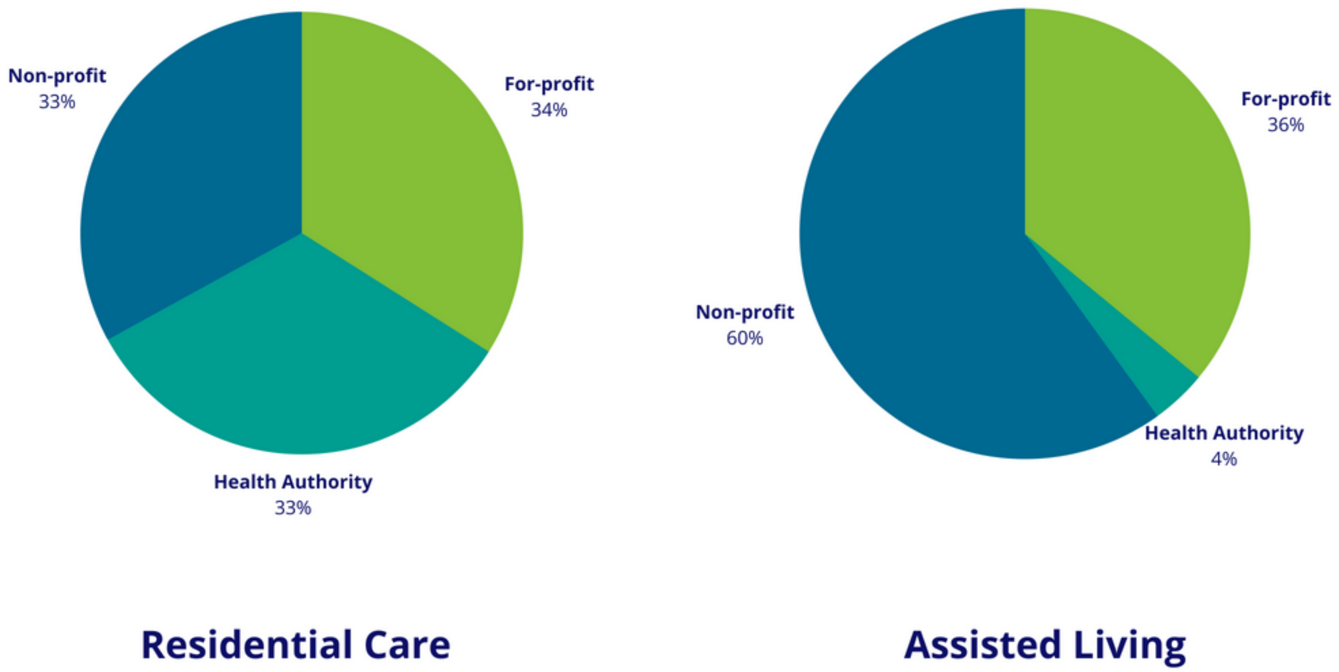


Figure 7: Change in Ownership of Residential and Assisted Living Services from 2001-2016 (80)

Living Experience of an OALHIV

"[…] The way that a company is able to meet the demands of beating out competitors to get a contract, is [by] keeping their cost lower than others. So they're hiring part-time people with less benefits or no benefits, right? Lower wages. [That's why] I've never known any of the new workers […]."



Residential Care

Assisted Living

Figure 8: Ownership of Residential Care and Assisted Living Facilities as of 2014 (79)

2.2 Fee Structures

Despite government subsidization, fee waivers, and fee exceptions, HCC costs remain burdensome to some seniors and their families. This is particularly pertinent given many seniors' precarious financial circumstances. Poverty among BC seniors has been increasing since the 1990s: in 1996, 2.2% of seniors lived in poverty, compared to 12.7% in 2014, a total of 96,000 seniors (98).

Poverty among OALHIV

Poverty rates are higher among both seniors and PLHIV; 44% of seniors compared to 17% of working-age adults have an income below or marginally above the poverty line (98). A quarter of PLHIV in BC have an income well below the poverty line, at $10,000 annually (99). OALHIV experience the risk factors that contribute to low income among both seniors and among PLHIV, which places private services out of reach for many, and creates greater need for financial assistance in order to access HCC (98).

The type of service being provided, and whether the service is purchased through private or public funding, determines HCC service costs. Clients purchasing privately funded services receive no governmental assistance, and must pay the full cost of service out of pocket or through a private insurance plan (93). As with other extended healthcare services in the public sector, healthcare consumers are required to pay a portion of the cost of their care, known as "co-payments", under the *Continuing Care Act* and the *Continuing Care Fees Regulation.*

Living Experiences of an OALHIV

"When he came into my house to tell me about these cuts, [...] I said 'what do you expect me to do?' So he comes up with this paperwork. The one sheet is a list of all of the [private] companies that do this. I think they went somewhere from $22 to $50 an hour. [...] So I hired independently [...someone who works] under the table, kind of, to make ends meet. Anyway, I hired her. I couldn't afford what I really need."

Monthly rates for subsidized home support, assisted living, and residential care services are determined by clients' after-tax annual income, subject to predetermined minimum and maximum rates **(See Table 1)**. Provincial medians and ranges for private services are also provided for comparison **(See Table 2, 3)**.

Cost of Receiving Care for OALHIV

OALHIV receive much more costly care than HIV negative seniors in their last year of life, due to greater use of acute care services and lower rates of home support (100). For example, healthcare costs for PLHIV in Ontario during their last year of life were 50% greater than their HIV negative counterparts (100). The availability and intensity of home support services may influence healthcare utilization among OALHIV.

Type of Care	Method of Calculating Monthly Rate	Minimum Monthly Client Co-Payment	Maximum Monthly Client Co-Payment
Residential Care	Client with income less than $19,500 per year: after-tax income, minus $3,900, divided by 12 months	$0	$1,300
	Client with income equal to or over $19,500: 80% of after-tax annual income, divided by 12 months.	$1,130.60	$3,278.80
Assisted Living	70% of after-tax annual income, divided by 12 months	$1,000.80	Based on market housing costs, hospitality services, and the real cost of services within the geographic region
Home Support	Multiply after-tax annual income by 0.00138889, divided by 12 months	$0	$300.00

Table 1: Client Fees for Publicly Funded Services (101)

Type of Care	Method of Calculating Monthly Rate	Provincial Range	Provincial Median
Residential Care	Determined by the care provider	$2,275.00-$9,900.00	$5,750.00
Assisted Living (One Bedroom Suite)	Determined by the care provider	$1,595.00-$6,700.00	$2,900.00

Table 2: Client Fees for Privately Funded Residential Care and Assisted Living Services (102)

Type of Home Support Service	Method of Calculating Hourly Rate	Provincial Range (Per Hour)	Provincial Median (Per Hour)
In-Home Meal Preparation	Determined by the care provider	$16.00-$40.00	$28.00
Laundry/Housekeeping	Determined by the care provider	$16.00-$40.00	$28.00
Personal Care (Bathing/Dressing)	Determined by the care provider	$16.00-$40.00	$29.88
Home Nursing	Determined by the care provider	$40.00-$75.00	$55.00
24 Hour Live-In Care	Determined by the care provider	$17.50-$34.70	$27.50

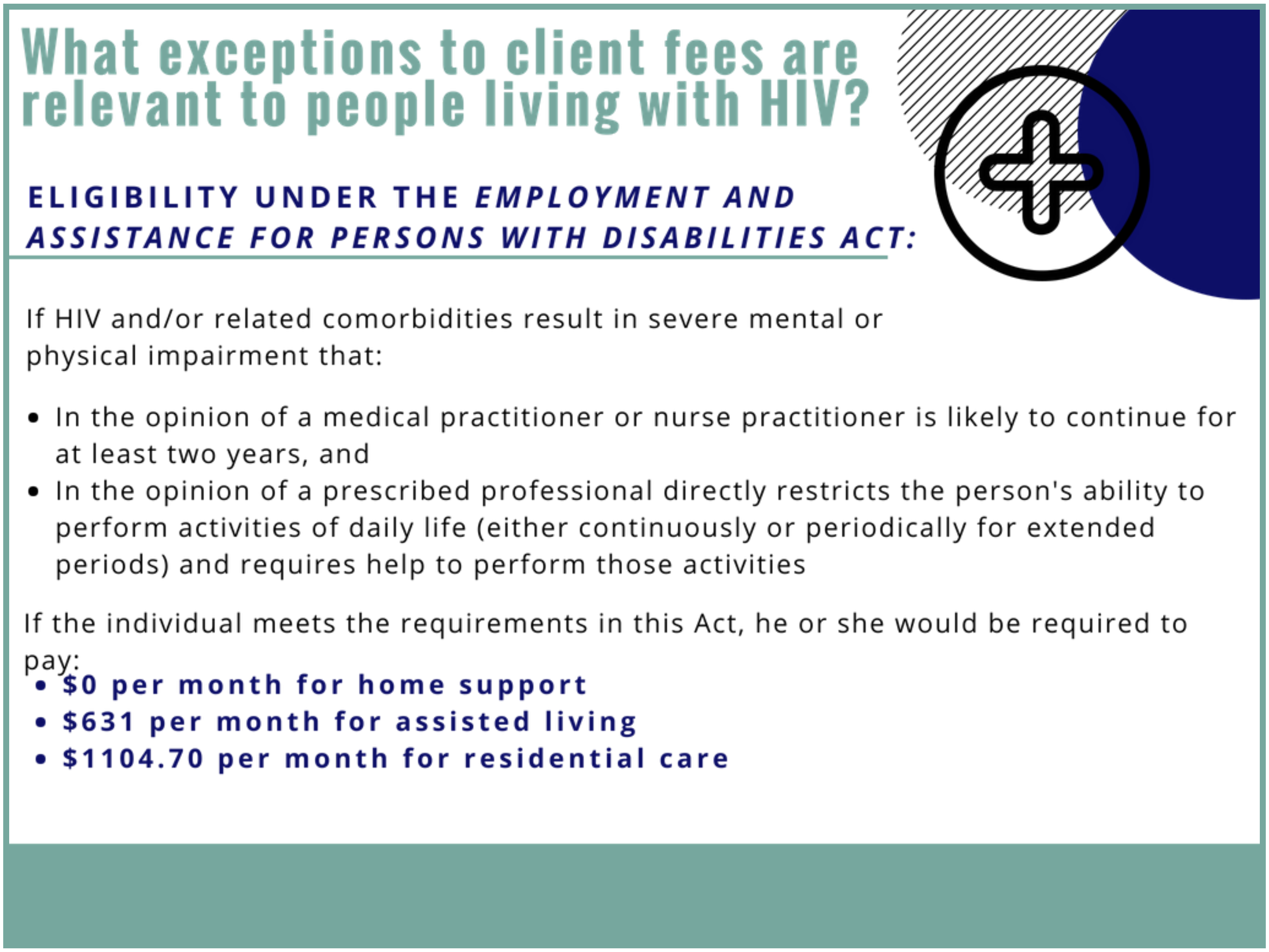
Table 3: Examples of Potential Fees for Different Private Home Support Services (102)

Services such as meal preparation and housekeeping are typically only provided through the private sector. If an individual can't afford to pay, they may be forced to go without, or be relegated to a higher level of care such as residential care.

2.3 Exceptions to Fee Structures

In circumstances outlined by the *Continuing Care Fees Regulation* and the *Home and Community Care Policy Manual*, client fees for publicly subsidized care may be waived, reduced, or covered by an alternate payer **(See Figure 9)** (101).

The health authority may grant up to one year of temporary reductions or waivers to clients who can demonstrate that they (or their spouses or dependants) will experience serious financial hardship as a result of paying their assessed rate (101). According to the Ministry, serious financial hardship manifests as a clients' inability to pay for housing and heating, adequate food, medication, or other required health services (101). Clients must submit an application for fee waivers or reductions to the health authority. The BC Ombudsperson has expressed concerns that seniors are not permitted to claim expenses such as hygiene products, gifts, and shoes when calculating their ability to meet financial needs, potentially hindering the accuracy of financial hardship applications (74).



What exceptions to client fees are relevant to people living with HIV?

ELIGIBILITY UNDER THE *EMPLOYMENT AND ASSISTANCE FOR PERSONS WITH DISABILITIES ACT*:

If HIV and/or related comorbidities result in severe mental or physical impairment that:

- In the opinion of a medical practitioner or nurse practitioner is likely to continue for at least two years, and
- In the opinion of a prescribed professional directly restricts the person's ability to perform activities of daily life (either continuously or periodically for extended periods) and requires help to perform those activities

If the individual meets the requirements in this Act, he or she would be required to pay:

- **$0 per month for home support**
- **$631 per month for assisted living**
- **$1104.70 per month for residential care**

Figure 9: Exceptions to Client Co-Payments for PLHIV with Disability Insurance (101)

Section 3

Guiding Regulations

3.1 Legislation Pertaining to Home and Community Care

Monitoring and regulatory procedures are instrumental to maintaining consistent standards of care across regions and services. An easily accessible complaint and incident reporting process, as well as inspections and investigations conducted by governing bodies, are key to ensuring that monitoring and regulatory procedures are successful (103). The onus is on health authorities to manage the performance of HCC services by determining performance standards and measures, reporting progress, and having quality improvement measures in place (104). The Ministry of Health, along with the Ministry of Healthy Living and Sport, govern legislative and regulatory provisions for HCC services. *The Home and Community Care Policy Manual*, published and updated by the Ministry of Health, is a comprehensive guide to the application of these regulatory frameworks. Unlike medical services, HCC services are not prescribed under the *Canada Health Act* and its principles of public administration, accessibility, comprehensiveness, universality, and portability. Instead, policy for HCC services is found in various acts and regulations, depending on the service provided.

For example, residential care is legislated by either the *Community Care and Assisted Living Act* or the *Hospital Act* **(See Figure 10)**. Critics contest that these acts create artificial distinctions between clients of facilities governed by the respective acts, as well as gaps in policy (83). Prospective residents are often unaware of this distinction, and maynot be able to access certain rights depending on in which type of facility they reside.

Hospitals and extended care facilities are governed by different regulations than assisted living and residential care facilities. Even though there are some differences between the two pieces of legislation, clients are often not told which type of legislation is applicable to where they are living.

An integral component to both the *Community Care and Assisted Living Act* and the *Hospital Act* is the Residents' Bill of Rights **(See Figure 11)**. This Bill distils much of the standards of care that are listed in the *Residential Care Regulation*, and is a coalescence of human rights, personal freedoms, and consumer rights. Although this list is not inclusive of all the rights that clients have when receiving residential care, the purpose of this list is largely educational, and thus all residential facilities must have the list publicly displayed.

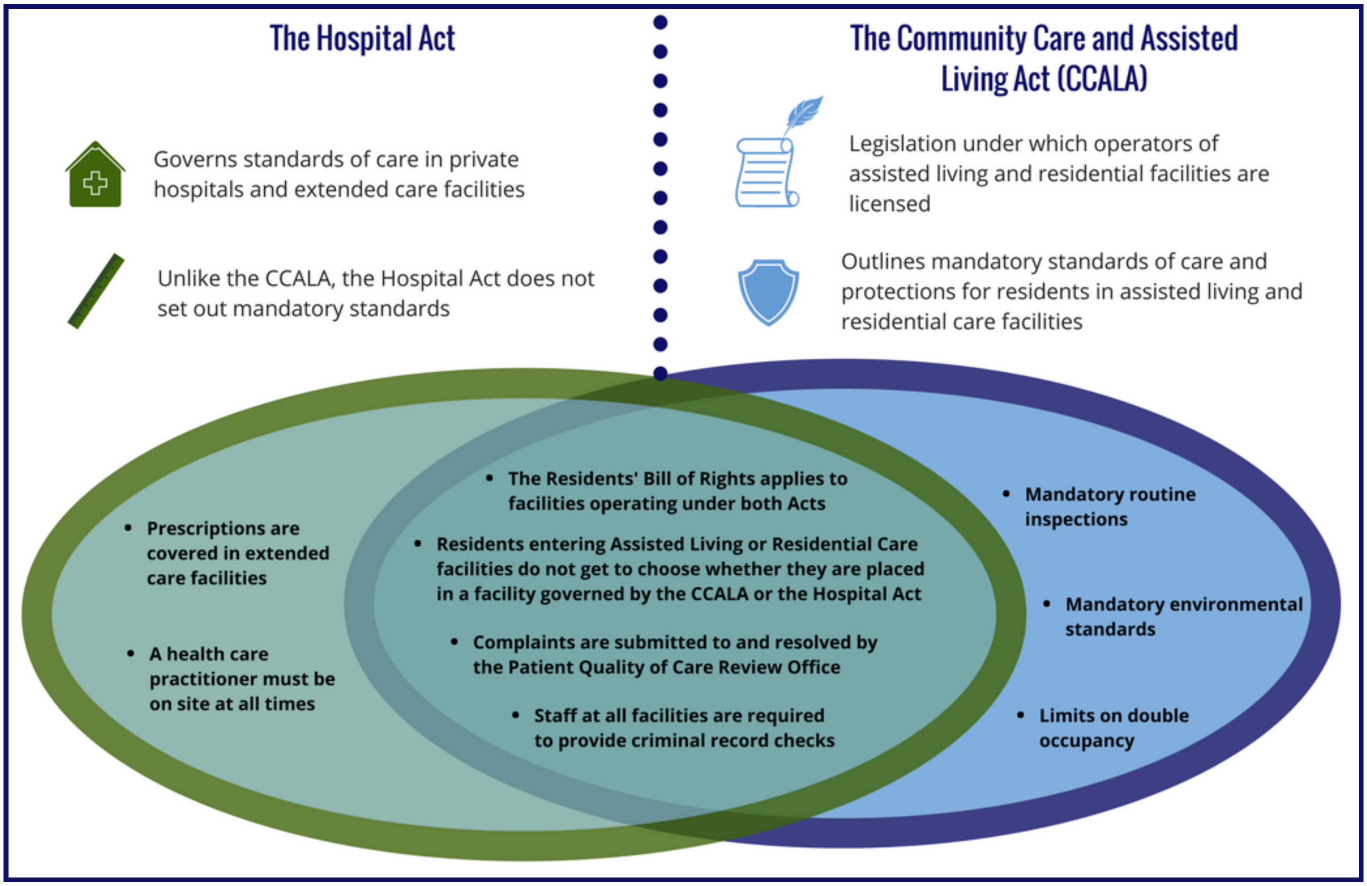
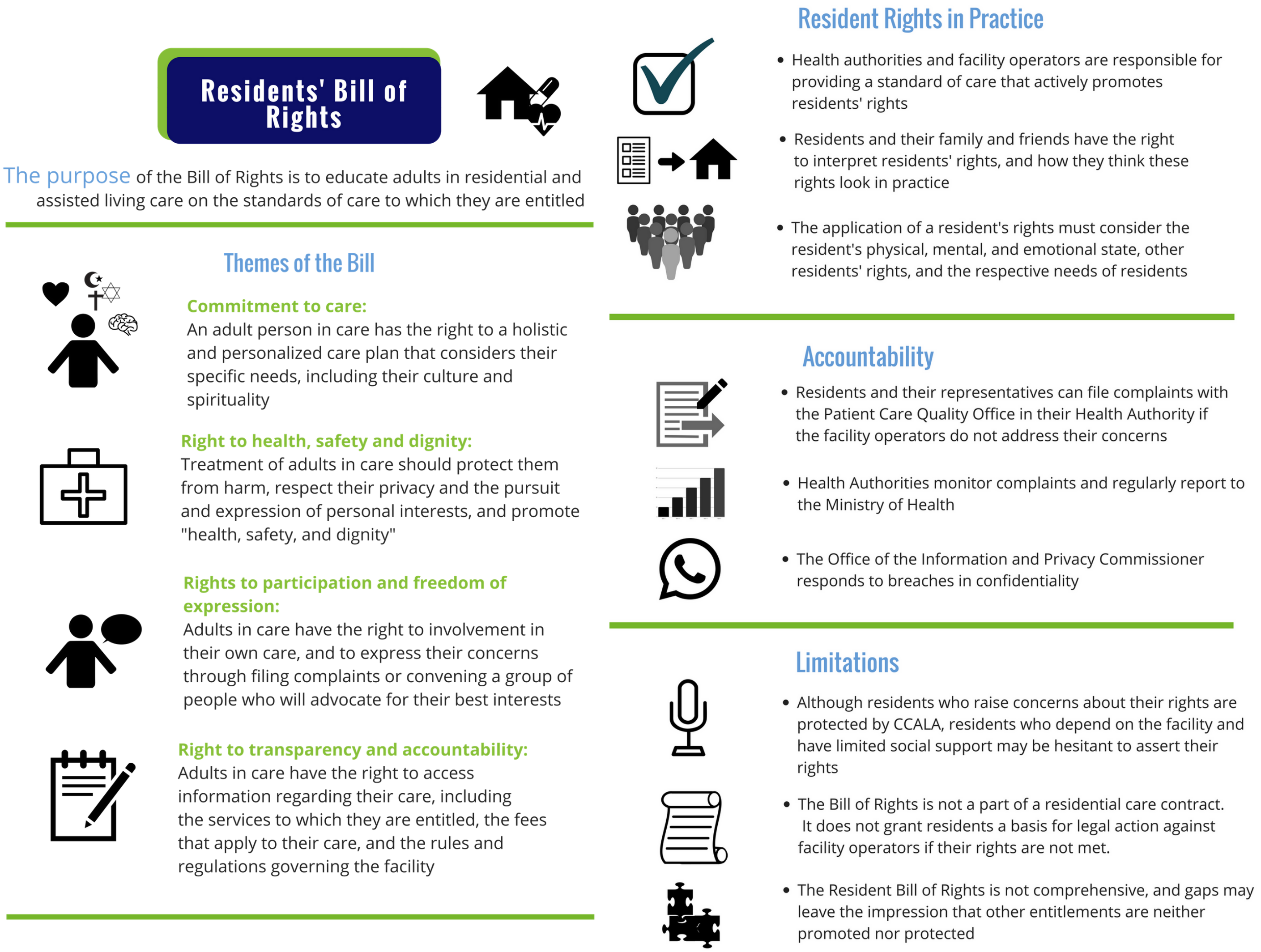


Figure 10: Guiding Acts and Regulations for Residential Care (74,105)

3.2 Patient Care Quality Offices and Boards

Recipients of residential care, assisted living, and home support services may lodge complaints to the Patient Care Quality Office in their health authority, which is governed under the *Patient Care Quality Review Board Act* (for examples, **See Table 4)** (106). Often times, complaints are submitted to a Patient Care Quality Office because they were not adequately resolved through mediation with the service provider or their local health authority (107). The process of submitting a complaint to a service provider can be unclear, given that each service provider may have unique internal policies and procedures for complaints. If an individual is not satisfied with the final decision on the complaint made by the health authority or service provider, they can request that the Patient Care Quality Review Board review the decision (74). The Review Boards operate independently of their respective health authorities and are accountable to the Minister of Health (74).



Residents' Bill of Rights

The purpose of the Bill of Rights is to educate adults in residential and assisted living care on the standards of care to which they are entitled

Themes of the Bill

Commitment to care:
An adult person in care has the right to a holistic and personalized care plan that considers their specific needs, including their culture and spirituality

Right to health, safety and dignity:
Treatment of adults in care should protect them from harm, respect their privacy and the pursuit and expression of personal interests, and promote "health, safety, and dignity"

Rights to participation and freedom of expression:
Adults in care have the right to involvement in their own care, and to express their concerns through filing complaints or convening a group of people who will advocate for their best interests

Right to transparency and accountability:
Adults in care have the right to access information regarding their care, including the services to which they are entitled, the fees that apply to their care, and the rules and regulations governing the facility

Resident Rights in Practice

- Health authorities and facility operators are responsible for providing a standard of care that actively promotes residents' rights
- Residents and their family and friends have the right to interpret residents' rights, and how they think these rights look in practice
- The application of a resident's rights must consider the resident's physical, mental, and emotional state, other residents' rights, and the respective needs of residents

Accountability

- Residents and their representatives can file complaints with the Patient Care Quality Office in their Health Authority if the facility operators do not address their concerns
- Health Authorities monitor complaints and regularly report to the Ministry of Health
- The Office of the Information and Privacy Commissioner responds to breaches in confidentiality

Limitations

- Although residents who raise concerns about their rights are protected by CCALA, residents who depend on the facility and have limited social support may be hesitant to assert their rights
- The Bill of Rights is not a part of a residential care contract. It does not grant residents a basis for legal action against facility operators if their rights are not met.
- The Resident Bill of Rights is not comprehensive, and gaps may leave the impression that other entitlements are neither promoted nor protected

Figure 11: Overview of the Residents' Bill of Rights (107)

	Number of Complaints	% Change Since Last Fiscal Year	3 Most Common Complaint Types
Residential Care	709	+14.2%	Inappropriate type or level of care; Dissatisfied with placement; Delayed or disruptive care or service
Assisted Living	73	+25.9%	Internal complaint policy; Resident abuse/neglect and/or self-neglect; Meal services
Home Support	430	-7.1%	Inappropriate type or level of care (based on expectation of client and/or their family); Care program or service denied; Lack of caregiver continuity

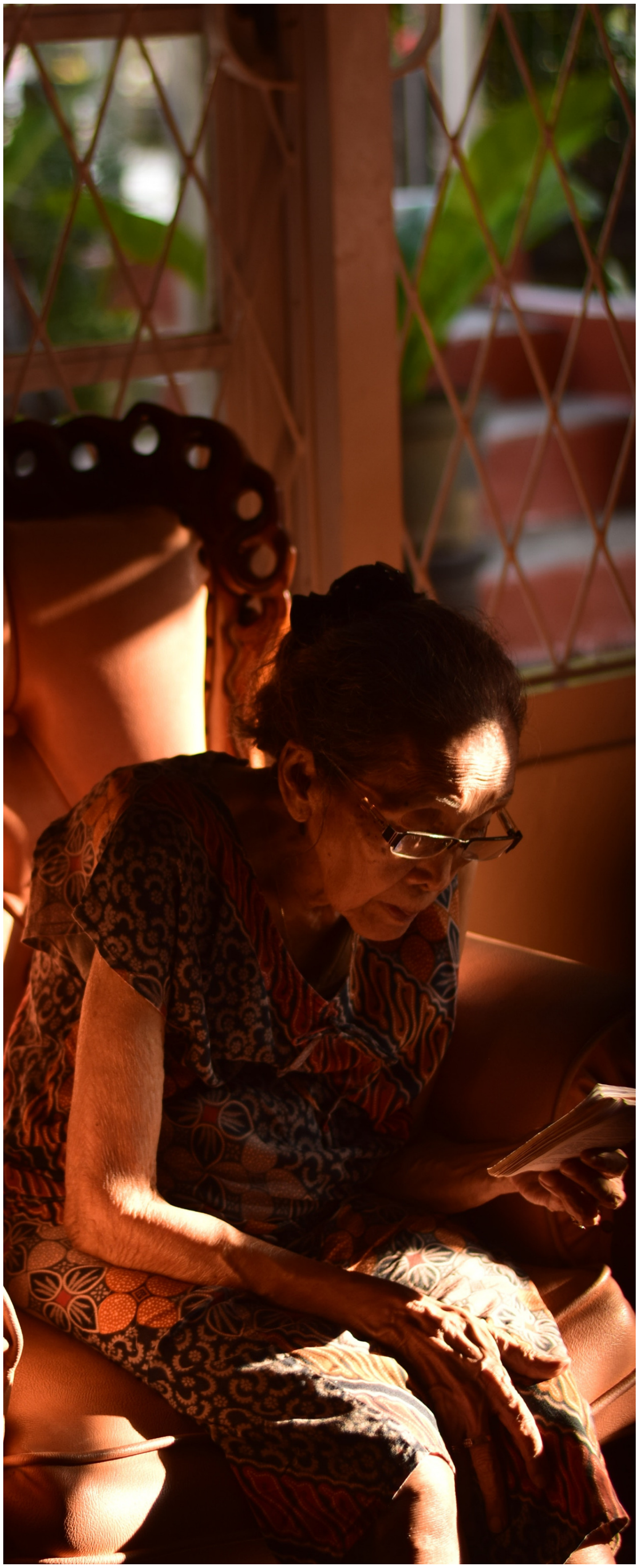
Table 4: Complaints Made to Patient Care Quality Offices (2015/16 Fiscal Year) (107)

3.3 Regulatory Authorities

Health authorities determine and oversee investigations for assisted living and residential care facilities (for regulatory bodies pertaining to each type of care, **See Table 5)** (83). As of December 2016, 84% of residential care facilities had a reported inspection within the past year (107). Home support services are only subject to regulation and monitoring determined by each individual provider.

OALHIV and Self-Advocacy

In order to improve HIV-related healthcare, PLHIV involved in activism have spearheaded powerful social movements, from the 1980s until today (109–111). However, as aging individuals enter higher levels of care, they are often relegated to playing a smaller role in self-determination of their healthcare (112–114). This is particularly true for some marginalized subpopulations of OALHIV, such as gbMSM or PWUD (115). Therefore, some OALHIV may face unique challenges to self-advocacy within the HCC system.



<table>
<tr><th colspan="2">Residential Care</th></tr>
<tr><td colspan="2">Main Legislation: <i>Community Care and Assisted Living Act</i></td></tr>
<tr><td>Regulatory Authorities</td><td>Responsibilities</td></tr>
<tr><td>Director of Licensing</td><td>• Sets policies and standards for facilities
• Suspends, terminates, or attaches conditions to facility licenses
• Charge fines, issues warnings, and formulate compliance agreements for facilities in violation of regulations</td></tr>
<tr><td>Health Authority</td><td>• Determines procedures for investigations</td></tr>
<tr><td>Medical Health Officers & Licensing Officers</td><td>• Monitor standards of care</td></tr>
<tr><td colspan="2">Assisted Living</td></tr>
<tr><td colspan="2">Main Legislation: <i>Community Care and Assisted Living Act</i></td></tr>
<tr><td>Regulatory Authorities</td><td>Responsibilities</td></tr>
<tr><td>Office of the Assisted Living Registrar</td><td>• Conducts investigations
• Suspends, cancels, or changes facility’s registration conditions</td></tr>
<tr><td colspan="2">Home Support</td></tr>
<tr><td colspan="2">Guiding Regulations: Providers’ internal policies</td></tr>
<tr><td>Regulatory Authorities</td><td>Responsibilities</td></tr>
<tr><td>Contracted Service Provider</td><td>• Monitors and regulates quality of care through conducting client surveys, case management, and contract reviews</td></tr>
<tr><td>Health Authorities</td><td>• Conduct audits and inspections of contracted providers
• Can withhold public funding or end contracts</td></tr>
</table>

Table 5: Regulatory Authorities for HCC (79, 108)

Section 4

Eligibility, Assessment, and Access

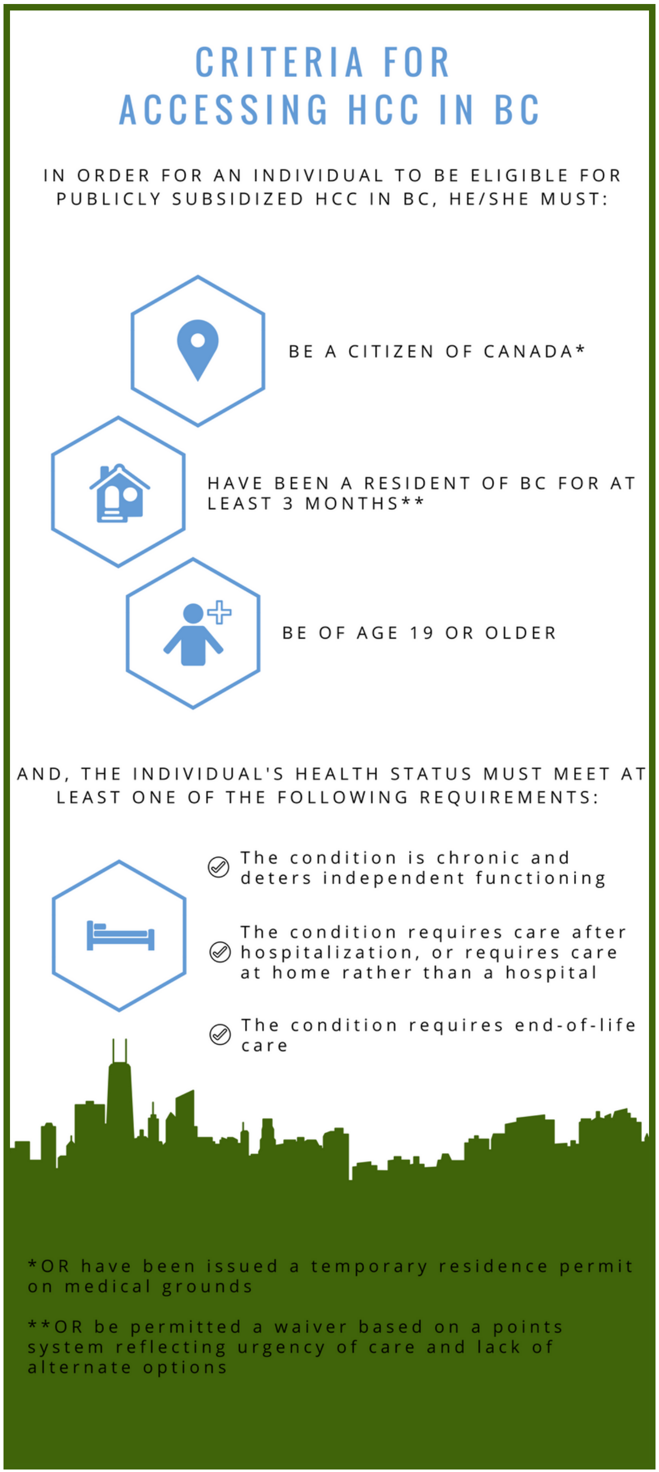
4.1 Overview of the Assessment Process

To ensure that HCC recipients receive an appropriate level of care, individuals must meet specific criteria **(See Figure 12)**. In BC, the Ministry of Health outlines this criteria, and the health authorities ensure that the criteria is met through a standardized assessment process **(See Figure 13)** (106). HCC can be requested by the individual and his or her family, a healthcare professional, or hospital staff. A clinician who is employed by the health authority can complete an assessment in the hospital or at home (114). These clinicians may be nurses, physiotherapists, or occupational therapists (114). The main tool used to complete the assessment is an extensive questionnaire created by a research organization called interRAI (114).

Living Experience of a Caseworker for OALHIV

We asked a CBO how often PLHIV get rejected for HCC services, and why.

They informed us that rejection for residential care happens quite often, because of long wait lists or because individuals are denied access to facilities. On the other hand, most clients receive home support, but the support is insufficient and not always useful.



CRITERIA FOR ACCESSING HCC IN BC

IN ORDER FOR AN INDIVIDUAL TO BE ELIGIBLE FOR PUBLICLY SUBSIDIZED HCC IN BC, HE/SHE MUST:

BE A CITIZEN OF CANADA*

HAVE BEEN A RESIDENT OF BC FOR AT LEAST 3 MONTHS**

BE OF AGE 19 OR OLDER

AND, THE INDIVIDUAL'S HEALTH STATUS MUST MEET AT LEAST ONE OF THE FOLLOWING REQUIREMENTS:

- ✓ The condition is chronic and deters independent functioning
- ✓ The condition requires care after hospitalization, or requires care at home rather than a hospital
- ✓ The condition requires end-of-life care

*OR have been issued a temporary residence permit on medical grounds

**OR be permitted a waiver based on a points system reflecting urgency of care and lack of alternate options

Figure 12: Minimum Criteria for Accessing HCC (116)

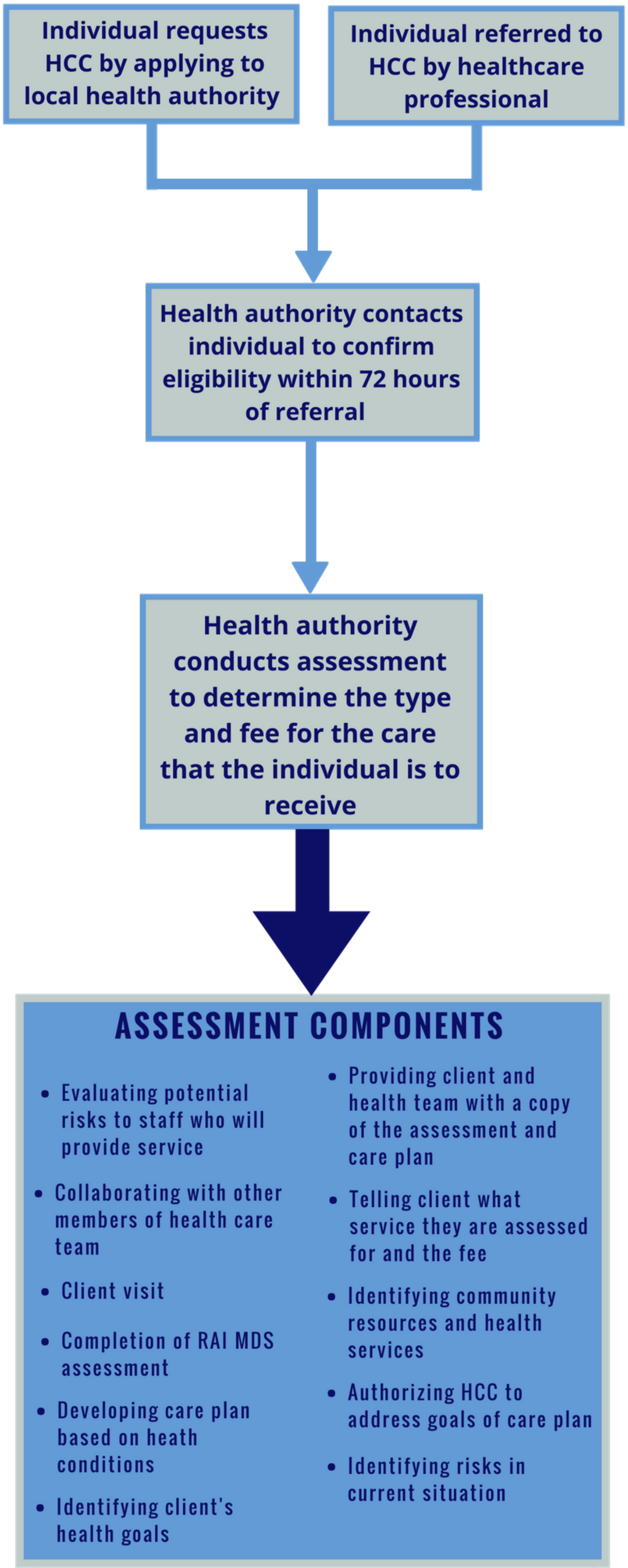


Figure 13: HCC Assessment Process (116)

Living Experience of a Caseworker for OALHIV

We asked a CBO how many of their clients rely on HCC.

They informed us 40% of active clients rely on HCC. Most clients are men over the age of 50.

An individual who is in need of care may face barriers to initiating the assessment process. They may not be connected to a regular healthcare team, may wish to avoid hospitals, or may not have stable housing in which to complete the assessment process or receive care.

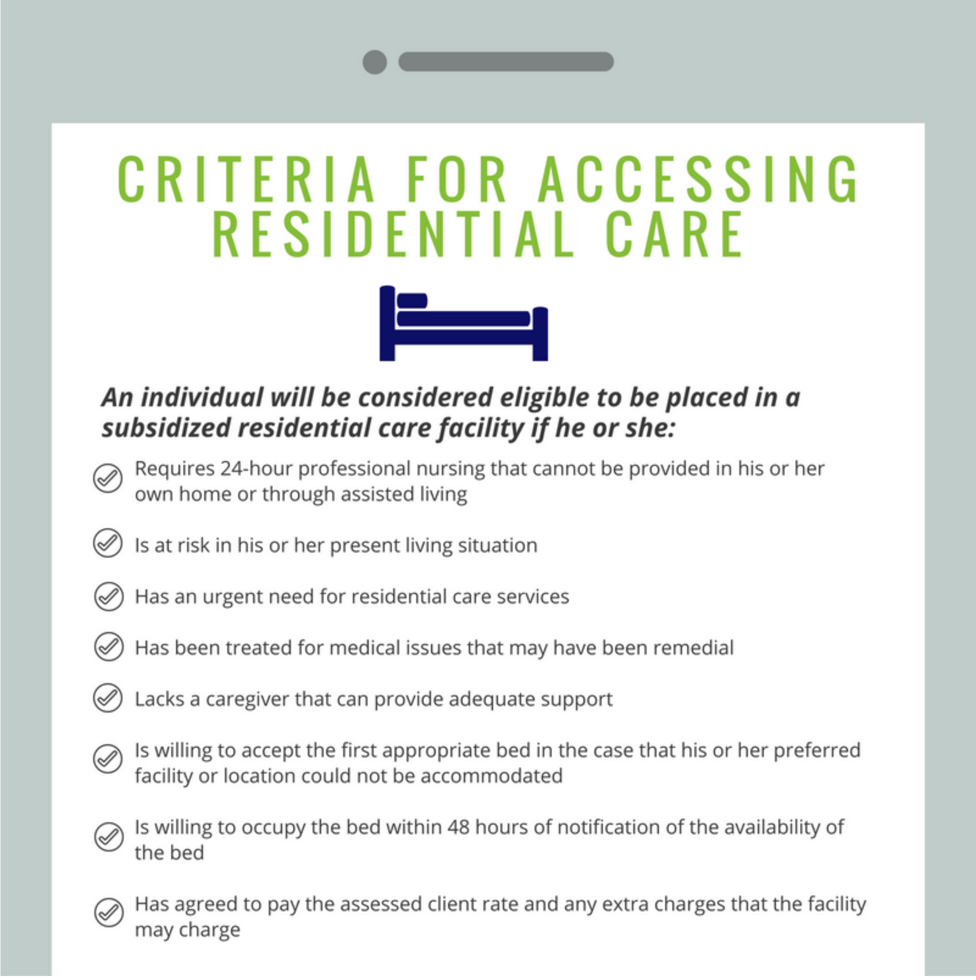
Living Experience of an OALHIV

An OALHIV expressed how the assessment process did not adequately meet her needs as an individual who experiences an episodic illness.

"When you first get assessed [...] you have a work plan made. Then the company gives the work plan to the worker. 'This is what you're going to do there.' But when you've known a worker for months if not years, they sort of know what you want more than the worksheet does. There are days when I don't get out of the bed. There are days when I don't look sick at all."

4.2 Access to Residential Care

As of 2017, approximately 28,000 BC residents lived in a residential care facility, and 1,484 individuals were on the waitlist to be placed in a facility (114,117). Often, sudden declines in health or the loss of an informal caregiver prompts a transition into residential care (114). Residential care is the most intensive and expensive care service provided by the HCC sector (for criteria to access residential care, **See Figure 14)**. With 93% of seniors reporting they wish to live in their own homes for as long as possible, it is clear seniors do not prefer to live in residential care (26). However, as many as one in five seniors who move into residential care are in fact capable of living in their own homes with appropriate home and community supports (118). When adequate community-based supports were taken into account for certain subpopulations, about one in three seniors could have been supported at home instead of in residential care (118). From this data, it is evident that home support and community-based services are underutilized by, or inaccessible to, many seniors, and consequently do not currently offset the need for residential care.



CRITERIA FOR ACCESSING RESIDENTIAL CARE

An individual will be considered eligible to be placed in a subsidized residential care facility if he or she:

✓ Requires 24-hour professional nursing that cannot be provided in his or her own home or through assisted living

✓ Is at risk in his or her present living situation

✓ Has an urgent need for residential care services

✓ Has been treated for medical issues that may have been remedial

✓ Lacks a caregiver that can provide adequate support

✓ Is willing to accept the first appropriate bed in the case that his or her preferred facility or location could not be accommodated

✓ Is willing to occupy the bed within 48 hours of notification of the availability of the bed

✓ Has agreed to pay the assessed client rate and any extra charges that the facility may charge

Figure 14: Criteria for Accessing Residential Care (116)

Without adequate community supports, the demand for residential care remains high across the province, as evidenced by the number of patients in Alternate Level of Care hospital beds (80). These patients have been formally discharged and no longer require acute care, but cannot go home due to a lack of available services. In 2015/2016, Alternate Level of Care beds accounted for 13% of all occupied hospital bed time, only 2% less than the 2001/2002 rate (80). Alternate Level of Care stays are neither cost-saving, nor beneficial for health: extended hospital stays tend to negatively affect mobility and the ability to live independently (80). Studies among the general population have shown that Alternate Level of Care beds often play a role in hospital overcrowding, resulting in infection, medical errors, and cognitive decline (118).

Two requirements specific to accessing residential care have been criticized as unreasonable (83). The first of these requires seniors to occupy the bed within 48 hours of notification of its availability (i.e. the ‘first available first appropriate bed policy’), and the second requires seniors to pay the assessed client rate and any additional charges. In the first case, clients may be forced to move into a facility that may not meet their needs and preferences, or risk losing their spot on the waitlist. Further, the 'first available first appropriate' bed policy may remove individuals from their social networks and community-based services. In the second case, clients may not be fully informed of the costs they will incur, because different facilities may have distinct additional fees. Although individuals may request to be placed in a certain facility or location, another area of concern is the Ministry’s requirement for clients to accept the first appropriate bed (83). Currently, there are no guidelines in place to determine what constitutes an “appropriate” bed (74,83). In addition, the health authorities’ success in initially placing clients in their preferred bed ranges widely, from only 17.6% in Vancouver Coastal to 98.5% in Northern Health (107). However, it should be noted that seniors in Northern Health also waited a median of 57 days to be admitted to residential care, compared to the provincial average of 17 days (53). Among communities in Northern Health, only Prince George has more than one publicly subsidized residential care facility option; this limited amount of choice may account for seniors’ acceptance to their preferred facility (119).

Living Experience of a Caseworker for OALHIV

We asked a local AIDS service organization how the ‘first available first appropriate’ bed policy impacts OALHIV.

They responded by explaining how this policy often forces an individual to be separated from their usual health team, and re-assigned to a new one closer to their facility.

4.3 Access to Assisted Living

As of 2017, there were 4,485 subsidized registered assisted living units in BC, and 750 individuals on the waitlist for a unit (117). Assisted living services are intended for those who can no longer safely live at home, but are still able to direct the majority of their care decisions (for criteria to access assisted living, **See Figure 15)** . In actuality, however, data published by the Office of the Seniors Advocate reveals that home support clients and assisted living clients are similar in terms of cognitive and physical function, mobility, and frailty (120). From this data, it is evident that clients are being placed in assisted living when they could be supported in their own homes with enhanced home support services. Similarly, seniors in assisted living residences are sometimes fast-tracked to residential care facilities due to restrictions limiting the number of services they may receive in assisted living facilities (120). Assisted living operators must only provide two of the following six prescribed services to clients (121):

1. Regular assistance with ADL (eating, mobility, dressing, grooming, bathing or personal hygiene)
2. Central storage, distribution, administration or monitoring of medication
3. Maintenance or management of cash resources or property
4. Monitoring food intake or adherence to therapeutic diets
5. Structured behaviour management and intervention
6. Psychosocial rehabilitative therapy or intensive physical rehabilitative therapy

If a client is in need of more than two services, or a service not provided by the operator, the client will be directly referred to residential care, despite the client's capacity for independent decision-making and not needing 24-hour care.

Eligibility and Assessment Considerations for OALHIV

Ability to perform activities of daily living (ADL), such as bathing and dressing, determine eligibility for home and community care services. Although OALHIV experience greater dependence on caregivers for ADL, factors other than ADL influence OALHIV's needs for HCC services (35). OALHIV are more likely to use a higher number of medications compared to younger PLHIV, but due to higher rates of cognitive decline may have difficulty managing and administering medications (24,35). Frailty and reduced capacity for ADL create barriers for adequate meal preparation, contributing to higher rates of food insecurity, which is an important component in achieving an undetectable viral load (122,123). Because OALHIV often experience difficulties with a wide range of ADL, it is possible that they are being fast-tracked into higher levels of care than they require.

Assisted living is for people who can make all their own decisions, but cannot live safely at home. However, many seniors placed in assisted living facilities are just as capable of living at home as home support clients.

4.4 Access to Home Support

As of 2016, 42,170 individuals in BC were accessing home support services (117). Each health authority has its own guidelines to determine the type of home support services and the number of hours each client requires (for minimum criteria to access, **See Figure 15)** (83). As with waitlists for assisted living and residential care services, there is a lack of regulatory frameworks indicating how long an individual should wait to receive home support services (83). Reports have indicated that home support can respond to a same-day request in urgent situations, while on average individuals will wait for approximately three weeks to receive services (74).

A demographic shift in the clientele requiring home support services has contributed to the current challenges in the home support system. Client classification has shifted from lower needs (i.e. requiring only prevention and maintenance supports) to more complex needs (i.e. requiring medical interventions) (72). Between 2016 and 2017, the number of home support hours provided to a client per year decreased by 3%, while the number of clients increased by 3.5% (117). As clients are presenting to home support with increasingly complex care needs, there has been a focus on offering higher levels of care, which has resulted in significant reductions to (and cancellations of) ADLs, such as meal preparation, housekeeping and transportation (72).

More and more home support clients are considered to have “high” or “very high” needs. As a result, home support services have become more focused on medical needs, rather than everyday tasks around the home.

Living Experience of an OALHIV

We asked an OALHIV how the reductions in maintenance and preventative services affected her daily life and experiences with home support.

She responded by giving an example of how home support workers used to pick up food for her when she would call ahead and order take-out. Since home support no longer provides this service, and she struggles with walking long distances and carrying groceries, she is often forced to eat food that is sold from a nearby corner store. As a result, she is rarely able to purchase fresh fruit and vegetables.

CRITERIA FOR ACCESSING ASSISTED LIVING & HOME SUPPORT SERVICES

An individual will be considered eligible to be placed in a subsidized assisted living facility if he or she:

- ✓ Requires hospitality and personal care services
- ✓ Is able to make decisions on his or her own behalf that will allow him or her to function safely in an assisted living residence
- ✓ Is at risk in his or her present living situation
- ✓ Has agreed to pay the assessed client rate and any additional charges

An individual will be considered eligible receive subsidized home support if he or she:

- ✓ Has been assessed as requiring personal assistance and/or respite for their caregiver as determined by a health care professional
- ✓ Has agreed to pay the assessed client rate

Figure 15: Criteria for Accessing Assisted Living and Home Support Services (116)

4.5 Cultural Safety in Home and Community Care

The First Nations Health Authority states that cultural safety is an “outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system” and “results in an environment free of racism and discrimination, where people feel safe when receiving care” (124). Achieving culturally safe care requires that providers reflect on their own assumptions and prejudices, recognize they are life-long learners about others’ experiences and ways of knowing, and develop relationships with clients based on mutual respect and trust (124). The discussion of cultural safety in HCC is particularly important for Indigenous Peoples, who bear the effects of colonial trauma and resulting structural oppression. The recognition and respect of diverse Indigenous cultural practices, and diverse understandings of health and wellness, is integral to providing care that supports the person as a whole. Cultural safety is particularly relevant to HCC because it takes place in a person’s home, which can bear significant cultural and personal meaning, and is a place where many partake in cultural ceremony and protocols, often using sacred items. BC is home to individuals of diverse ethnic and cultural backgrounds to whom the concept of Indigenous cultural safety can also be extended. Indigenous understandings of health and wellness – which are grounded in the medicine wheel’s teachings to seek balance and harmony between one’s body, mind, heart and spirit – are not fully supported by HCC services, which are becoming increasingly fixated on maintaining physical wellness. In addition, Indigenous Peoples may have distinct perspectives on what it looks like to age well: qualitative research has found a strong emphasis on the role of informal caregivers, and the importance of being able to age and pass through the end stages of life at home (125,126). Further challenges to providing culturally safe home and community care for Indigenous peoples aging with HIV involves the lack of opportunities to harvest, prepare, and eat traditional foods in care homes, especially for urban and off-reserve Indigenous people. Restrictions on smoking in care homes also limit use of ceremonies involving traditional medicines, such as pipe ceremonies and/or smudging, which is the burning of sacred medicines. Finally, use of the term “residential care” to describe long-term care homes may bear historical significance for the survivors of the residential school system and their descendants.

Long-term care homes offer limited or no opportunities for Indigenous people to participate in cultural ceremonies, like traditional food preparation and burning medicines. Care homes may even prohibit some of these practices.

HCC that recognizes and respects Indigenous cultural practices and understandings of wellness is key to providing good care and supporting a person as a whole. The concept of cultural safety also applies to the many cultures and ethnicities in BC.

Living Experience of Indigenous OALHIV

Several Indigenous OALHIV spoke about ways in which the HCC sector could support culturally safe care, and help achieve balance and harmony between a person's body, mind, heart, and spirit. The first is to provide training for non-Indigenous HCC workers by inviting them to participate in cultural and ceremonial practices, so they can learn about Indigenous ways from Indigenous people. Willing non-Indigenous HCC workers could also participate in ceremonies with their clients on an ongoing basis. Secondly, while some Indigenous clients are willing to share teachings with their workers about Indigenous ways and how to show respect for cultural practices and items, or honoured places for these items and practices, others would be more comfortable with having a worker who is Indigenous and already familiar with their culture. Community Health Workers can respect sacred items and spaces by asking their clients if there is anything in the home not to be touched or disturbed. The inclusion of Elders in HCC is a culturally safe way to meet the needs of Indigenous OALHIV's minds, hearts, and spirits, which will benefit their bodies. Some clients may prefer seeing a worker or Elder of their own nation, however, not every Indigenous person is familiar with their ancestry due to the impacts of colonial initiatives, such as residential schools and colonial child welfare policies. This wholistic approach is an Indigenous way of life. To make the way these services are offered culturally safe, an Indigenous navigator or case manager could speak with clients and make plans for involving Indigenous workers and Elders.

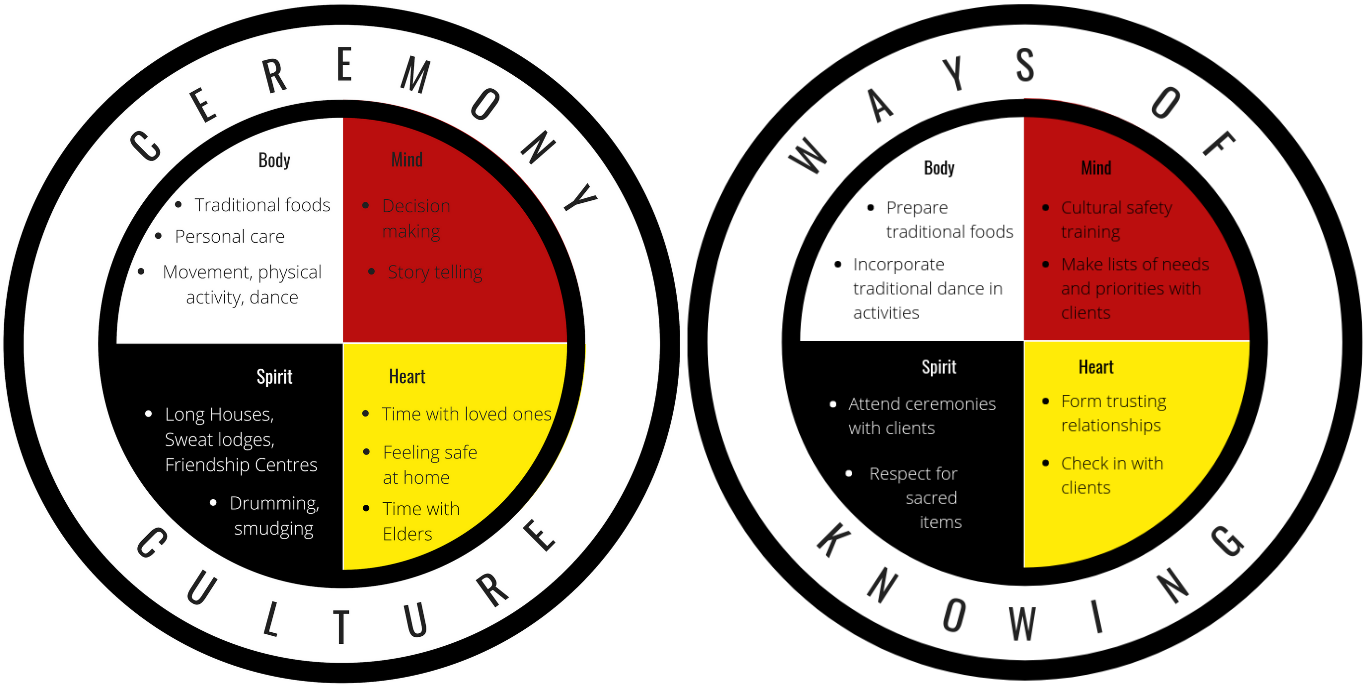


Figure 16: Practices embedded in Indigenous culture and ceremony (left) that work together to support the whole person, and corresponding practices (right) that Home and Community Care could integrate to facilitate cultural safety

Section 5

Staffing

5.1 Staffing Mix and Community Health Workers

Employees of the HCC sector have a significant impact on the day-to-day lives of seniors, and the quality of care that they receive. They are tasked with maintaining the satisfaction of patients and families, while adhering to professional standards and policies set by their organizations. Individuals providing care can have a diverse range of educational backgrounds, such as training as a Registered Nurse (RN), a Licensed Practical Nurse (LPN), a dietician, or a Community Health Worker (CHW). Professional Colleges and Registries that provide individuals with certification play an important role in monitoring and regulation. In addition to formal HCC services, family members, spouses, and other informal caregivers often provide unpaid care to their loved ones who are aging, and play an integral role in caring for our population's seniors. This section will discuss the role of both formal and informal caregivers in each sector of HCC.

CHWs – also referred to as home support workers and care aides – work in people's homes, assisted living residences, and residential care facilities (83). They often assist individuals with ADLs, such as bathing and eating. CHWs employed by a publicly funded institution must be registered with the BC Care Aide & Community Health Worker Registry (83). While CHWs play an essential role in the day-to-day lives of HCC clients, there has been recent concern about the continuity of CHW staff across HCC sectors (74,114). For example, in a survey of residential care clients, 49% of residents reported that they sometimes, rarely, or never have the same CHW on weekdays (114).

This lack of continuity in staffing has implications for the development of staff-client relationships, which can impact quality and appropriateness of care.

5.2 Staffing in Residential Care

According to the *Residential Care Regulation*, a licensed facility must ensure it is sufficiently staffed to meet client needs "in a manner consistent with the health, safety and dignity of persons in care" (127). In 2008, the Ministry of Health published detailed guidelines for staffing levels and mix to clarify "sufficient" staffing (128). These guidelines specified that there should be one registered nurse for every 75 beds, and that each resident should receive 3.36 hours of direct care per day from nurses, CHWs, and allied healthcare professionals (e.g. occupational therapists, social workers, recreational therapists). Eight years after the guidelines were implemented, the Office of the Seniors Advocate found that 81% of facilities did not meet the guideline of 3.36 hours (107). In response, the BC Ministry of Health issued a strategy to achieve the standard of 3.36 direct care hours, and committed to an increase in funding and monitoring of services (128).

The Ministry of Health set a benchmark of 3.36 hours of direct care per day for each resident to help guide staffing requirements. Less than 20% of facilities met this guideline in 2016.

A 2017 report by the Office of the BC Seniors Advocate indicated that 83% of residents believe that staff know what they are doing, and 86% of residents report being treated with respect by staff (114). However, only 46% of staff are able to regularly make time for casual conversation with residents (114). A key recommendation from the BC Seniors Advocate was to provide education for care staff about the importance of residents' emotional and social well-being (114). Despite recent efforts to improve staffing levels, lack of available staff continues to be a critical issue for residential care clients.

5.3 Staffing in Assisted Living

Staffing guidelines for assisted living are currently not legislated in the *Community Care and Assisted Living Act* or the *Assisted Living Regulation*. Instead, policy is provided through the Office of the Assisted Living Registrant Handbook. The Handbook specifies that facilities must have sufficient number of adequately trained staff available, without indicating what levels constitute sufficient staffing (129). Within the residence itself, personal assistance is provided by CHWs, who are supervised by contracted health professionals.

5.4 Staffing in Home Support

Staff trained as CHWs provide the vast majority of home support services. In addition, professional staff such as nurses,

occupational therapists, and physiotherapists provide home nursing and other specialized health services that extend beyond personal care. Currently, there are no province-wide policies or legislation that address staffing for home support. In a province-wide survey of home support services, 92% of clients report that their workers are mostly or always caring.

In recent years, there has been ongoing concern regarding the continuity of care in home support. For example, a report by the Office of the Seniors Advocate found that 28% of clients think that they are visited by too many different workers (130). As clients with higher needs are presenting in a home support environment, complex and medically oriented tasks, such as wound care, are being delegated to CHWs without adequate training or a change in pay grade, due to a lack of funding (72). Additionally, as home support regulations have changed to permit only a 15-20-minute visit, these tasks must be completed in less time. In a province-wide survey of home support services, 80% of clients reported that their worker mostly or always had enough time to complete their required services (130). However, this figure varies widely across health authorities: in the Vancouver Coastal region, only 68% of clients reported that their worker mostly or always had enough time to complete their services (130). Given that 20% to 33% of workers are unable to provide the required services in the time allotted, CHWs may be expected to complete onerous work plans in less time. This may impact quality of care and increase risk of human error. It also may mean that the client-CHW relationship has a transactional rather than relational nature.

Living Experience of an OALHIV

I know I have plenty of part-time people that come in that are shocked, when they… find out that I [am living with HIV] – 'Well what's wrong with you?' I'm like, 'Well didn't they tell you?' It becomes an issue sometimes with home care. At the beginning, there used to be [continuity] and I became friends [with my worker].

There has been a 2% decrease in the average home support hours allocated to clients per year between 2014/2015 and 2015/2016, but an increase in clientele of approximately 2% (9). This increase in service demand impacts the quality of care the client is receiving, and places additional stress and burden on workers, who generally work more hours than they are paid for (118). Furthermore, the shift towards casual and split-shift hours has altered worker and client interactions; clients are no longer obtaining care from one worker. This limits workers' ability to form relationships with clientele and monitor changes in health status, which could ultimately prevent critical health situations from occurring (72).

Living Experience of an OALHIV

When I started with [home support], a minimum service was two hours. They can now do 15 minutes. I don't understand how."

5.5 HIV-Related Training and Home and Community Care Settings

Education initiatives that have the potential to increase HIV-related knowledge, and thus improve care, are sparse among providers that work with OALHIV (131–133). Many of these gaps in knowledge result in stigmatizing practice, such as fear of casual contact stemming from misinformation about transmission, and the association of HIV with certain health risk behaviours (134). Research about initiatives that have the potential to reduce stigma towards OALHIV in HCC settings is lacking (133). However, one study that piloted an HIV-specific training program for residential care staff evidenced the growing need for these initiatives (133). For example, HCC staff who took part in the training program reported learning for the first time that HIV cannot be transmitted through casual contact (133). Many HCC staff expressed a lack of confidence in their facilities' preparedness for caring for the growing population of OALHIV (133). Existing research suggests future HIV-related education initiatives, including those in HCC settings, need to be led by OALHIV (134,135).

Living Experience of an OALHIV

An OALHIV told us how the absence of HIV-specific training for CHWs often contributes to stigmatizing practices.

"[...] I have one particular worker, who it takes her up to ten minutes after I buzz her in. I wondered for the longest time why it took her so long. Because she gloves up and masks and everything. Puts everything in a bag and zips it in her thing before she'll come in my house and actually put her bag down. Everything is inside a bag. So it's like the old days."

5.6 The Role of Informal Caregivers

An informal caregiver is an individual who provides unpaid support to an individual requiring HCC. The Ministry of Health mandates that home support services are "to provide caregivers with temporary relief from the demands of providing care" (121). As such, informal caregivers play an integral role in the care of individuals who are accessing home support. In fact, 94% of clients accessing publicly subsidized home support have an informal caregiver, frequently being an adult child or a spouse (136). In total, these individuals account for approximately one million caregivers in the province, and $3.5 billion worth of unpaid care (136). Complexity of seniors' needs and greater burden on caregivers is associated with caregiver distress (136). The Office of the Seniors Advocate found that 31% of clients have a primary caregiver in distress,

representing a 14% increase in the absolute number of caregivers in distress between 2015 and 2017 (136). From the increasing number of caregivers who are reporting distress, it is evident that services such as home support, adult day programs, and temporary residential care are not yet providing caregivers with sufficient respite.

Living Experience of an OALHIV

"[My friend with HIV has] a partner that literally, around the clock is caregiving him. And he's sick. [...] Our partners died taking care of us, because whoever's the least sick, you know what I mean? It's really bad."

94% of HCC clients also have informal caregivers. 31% of these caregivers reported feeling distressed, and in need of more assistance from HCC.

Informal Caregivers for OALHIV

PLHIV tend to have smaller social networks, and less support from family members who traditionally provide informal caregiving (11,22,57). Many OALHIV experienced the passing of friends and partners during the earlier days of the HIV epidemic, or were excluded from social circles because of stigma and discrimination (41,50,58). One study found that two-thirds of OALHIV did not have a significant other, and 71% lived alone (11). Further, the existing social networks of OALHIV are often comprised of other OALHIV (11). While these relationships have many advantages (e.g. comfort in sharing HIV-related information (57)), they are also vulnerable to higher rates of illness and loss (40).

OALHIVs' smaller social networks have several implications for the quality of HCC. The first is that informal caregivers of OALHIV may experience more distress, as there are fewer other individuals available to assist with caregiving. This may place strains on both the health of the OALHIV, and the relationship between the OALHIV and his or her informal caregiver. The second is that OALHIV may need to depend more heavily on the formal HCC system to meet their caregiving needs (22). For example, if an OALHIV does not have an individual who can act as an informal caregiver, they may be fast-tracked into a residential or assisted living facility, as home support is limited to only respite care. Overall, the current HCC system operates under the assumption that informal care will be available to HCC clients, whether through personal relationships or community-based supports, and that these supports will act as the primary source of assistance with daily tasks. Individuals who do not have access to sufficient care from an informal caregiver may be without adequate support, which has implications not only for the individual's physical health, but psychological, emotional, and spiritual health as well.

Section 6

Home and Community Care in Different BC Regions

Maintaining consistent standards of care across the diverse regions of British Columbia is critical to ensuring that our population has the tools to age well, and that all individuals have access to the care they require, regardless of where they live. Differences in policy and procedures between regions can often be useful: for example, a CHW employed in the Northern Health Authority may require much more paid travel time between clients than a home support worker in the Vancouver Coastal Health Authority. In some cases, however, discrepancies in practice exist because of gaps in province-wide regulatory frameworks. For instance, Vancouver Coastal Health allots 30 minutes for a community health worker to prepare a meal, while Fraser Health allots 10 minutes for meal preparation and clean-up (83). **Table 6** outlines some of the recent changes in care between the health authorities, demonstrating the complexity of balancing consistent standards with tailored approaches to care.

Some regional differences in HCC are by design and help serve the province's diverse population better.

% Change between 2014/15 and 2015/16	Vancouver Island Health	Fraser Health	Vancouver Coastal Health	Interior Health	Northern Health
Number of professional home support service visits	+2.2%	+3.8%	+1.3%	+4.7%	-18.3%
Number of home support complaints	-2.2%%	-20.3%	+21.5%	-0.8%	-7.7%
Average length of stay in residential care	+1.9%	-8.1%	-14.5%	+15.6%	-3.2%
Number of admissions to residential care facilities	-2.0%	-8.4%	-3.5%	-7.0%	-21.4%
Percent of seniors admitted to a residential care facility within the target window of 30 days	-7.9%	-8.8%	+3.7%	-35.5%	+22.2%
Number of residential care complaints	+18.1%	-6.9%	+41.2%	+34.7%	-20.8%

Table 6: Percent change in services in the five health authorities (107)

Challenges for OALHIV in Rural Areas

In addition to regional differences in HCC services, PLHIV also contend with regional differences in relation to HIV care. In particular, PLHIV who live in rural areas face additional barriers, such stigma, concerns about HIV status disclosure, limited mental health services, and lack of awareness about HIV-related issues among care providers (137–140). A study based in BC showed that PLHIV living in rural areas had a lower quality of HIV care during their first year on combination antiretroviral therapy, which is often predictive of higher rates of all-cause mortality and other adverse clinical outcomes (139). OALHIV who live in rural areas may face additional barriers to aging well, in respect to both HCC and HIV-related care.

Conclusion

As BC's population ages, so does the population of PLHIV. OALHIV are experiencing unprecedented health challenges, being the first cohort to live into older age with HIV. Not only is the population of PLHIV aging, HIV diagnoses among older individuals are more common than ever before. HCC services are integral to supporting individuals as they age. As the population of OALHIV continues to grow, BC's HCC system must adapt in order to meet the needs associated with this demographic shift.

OALHIV may be more affected by gaps in the HCC system. HIV-related stigma and ageism experienced alongside multi-morbidities and complex treatment regimens result in distinct physical and mental health challenges. Home support services operate under the assumption that clients have family, friends or other informal caregivers providing the bulk of support. OALHIV, who have lost members of their community, may not have individuals in their lives who can fill this role.If home support services do not meet their needs, and they are not able to pay for private service, OALHIV may be forced to go without the care they need or be relegated to residential or assisted living facilities. HCC service providers are not provided with education about HIV, which can lead to stigmatizing experiences.

The BC HCC system is navigating uncharted territory. The voices of OALHIV need to be heard as we determine how HCC may be optimized to support the distinct needs of this population.

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