The Place of Assisted Living in BC's Seniors Care System

Assessing the promise, reality and challenges

By Dr. Karen-Marie Elah Perry

JUNE 2020

CCPA
CANADIAN CENTRE for POLICY ALTERNATIVES
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This report is dedicated to the memory of Frances Belich (1927–2016) and of Carol Pearlstone (1940–2019).

This report is co-published with the Hospital Employees' Union and the BC Health Coalition.

BCHealth Coalition

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The CCPA–BC is located on unceded Coast Salish territories, including the lands belonging to the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh (Squamish) and səl̓ílwətaɁɬ /Selilwitulh (Tsleil-Waututh) Nations.

ABOUT THE AUTHOR

DR. KAREN-MARIE ELAH PERRY is an applied medical anthropologist with a focus on social justice and the ways inequalities shape access to health care. Karen-Marie has researched, lectured on and written on a variety of topics over the past 20 years, including through the CCPA- and Simon Fraser University-led Economic Security Project (which ran from 2004 to 2009), which resulted in enhanced supports for individuals receiving disability benefits in BC. More recently, Karen-Marie has released *Virtual Reality and the Clinic*, a short documentary that addresses social exclusion and new medical technologies. (It can be viewed at www.karenmarie-perry.ca/multimedia.) She has received multiple scholarships from the Social Sciences and Humanities Research Council of Canada, and a PhD, with a specialization in medical anthropology, from the University of Victoria after conducting fieldwork at the Ottawa Hospital in Ontario. More than 300 practitioners and experts in disaster emergency management have cited her work after she spent several years developing disaster planning, mitigation and response frameworks, including attention to the resiliency of health-care systems to disaster and pandemics and to the impacts of disaster on marginalized communities. Karen-Marie believes that while statistics can indicate trends in health care, qualitative research has the capacity to give voice to health-care practitioners and patients in ways that contribute to deeper understandings of inequalities and barriers to care.

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This research was conducted on traditional unceded Coast Salish territory, including the lands belonging to the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh (Squamish) and səl̓ílwətaʔɬ /Selilwitulh (Tsleil-Waututh) Nations. However, it takes so much more than an acknowledgement to enact change. It takes the clarity and courage to recognize our own role in ongoing systems of colonization and to push for change, especially when it is difficult to do so.

First and foremost, the author would like to acknowledge the front-line care providers, families and residents, who provided feedback for this study. Many front-line care providers spoke out about gaps in seniors' care despite fears of professional repercussions and job loss. The reach of COVID-19 into long-term care homes and assisted living residences at the time of publication of this report further highlights the immense challenges front-line care providers face, their skill, and the value of publicly funded health-care at a time when it is needed the most.

Thank you to the Project Advisory Committee, particularly Anita Dickson, who brought invaluable insight as a practitioner in seniors' care.

Finally, a warm thank you to Andrina Perry and, last but not least, the whole team at the CCPA, who shepherded the final report to publication.

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Summary

The place of assisted living in BC's seniors' care system: Assessing the promise, reality and challenges

COVID-19 has shone a light on the state of long-term care for seniors in Canada, including problems resulting from years of underfunding, privatization and precarious working conditions faced by an undervalued, marginalized workforce dominated by racialized and immigrant women. These problems are not isolated to long-term care—rather, they are symptoms of a larger crisis in our fragmented system of home- and community-based health care for seniors.

This qualitative study looks at the state of assisted living prior to the pandemic in terms of the quality and appropriateness of services it provides to seniors, the conditions for both residents and workers, and the legislative and regulatory frameworks that govern assisted living.

The research findings reinforce the urgent need for action driven by the experiences and voices of seniors, their families and the front-line workers who provide care amid frequently impossible circumstances. This study is by no means a comprehensive review of the assisted living sector—but it raises serious concerns that warrant such a review by the BC Seniors Advocate.

The study draws on:

- Qualitative interviews with care aides and licensed practical nurses (LPNs) working in assisted living, and with a smaller number of seniors living in assisted living facilities and family members of residents. In total, 28 individuals participated in the study, with experience in publicly subsidized and private-pay assisted living residences. Participants were from Vancouver Island, BC's Interior and the Metro Vancouver area.
- A detailed look at the public policy changes that shaped the introduction and growth of assisted living in BC since 2002.
- The peer-reviewed health services and policy literature on assisted living.

Assisted living was introduced as a substitute for long-term care with the aim of providing a less institutional, more home-like environment. But for the government of the day, it was also attractive as a cost-saving measure.

The evolution of assisted living in BC

BC's home and community care system has seen substantial changes over the past two decades, at the same time as the population of seniors has grown dramatically. The CCPA–BC has documented these changes, most notably a steep decline in access to publicly funded services. Another key change was the introduction of assisted living in 2002, a housing model for supporting seniors with modest to moderate care needs.

Assisted living was introduced as a substitute for long-term care (nursing homes) with the aim of providing a less institutional, more home-like environment—which is important and highly valued by seniors. But for the government of the day, it was also attractive as a cost-saving measure (i.e., by their calculation about as half as expensive to provide as long-term care).

Concerns have been raised by assisted living residents, and their families, and care workers about the living and working conditions in these residences.

In long-term care, operators are responsible for the overall care of residents. They provide 24-hour nursing care and personal supports for residents with severe dementia and/or limited or no mobility, and increasingly for people who are palliative. Assisted living, in contrast, is considered a housing model, and the assisted living unit is seen as the individual's home. Operators can provide any number of non-medical assisted living services (e.g., assistance with dressing, bathing, medication administration, etc.) but are not responsible for providing traditional medical care (i.e., nursing, physician or rehab services) or mobility aides, as would be found in long-term care.

Some assisted living residences are publicly subsidized; others are entirely private pay. In publicly subsidized assisted living, residents pay a monthly charge of 70 per cent of their after-tax income and are deemed eligible to access services by their health authority. In private-pay assisted living, residents pay 100 per cent of the cost directly to the operator, and if the resident requires an additional service, it comes with an additional charge.

Since its introduction in 2002, the assisted living sector has grown to more than 7,600 units provincewide. Troublingly, the majority are owned and operated by for-profit companies, and more than 40 per cent are entirely private pay. The growth of for-profit and private-pay assisted living, and related affordability concerns, are analyzed in detail in a companion paper to this study *Assisted Living in British Columbia: Trends in Access, Affordability and Ownership*.

In 2016, the provincial government initiated legislative changes with the goal of increasing access to assisted living so that more seniors could age in place. This is a positive goal—however, the changes were introduced without a review of the sector to determine if it was, in fact, providing access to quality, affordable services. As a result, many key issues were not examined, including how effective the system was at responding when the physical and/or cognitive health of a resident deteriorated; the implications of having a large portion of the residences that are entirely private-pay; and an assessment of the funding and staffing that would be required to support more seniors to age in place.

Since that time, concerns have been raised by assisted living residents, and their families, and care workers about the living and working conditions in these residences. In response to these concerns, this research project focused on gaining a better understanding of the current state of assisted living in the province.

RELATIONAL CARE

A key ethical value meant to underpin policy related to assisted living is *respecting people's autonomy*—that is, respecting their capacity to maintain a level of independence and make meaningful informed choices regarding their care. Currently, BC's philosophy of care in assisted living emphasizes residents' "right to choose to live at risk" but without acknowledging the realities surrounding resident "choice."

When faced with the choice between institutional care or embracing greater health risks in exchange for more independence, many of us would choose the latter. Studies also show that seniors who age in place can experience greater levels of life satisfaction, connections to community and even life expectancy.

The challenge with the philosophy of *living at risk* in assisted living is that it is not always a genuine choice, nor are the resources needed to support residents, their family members or staff consistently available. Financial limitations (e.g., to pay out-of-pocket for additional needed services), more complex health conditions (such as moderate or advanced dementia) and low staffing levels can undermine a resident's ability to meaningfully choose to live at risk.

An alternative philosophy to living at risk is *relational care*. Relational care respects a resident's choice and autonomy but with a much greater emphasis on the level of support and positive social connections. At a practical level, providing relational care means increased staff and training to enable meaningful relationships with residents and to help staff support residents' autonomy even as their health-care challenges increase. Relational care also requires a strong focus on culturally appropriate care, as well as less hierarchical work environments where consistent communication—in the form of team huddles, for example—between care aides, nurses, managers and other providers is a regular practice.

Key findings

This study, together with the companion paper on ownership trends, uncovers a number of concerns that need to be further examined by the BC Seniors Advocate, including:

Unmet care needs due to affordability challenges, especially in the private-pay sector

The size of the private-pay assisted living sector increased dramatically between 2010 and 2017 (1,130 private-pay units added) and is largely run by for-profit businesses (81 per cent). The number of publicly subsidized assisted living units barely increased over the same period (with a mere 105 units added). Across the interviews, research participants commented on difficulties experienced by moderate- and lower-income residents in accessing the services they needed in private-pay assisted living residences. As a result, these residents are living at risk not by choice but because they can't afford the fee structure in private-pay assisted living residences, where seniors pay more for each additional service provided beyond the basic minimum required by law.

Research participants commented on difficulties experienced by moderate- and lower-income residents in accessing the services they needed in private-pay assisted living residences.

While the issue of affordability is much less acute in subsidized assisted living, there are still challenges, particularly for low-income seniors. For example, across both private-pay and subsidized assisted living, LPNs and care aides reported residents using towels as adult diapers or for wound care, skipping meals not included in basic food packages, or wearing dirty clothing because laundry detergent was too expensive or residents could not afford to buy new clothes.

> [One resident] fell outside on the patio… She tripped on something and fell and she said there was something in the way… They didn't even come and see her and ask her what had happened and how she fell and what she fell on. And she has glaucoma so she smashed up her hand and couldn't put her drops in, so they charged her for putting in the drops. They charge for every little thing. (Nava, resident)

A significant number of seniors in assisted living residences who do not appear to qualify for assisted living under provincial legislation

Residents in assisted living must be able to direct their own care. Specifically, the Community Care and Assisted Living Act states that operators "must not allow a person to reside in the residence if the person (a) is unable to make, on their own behalf, decisions that are necessary to live safely; (b) cannot recognize an emergency, take steps to protect themselves in an emergency or follow directions in an emergency….[or] (d) requires, on a regular basis, unscheduled professional health services," unless they reside with someone who can make decisions on their behalf (such as a spouse).

LPNs and care aides overwhelmingly reported struggling to meet the needs of residents who did not meet the criteria but were nevertheless living on their own in assisted living .

Many of the interviewees and focus group participants commented that assisted living increasingly looks like under-resourced long-term care. LPNs and care aides overwhelmingly reported struggling to meet the needs of residents who did not meet the criteria above but were nevertheless living on their own in assisted living (both publicly subsidized and private pay). This included residents with significant mobility limitations (including those requiring lifts and other mobility aides not provided in assisted living facilities), moderate to advanced dementia, and/or some who are palliative.

To understand the scope of this problem, it is important to determine how many assisted living residents fall into this category and specifically why they are not being transferred to long-term care or another appropriate level of care (e.g., hospice care). It is also important to determine if some of these residents could be properly supported to age in place if there were increases in staffing levels, and more access to basic health services and equipment, as well as changes in the philosophy of care—from one of living at risk to that of relational care.

> [The] local hospital is very bad at giving them [assisted living residents] a quick assessment and sending them back, returning them back, and I spend days…every day…on the phone talking to the hospital explaining to them…that if they cannot call for help on their own, they cannot mobilize in their room on their own, they can't come back to assisted living… You can't send somebody back that's not walking anymore, that can't call for that help, that's not getting out of their room on their own… They're just arriving back in the building again with their family members or from the ambulance or the hospital transfer bus has brought them back. (Saoirse, LPN)

Problems created by the living-at-risk philosophy in the context of inadequate staffing levels and private-pay, for-profit services

The findings from the interviews and focus groups show that in both publicly subsidized and private-pay assisted living residences, *living at risk* is being interpreted to mean non-interference. Assisted living workers noted that mandating staff to allow people to live at risk through policies of non-interference easily translates into a way for operators to cope with, or justify, low staffing levels. One LPN manager in a private-pay assisted living residence reported that interpreting living at risk as non-interference all too often leads to situations that border on neglect.

> I was asked to assess a resident by the health-care assistant, that was refusing to leave her room, not eating anything on her tray, very little in her refrigerator, curtains never open, client sitting in the dark and had not changed her clothes for unknown period of time. Upon entrance I found a resident sitting in her chair, frail looking, clothes with holes, not wanting to move, a tray in front of her with untouched food and beverages, I asked this resident to stand, she was unable to pull herself up due to weakness, she had barely eaten in weeks according to a chart in her room, she had tattered soiled underwear with no replacements. I spoke to the General Manager stating we need to get involved in her care as she was deteriorating and not aware of her declining condition, I was told this was not my concern, the resident has the right to live at risk, I called her son who stated she was "fine", I continued to push anyways to finally have her case worker come in to assess, she was immediately placed in long-term care and passed away within a week. She was suffering and I was helpless to intervene without putting my position at risk with the employer. (Ava, LPN manager)

Quality of care impacts resulting from undervalued and overworked staff

Research participants in this study had a lot to say about current working conditions for LPNs and care aides. Virtually all care aide and LPN participants in the study emphasized the need for more staff to cope with the increasing complexity of resident care needs. Many reported missing lunch or coffee breaks or paying out-of-pocket for supplies residents could not afford. Care aides also emphasized the wide breadth of their duties, the inadequacy of wages as compared to their counterparts in long-term care, heavy workloads and very high injury rates. Many care aides experienced precarious part-time working conditions throughout their career, often working on call.

Care aides emphasized the wide breadth of their duties, the inadequacy of wages as compared to their counterparts in long-term care, heavy workloads and very high injury rates.

In subsidized and especially private-pay assisted living, front-line staff reported being unable to do what they ethically know they should as a result of institutional constraints like low staffing levels and a lack of resources. These constraints create moral distress for both care aides and LPNs.

> [We have] residents coming into care, not accurately or adequately assessed, it happens. And to watch somebody struggle to try to get up because my co-worker is busy, like it just…I feel terrible and it shouldn't happen, but it does. And ultimately, it's the residents who suffer for it, you know, physically, [and with their] dignity. (Devorah, care aide)

Higher costs to the health system due to unnecessary emergency room visits and hospitalizations

In assisted living the costs of inadequate care are off-loaded to residents and families; however, front-line staff participating in this study reported a high rate of ER visits and hospital admissions of residents in assisted living, particularly due to falls. There were multiple reports in the interviews and focus groups of residents themselves attempting to lift other residents who had fallen. Some research participants also reported concerns about the over-prescription of antipsychotic medications—a trend previously documented in BC's long-term care facilities.

There is a significant mismatch between the care and social-support needs of residents and the low funding provided to operators of publicly subsidized units.

Acute care is the most costly part of the health-care system, and public resources would be better spent on increased staffing levels along with access to training and equipment to support assisted living staff to reduce the risk of falls and staff injury rates, build more support relationships with residents and provide basic health services (e.g., services related to urinary tract infections, complex wound care and palliative care).

There is a significant mismatch between the care and social-support needs of residents and the low funding provided to operators of publicly subsidized units. Improving the working and caring conditions in assisted living could significantly reduce costs in other parts of the health system. This would include improved care coordination with health authorities to ensure that assisted living staff have accurate and up-to-date information on the health needs of residents.

Recommendations

The provincial government should:

1) Immediately enhance the capacity of the assisted living registry to enforce the Community Care and Assisted Living Act by substantially increasing the number of assisted living investigators, and by developing policies that build on the inspection provisions in the act.

These policies should mandate yearly inspections of all private-pay and publicly subsidized assisted living residences. They should also mandate all publicly subsidized and private-pay assisted living residences to post clear and detailed information about how and where residents, families and staff can access the complaints process of the assisted living registry, including public reporting on compliance.

2) Support a review of seniors' assisted living residences conducted by the BC Seniors Advocate, with support from a multi-stakeholder advisory committee.

The review would gather input from assisted living residents, their families and friends, staff and community members on how this sector should be reconfigured, and on the supports required to ensure a viable relational model of care. The review would also address oversight issues not covered by the existing assisted living registry (e.g., tenancy and quality-of-care issues), the need for provincial regulations or protocols for information sharing between assisted living operators and health authorities, and the need for assessment processes to determine if assisted living is the appropriate level of care for a resident. To ensure that the review reflects the current reality of both publicly subsidized and private-pay assisted living residences, the Seniors Advocate would begin by gathering information—through mini audits and reports from the heath authorities—to

determine the extent to which there is a mismatch between the care needs of residents and the services provided, as well as the cost to other parts of the health system due to the underfunding of publicly subsidized assisted living services and the over-reliance on private-pay providers.

3) Establish an expert panel of both academic and practice leaders in relational care to help shift assisted living from a philosophy of living at risk to a philosophy of relational care.

This panel's work should begin with a report for the review process (above) on how to replace Managed Risk Agreements (currently in use) with Relational Care Agreements. Such agreements would acknowledge both the resident's autonomy and the responsibility of assisted living operators to provide residents with the support, education and social connections required to maintain and/or enhance their well-being and autonomy.

4) Address existing and future needs of the assisted living workforce:

a. Adopt a process for moving the wages and benefits for health care workers in assisted living to an existing provincial standard established by the appropriate health sector bargaining association and the Health Employers Association of British Columbia;

b. Create a workforce development plan that ensures clear training standards are developed for all staff working in front-line and health-care supervisory positions in both private-pay and publicly subsidized assisted living residences;

c. Mandate the new provincial health sector occupational health and safety organization (announced in 2019) to analyze injury levels and risk factors in assisted living, and develop an injury-prevention strategy and plan for the sector; and

d. Include in the health authorities' service contracts with assisted living residences the requirement that they collaborate with the joint occupational health and safety committee at their site to develop comprehensive processes for monitoring injury rates, identifying risk factors and preventing and reducing injury rates over time.

Introduction

A STRONG AND WELL-INTEGRATED SYSTEM OF HOME and community care is essential for BC seniors' quality of life and their ability to age and die with dignity. Home- and community-based seniors' care includes a continuum of services ranging from meal and exercise programs and home support to assisted living, residential long-term care and palliative care. When these services are properly funded and coordinated, they allow seniors to access appropriate types and levels of care quickly as their health needs change, reducing pressure on more expensive hospital care and enhancing seniors' quality of life.

BC's seniors' care system has seen substantial changes over the past two decades, at the same time as the population of seniors has grown dramatically. The Canadian Centre for Policy Alternatives' BC Office has documented these changes, most notably a steep decline in access to publicly funded services.[1] Another key change has been the introduction of assisted living in 2002 as a form of supportive housing for people with modest care needs. Assisted living was introduced as a substitute for long-term care with the aim of providing a less institutional, more home-like environment at a much lower cost. At the same time, access to long-term care was restricted to seniors with the most complex care needs.[2]

Since its introduction in 2002, the assisted living sector has grown to more than 7,600 units provincewide. Troublingly, the majority are owned and operated by for-profit companies, and almost half are entirely private-pay (i.e., not publicly subsidized). The growth of for-profit and private-pay assisted living and related affordability concerns are analyzed in detail in a companion paper to this study, *Assisted Living in British Columbia: Trends in Access, Affordability and Ownership*. This paper looks at the state of assisted living today in terms of the quality and appropriateness of services it provides to seniors, the conditions for both residents and workers, and the legislative and regulatory frameworks that govern assisted living.

Part 1 provides an overview of the study's research methods, which included interviews with seniors and their family members,[3] as well as care aides, licensed practical nurses and front-line managers working in assisted living. Part 2 reviews the evolution of assisted living in BC, including recent policy changes made through Bill 16, and the Community Care and Assisted Living Amendment Act. Part 2 also contrasts the philosophy of *living at risk* currently underpinning BC's

This paper looks at the state of assisted living today in terms of the quality and appropriateness of services it provides to seniors, the conditions for both residents and workers, and the legislative and regulatory frameworks that govern assisted living.

1 Vogel, 2000; Cohen et al., 2005, 2009; Cohen, 2012; Longhurst, 2017.

2 Cohen et al., 2005, 13.

3 For many seniors, *family* includes close networks of friends who provide support and care.

approach to assisted living with an alternative philosophy of *relational care*. Part 3 presents key findings from the interviews and focus groups, which uncovered serious concerns, including residents with severe physical and cognitive disabilities and other complex care needs who should not be in assisted living according to the province's own legal criteria; inadequate staffing levels and training; moral distress for caregivers who are placed in impossible situations; and a poorly coordinated sector that increasingly resembles under-resourced and more lightly regulated long-term care. This report concludes with recommendations to the provincial government that provide a road map for a more comprehensive assessment of the problems in assisted living and how they can be addressed.

PART I

Research methods

THIS RESEARCH STUDY INVOLVED THREE KEY COMPONENTS:

- A review of the peer-reviewed health-services and policy literature on assisted living, including the literature on *living at risk* and the evolution of assisted living over time in different jurisdictions.
- A detailed review of the public policy changes that shaped the introduction and growth of the assisted living sector in BC, along with the larger home and community care system, over the last 18 years.
- Qualitative interviews with seniors living in assisted living facilities, family members of residents, care aides, licensed practical nurses (LPNs) and front-line managers working in assisted living.

This research involved qualitative interviews with seniors living in assisted living facilities, family members of residents, care aides, licensed practical nurses and front-line managers.

In total, 28 individuals participated in this study, with experience in both publicly subsidized and private-pay assisted living residences. Participants were from Vancouver Island, BC's Interior and the Vancouver area.

Five two-hour focus groups were conducted with 14 care aides and five LPNs, including one session focused on rural BC. In-depth interviews averaging one hour were also conducted with three assisted living facility managers with nursing backgrounds, and with six participants with first-hand experience navigating assisted living care services, including residents and family members. The majority of family members navigating care for loved ones were seniors themselves. Some care aides and LPNs concurrently work, or have worked, in different types of assisted living residences. See Appendix B for additional details about the participants. This variety of experience allowed participants to compare work and care environments across publicly subsidized and private-pay assisted living, in facilities owned by health authorities, non-profit organizations and for-profit companies. Interviews and focus groups were conducted between December 2017 and November 2018.

This qualitative research serves as a companion to the 2020 CCPA–BC report *Assisted Living in British Columbia: Trends in Access, Affordability and Ownership*.

Participants were recruited through Facebook groups, posters, sign-up sheets at conferences and events, and mass emails distributed through project-partner listserves. Interviews and focus groups were transcribed by a transcriptionist subject to a confidentiality agreement, and pseudonyms were assigned to all participants in the study. Participants also signed informed-consent forms providing study information, and identifying information has been altered or removed to further protect confidentiality.

This research was conducted under the guidance of a research advisory committee, with members from community-based health groups, professional and labour organizations, and researchers, including a bioethics adviser from the University of British Columbia. The advisory committee commented on and reviewed the report and its findings, providing insight and guidance on associated recommendations. The research strongly benefited from community-based connections to seniors' centres, non-profit organizations, health authorities and unions.

This qualitative research serves as a companion to the 2020 CCPA–BC report *Assisted Living in British Columbia: Trends in Access, Affordability and Ownership*.[4] The in-depth interviews and focus groups conducted in this study complement the report's analysis of changes to the availability, affordability and ownership of BC's assisted living services. The study includes a limited sample size but provides a window into experiences in the sector and raises concerns that warrant further investigation (see the recommendations section for details). While quantitative research can focus on large statistical samples, qualitative research provides a detailed view of participant perspectives on health-care services, "offering a more complete picture of what happened in the program and why."[5] Collectively, these studies draw attention to problems with the policy approach to assisted living in BC, and to opportunities to improve the care that seniors receive, while also supporting less institutionalized philosophies of care.

4 Longhurst, 2020.

5 Boyce and Neale, 2006, 3.

PART II

The evolution of assisted living in BC

ASSISTED LIVING IS A TYPE OF SUPPORTIVE HOUSING for people with minimal to moderate levels of disability, who must be able to direct their own care and who require daily personal assistance to live independently.[6] In assisted living, residents receive housing, hospitality services (including two meals per day) and a variety of primarily non-medical support services (ranging from help with getting dressed and bathing to assistance with taking medications). Provincially registered assisted living is regulated under BC's Community Care and Assisted Living Act. Assisted living is available to seniors and non-seniors with disabilities; this paper focuses specifically on seniors.

In assisted living, residents receive housing, hospitality services and a variety of primarily non-medical support services.

When assisted living was first introduced into BC in 2002, a maximum of two non-medical support services could be provided. These were called *prescribed services* and have since been renamed *assisted living services*. The limitation to two such services established a clear threshold between assisted living and long-term care. When residents required more than two assisted living services, a transfer to long-term care was required. In 2007, this restriction was loosened to allow the provision of more than two assisted living services, and as of December 2019 any number of such services can be provided.

In contrast, long-term care is a more intensive form of seniors' care that provides institutional supports for older adults with significant needs.[7] It includes 24-hour nursing care and supports for residents with dementia and limited or no mobility, and increasingly for people who are palliative. The operators of long-term care facilities are responsible for the overall care of residents, and as a result, the majority of accommodation and health requirements of residents are covered through one monthly charge—compared with assisted living, the number of additional fees are quite limited (see Appendix A for details).

6 Longhurst, 2017, 8.
7 BC Ministry of Health, 2019a, section C.

Table 1: Publicly subsidized and private-pay assisted living units by ownership in BC, 2016

	Publicly subsidized units		Private-pay units		Total units	
	Publicly subsidized units	Share of publicly subsidized units in BC	Private-pay units	Share of private-pay units in BC	Total units	Share of total units in BC
Public health authority	183	4.1%	-	0.0%	183	2.4%
For-profit business	1,438	32.6%	2,600	81.4%	4,038	53.1%
Non-profit organization	2,792	63.3%	596	18.6%	3,388	44.5%
Total	**4,413**		**3,196**		**7,609**	

Source: Compiled from BC Ministry of Health Assisted Living Registry website, April 2016.

In 2016, more than half of assisted living units—53 per cent—were owned by for-profit companies, 45 per cent were owned by non-profit organizations, *and only 2 per cent* were owned by public health authorities.

Assisted living, on the other hand, is considered to be a housing model, and the assisted living unit is seen as the individual's home. Operators can provide any number of non-medical assisted living services but are not responsible for providing traditional medical care (i.e., nursing, physician or rehab services) or mobility aides, as would be found in long-term care.

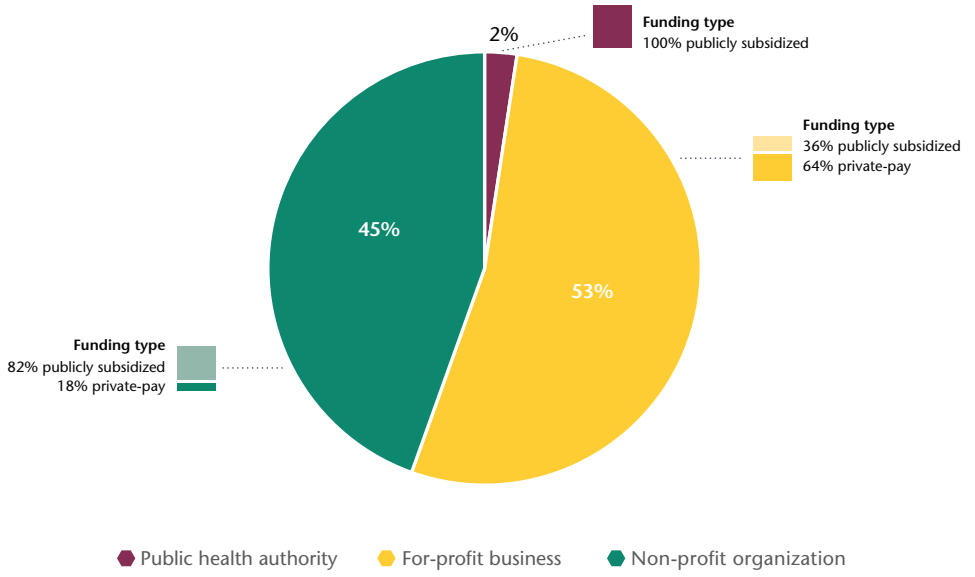
Some assisted living residences are publicly subsidized; others are entirely private pay. In publicly subsidized assisted living, residents pay a monthly charge of 70 per cent of their after-tax income and access services through their health authority. In private-pay assisted living, residents pay 100 per cent of the cost directly to the operator. The cost is determined entirely by the operator, and there are no maximum or minimum rates (see Appendix A).

In publicly subsidized assisted living, additional services may be provided at no extra cost to the resident for a limited time if the person is assessed as temporarily requiring these services; otherwise, they must pay out-of-pocket. In private-pay assisted living, additional services *always come at an additional cost*. Compared with long-term care, the assisted living model—especially private pay—gives operators the opportunity to charge residents for services and supplies that are not included in the basic monthly charge.

It is also important to distinguish between who pays for assisted living (the funding model) and who delivers it (the ownership type).

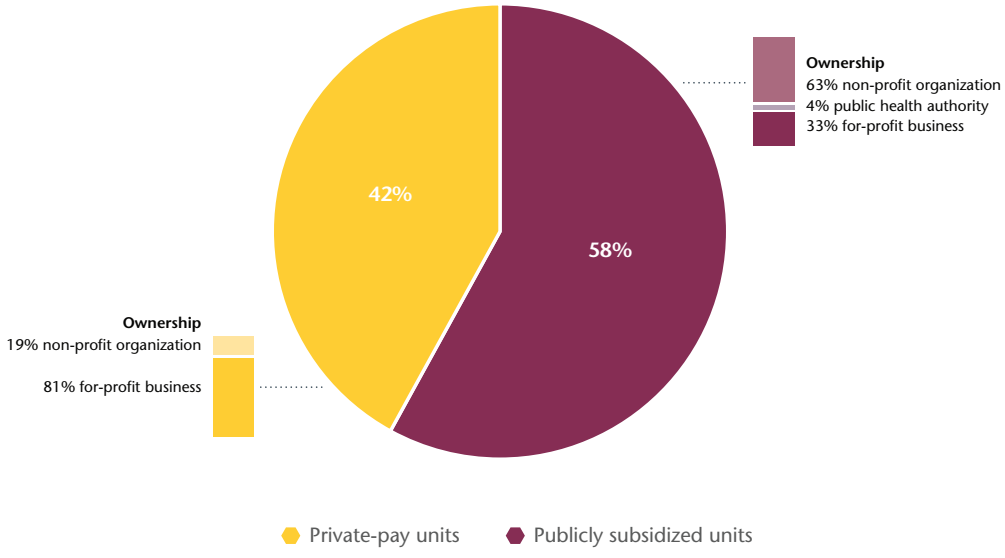
On the delivery/ownership side, health authorities contract with both for-profit companies and non-profit organizations to provide publicly subsidized assisted living. There are also a very limited number of assisted living units owned and operated by health authorities themselves. In 2016, more than half of assisted living units—53 per cent—were owned by for-profit companies, 45 per cent were owned by non-profit organizations, *and only 2 per cent* were owned by public health authorities (see Table 1 and Figure 1).

Figure 1: Assisted living units by ownership in British Columbia, 2016



Source: Andrew Longhurst, *Assisted Living in British Columbia: Trends in Access, Affordability and Ownership* (Vancouver, BC: Canadian Centre for Policy Alternatives, 2020), Figures 1 and 2.

Figure 2: Assisted living units by funding type in British Columbia, 2016



Source: Andrew Longhurst, *Assisted Living in British Columbia: Trends in Access, Affordability and Ownership* (Vancouver, BC: Canadian Centre for Policy Alternatives, 2020), Figures 1 and 2.

On the funding side, as of 2016, 58 per cent of regulated assisted living units in the province were publicly subsidized, while 42 per cent were private pay.[8] As the companion CCPA–BC report notes, between 2010 and 2017, private-pay units in BC increased at a much faster rate (46 per cent) than publicly subsidized units (2 per cent).[9]

Concurrently there has been rapid growth of market-based seniors' housing, referred to as the independent living sector, which resembles assisted living but remains unregulated.[10] By 2018, there were 18,978 private-pay independent living units in BC.[11] The focus of this paper is the regulated assisted living sector, often referred to as registered assisted living.

Assisted living as a substitute for long-term care? The evolution of assisted living in BC

In 2002, the province changed eligibility requirements in order to restrict access to long-term care to individuals with only the most complex care needs. The effect of this change was to artificially reduce demand for long-term care at a time when beds were being cut and the population of seniors was growing rapidly.

In 2001, the BC Liberal Party made an election campaign commitment to build 5,000 new non-profit long-term care beds by 2006. Shortly after the May 2001 election, however, the new government announced a shift in focus to "de-institutionalize" seniors' care, introducing assisted living with the promise that it would allow seniors to live in a more home-like environment.[12]

Instead of adding 5,000 new long-term care beds, the provincial government closed more than 2,500 beds in just three years.[13] Assisted living was introduced into BC's home and community care system as a substitute; the government announced that 3,500 of the 5,000 promised long-term care beds would instead be assisted living units.[14] This direction was attractive to the government because it assumed that the cost of assisted living would be about half as much as long-term care.[15] In 2002, the province also changed eligibility requirements in order to restrict access to long-term care to individuals with only the most complex care needs.[16] The effect of this change was to artificially reduce demand for long-term care at a time when beds were being cut and the population of seniors was growing rapidly.[17]

Indeed, since that time, access to long-term care has fallen precipitously. *Between 2001 and 2016, access to publicly subsidized long-term care spaces declined by 32 per cent* (measured as beds relative to the population of people 75 and over).[18] Access fell in all of the province's five health regions. This has put tremendous pressure on assisted living to provide a level of care that would have been provided to seniors in long-term care if publicly subsidized long-term care was readily available. These changes have also created market opportunities for the for-profit sector to offer expanded private-pay options to seniors and families who are desperate to find care.

8 Office of the Seniors Advocate, 2018b, 14.
9 Longhurst, 2020.
10 Office of the Seniors Advocate, 2018b, 14.
11 Office of the Seniors Advocate, 2018b. BC's Seniors Advocate refers to private-pay independent living as *private unregistered assisted living*. However, since *assisted living* refers to a regulated service model under the legislation, we do not use this terminology since it is likely to create greater confusion (*assisted living* is defined under the Community Care and Assisted Living Act, whereas *independent living* is not). Hence we use *private-pay independent living*. The service model may resemble assisted living, but it is a segment of the market that remains entirely unregulated.
12 Cohen et al., 2005, 13.
13 Cohen et al., 2005, 19.
14 Mick, 2002; Cohen et al., 2005.
15 BC Ministry of Health Planning, 2002, 34.
16 Araki, 2004, 24.
17 Cohen et al., 2005, 19.
18 Longhurst, 2017, 12.

One of the topics explored in the interviews and focus groups is the consequences of reduced access to long-term care in terms of both an increase in the number of higher-needs seniors living in assisted living and the growing gaps in care that may be emerging. This is a troubling finding given the fact that assisted living is a housing model with minimal staff that was never intended to provide complex care.

In fact, concerns about the mismatch between residents' care needs and the services provided in assisted living have existed since the model was first introduced in Canada approximately two decades ago.[19] Alberta was the first province in Canada to embrace the private-sector assisted living delivery model, characterized by low staffing levels, user fees and the off-loading of costs and care responsibilities onto residents and families.[20] In BC, beginning in 2004, researchers also began questioning the appropriateness of using assisted living as a substitute for long-term care.[21] Based on a survey and interviews with assisted living operators, these researchers found that many residents entering assisted living had care needs that were too high to be properly accommodated in that setting.[22]

By 2007, it was increasingly apparent that BC's assisted living substitution model was not working in practice. Many seniors required a higher level of care than could be provided for in assisted living. In August 2007, the Ministry of Health developed a policy that allowed assisted living operators to offer additional services in recognition that many seniors required more than the maximum two "prescribed services" (now called assisted living services) that operators were legally allowed to provide at that time.[23]

One of the topics explored in the interviews and focus groups is the consequences of reduced access to long-term care in terms of both an increase in the number of higher-needs seniors living in assisted living and the growing gaps in care that may be emerging.

In 2008, the BC Ombudsperson launched a systemic investigation into seniors' care, amid a growing crisis driven in significant part by the province's restructuring of home and community care. In her landmark report, released in 2012, the Ombudsperson wrote that [the Ministry of Health's] Office of the Assisted Living Registrar "told us that strictly confining operators to the provision of two prescribed services limits their ability to meet the care needs of residents."[24] The Ombudsperson concluded:

> The Ministry of Health has weakened the distinctions between assisted living residences [and] long-term care facilities… Permitting assisted living residences to provide additional services to house seniors with higher-level care needs while not protecting them with a higher level of oversight is a concerning shift in practice.[25]

The Ombudsperson's concern with the ministry's unofficial shift to allow additional prescribed/assisted living services indicated that the assisted living model was not working in practice—and that seniors needed the option of more care than could be provided under existing legislation.

Beginning in 2015, BC's Seniors Advocate looked at this same problem from a very different perspective. She argued that limitations on the number of services under the initial (i.e., 2002) legislative framework for assisted living meant that too many seniors were prematurely transferred to long-term care. She recommended that assisted living "be fundamentally redesigned and regulations changed, to allow for a greater range of seniors to be accommodated and age in

19 Meier, 2001.
20 Armstrong, 2002.
21 Araki and Gutman, 2004.
22 Araki, 2004, 126.
23 Office of the Ombudsperson, 2012, 153.
24 Office of the Ombudsperson, 2012, 155.
25 Office of the Ombudsperson, 2012, 51.

CONCERNS ABOUT THE ACCURACY OF THE RAI-MDS DATA

Despite the fact that care aides provide 80 to 90 per cent of direct care to residents in long-term care homes, care aides are not able to input information about residents into RAI-MDS. As one study notes, "Although the HCAs [health care aides] or PSWs [personal support workers] know the residents best, they are not allowed to provide contextualized information… Narrative input has to be left to the nurse who staffs the computer."[a] In another Canadian study of RAI-MDS, the researchers concluded that "this gap between planning and delivery suggests that the growing movement towards standardized care through the RAI-MDS may, in fact, undermine quality care by neglecting the importance of decision making and care practices undertaken by [care aides]."[b] The RAI-MDS has also been criticized for failing to accurately capture psychosocial well-being and the care needs of residents.[c] RAI-MDS data should not be the exclusive source of information used to inform home and community care services planning in the province. Indeed, many LPNs and care aides participating in this study highlight ongoing concerns regarding seniors' unmet care needs in BC's subsidized and private-pay assisted living residences.

a Armstrong et al., 2016, 259. Based on a large multijurisdictional study of long-term care, study authors came to the following conclusion about RAI-MDS data: "We have found that direct care staff are seldom involved in decisions about how and by whom the data are collected, and we have heard that the actual data are often either unknown to or ignored by these staff. Data collection tends to divert attention away from care; to promote staff distress; to reduce holistic, social care and staff judgement; and to prompt staff hierarchy and resentment" (361).

b Kontos et al., 2010, 352.

c Kontos et al., 2010, 353.

Living at risk is a philosophy that emphasizes seniors' right to choose how and where to age.

place as much as possible."[26] She based this on the increasing number of seniors who want to *age in place* in less institutional settings and the data she collected suggesting that a significant share of residents living in long-term care homes could be accommodated in the community with home supports or assisted living.[27] She reiterated this conclusion in two subsequent reports.[28]

Her conclusion was based on data from the Resident Assessment Instrument-Minimum Data Set (RAI-MDS). RAI-MDS is a standardized assessment tool used by regulated health-care professionals to assess seniors' physical and cognitive functioning in order to determine initial eligibility and continuing appropriateness for publicly subsidized home health services (e.g., home support, assisted living and long-term care). Researchers have raised concerns about the accuracy of relying on RAI-MDS data (see box for further details).

For the advocate, support for seniors to live in a more home-like assisted living environment reflects a desire to enable people to live with autonomy as they age, and concerns about the lack of autonomy in more institutional settings. Her approach is grounded in the idea of *living at risk*—a philosophy that emphasizes seniors' right to choose how and where to age (see "Confronting ethical tensions" for a more in-depth discussion of the living-at-risk philosophy).

26 Office of the Seniors Advocate, 2015, 49.
27 Office of the Seniors Advocate, 2015, 38 and 52.
28 Office of the Seniors Advocate, 2018a, 31; 2018c, 7.

Bill 16: A problematic effort to support aging in place

In 2016, the provincial government brought forward legislative changes through Bill 16, the Community Care and Assisted Living Amendment Act, with the goal of increasing the number of seniors who could age in place in assisted living. The act fully removed any limits on the number of non-medical services that could be provided, and at the same time clearly defined those populations for whom assisted living is not appropriate, such as people who are unable to make decisions on their own to live safely (discussed further below).

There was no public consultation process associated with the legislative changes in the act. The Ministry of Health did convene a 16-member advisory committee to review the draft regulations associated with the act. The committee's membership, however, was drawn primarily from government and industry.[29] Only one community-based seniors' organization was included, the Coalition of Senior Citizens' Organizations of BC (COSCO), which raised concerns about the exclusion of labour unions and other seniors' groups.[30]

While Bill 16 was passed in the BC Legislature in October 2016, it was not brought into force by the government of the day.

In May 2017, a minority NDP provincial government was elected. The new government has made a series of significant changes to BC's overall health-care system, including major improvements to home and community care services, notably substantial increases in funding to improve staffing levels in long-term care. The government also modestly increased funding for assisted living, with $26 million committed over a three-year period to increase staffing and care coordination.[31]

In the spring of 2018, the provincial government brought some provisions of the Community Care and Assisted Living Amendment Act into force to increase the oversight powers of the assisted living registrar (including investigating unregulated supportive housing residences) and mandate more extensive public reporting—positive steps toward increasing regulation in the public interest.[32] The remaining provisions of the act came into force on December 1, 2019, at which time the associated regulations also came into force.[33]

With the full implementation of the act, assisted living residents are able to receive an unlimited number of "assisted living services."[34] On the surface, this greater flexibility appears very positive. Many seniors would prefer the option of aging in place based on a care philosophy that supports autonomy and independence without resorting to what can be a paternalistic approach to care.[35]

Many seniors would prefer the option of aging in place based on a care philosophy that supports autonomy and independence without resorting to what can be a paternalistic approach to care.

29 The advisory committee was made up of representatives from the following organizations: the Ministry of Health, regional health authorities, the Denominational Health Association, the BC Law Institute, assisted living operators, two patient representatives, two industry lobby groups, the BC Care Providers Association, the BC Seniors Living Association and COSCO, an umbrella organization of seniors' groups from across BC that advocates for the rights and needs of seniors and their families).

30 Grewal and Jamieson, 2017, 5–6.

31 BC Ministry of Health, 2019b, 53.

32 Bill 5, 2018, Community Care and Assisted Living Amendment Act.

33 Assisted Living Regulation, 2019.

34 See the definition of "assisted living services" in Bill 16, 2016, Community Care and Assisted Amendment Act, section 1(b). The updated Community Care and Assisted Living Act, S.B.C. 2002, now has this definition.

35 It should be noted, however, that the promising practices and greater flexibility shown in some residential care homes elsewhere in Canada and in other jurisdictions—often intended to make residential care more home-like and less institutional—have not become commonplace in BC despite many great examples (such as Baines and Armstrong, 2015). In addition, BC's earlier multilevel residential care system (which included intermediate levels 1, 2, and 3, and extended) had been intended to account for residents' changing care needs. The multilevel residential care system was dismantled in 2002 with the passage of the Community Care and Assisted Living Act.

But the changes brought about through Bill 16 are contradictory. On the one hand, they reflect a desire to support people with greater health needs, including those who require palliative care, to age in place.[36] On the other hand, Bill 16 amendments define those for whom assisted living is not appropriate, including people who:

- Are unable to make, on their own behalf, decisions that are necessary to live safely;
- Cannot recognize an emergency, take steps to protect themselves in an emergency or follow directions in an emergency;
- Behave in a manner that jeopardizes the health and safety of others; or
- Require, on a regular basis, unscheduled professional health services.[37]

These restrictions mean assisted living is not appropriate for people living with moderate to severe dementia, for example, or for many who are palliative. Nor is it appropriate for many others who, because of significant mobility challenges, memory loss and/or because they are palliative, may not be able to protect themselves in an emergency or make the decisions needed to live safely. In addition, many seniors with higher needs, and certainly people who are palliative, are very likely to require regularly *unscheduled* health services and so are also defined as not appropriate to remain in assisted living. In other words, assisted living as defined in Bill 16 may not be an appropriate model of care for many of the seniors who are hoping to age in place.

Gaining a better understanding of how to support people's desire to age in place and address the limitations of BC's current assisted living model of care is the focus of this report.

Confronting ethical tensions: Living at risk or living with relational care?

The problem with the philosophy of living at risk in assisted living is that it is not always a genuine choice, nor are the resources needed to support residents, their family members or staff consistently available.

A key ethical value meant to underpin policy related to assisted living is *respecting people's autonomy*—that is, respecting their capacity to maintain a level of independence and make meaningful informed choices regarding their care. Currently, BC's philosophy of care in assisted living emphasizes residents' "right to choose to live at risk" but without acknowledging the realities surrounding resident "choice."

When faced with the choice between institutional care or embracing greater health risks in exchange for more independence, many of us would choose the latter. Aging in place also has benefits. Studies show that seniors who age in place can experience greater levels of life satisfaction, connections to community and even life expectancy.[38] Research has identified that much of this has to do with the quality of social connections seniors' experience close to home.

The problem with the philosophy of living at risk in assisted living is that it is not always a genuine choice, nor are the resources needed to support residents, their family members or staff consistently available. For example, financial limitations, certain health conditions and low staffing levels can undermine a resident's ability to make the choice to live at risk. Increasingly, bioethicists point out that context matters in health care: at the policy level, in supports available to health-care providers, and in the day-to-day needs and resources of those accessing services.[39]

36 Institute for Health System Transformation and Sustainability, 2018, 13.
37 Bill 16, 2016, Community Care and Assisted Living Amendment Act.
38 Wiles et al., 2012; Gardner, 2011; Haight et al., 1998; Lander et al., 1997.
39 Hoffmaster, 2018; Pollard, 2015.

There are two ways that context is important in understanding how "choosing to live at risk" is interpreted in BC's assisted living sector. The first is the increasing shift from a publicly subsidized to private-pay model (as detailed in the companion report *Assisted Living in British Columbia: Trends in Access, Affordability and Ownership*).[40] In this context, ability to pay often overrides the ability to freely choose to "live at risk" because access to services in private-pay residences entirely depends on the ability of the resident and their family to pay for these services. The second is the disconnect between the philosophy of supporting people to live at risk and the reality of low staffing levels and how residents now living in assisted living tend to have more complex care needs. In both private-pay and publicly subsidized assisted living, *living at risk* is being interpreted as non-interference. (For more information on this point, see the section called "Choosing to live at risk interpreted as 'non-interference'" in Part 3.)

An alternative philosophy to living at risk is relational care. Relational care also supports and respects resident choice and autonomy but with a much greater emphasis on the level of support and positive social connections.[41] It assumes that by fostering compassionate and meaningful relationships with residents, it is possible to improve their well-being and enhance their sense of autonomy. This notion is supported by research in a qualitative study that looked at the benefits of relational care and relational autonomy in a residential care setting. The authors provide data suggesting "that multidimensional relationships between residents, staff members, and even the wider community offer a kind of socioemotional care that is both meaningful and therapeutic."[42] In other words, relational care acknowledges "the broader facility and policy context that set the conditions for care" and builds on the social circles of support (e.g., care staff, family members, friends and/or broader community) that contribute to a resident's health, well-being and quality of life.[43]

Ability to pay often overrides the ability to freely choose to "live at risk" because access to services in private-pay residences entirely depends on the ability of the resident and their family to pay for these services.

At a practical level, providing relational care means increased staff and training so that staff are able to establish meaningful relationships with residents and learn how to respectfully support and enhance resident autonomy even as a resident's health-care challenges increase. To make relational care a reality, it also means less hierarchical work environments where consistent communication—in the form of team huddles, for example—between care aides, nurses, managers and other providers is a regular practice.

40 Longhurst, 2020.

41 Kadowaki and Cohen, 2017.

42 Rockwell, 2012, 246–47.

43 Banerjee, 2018, 39. A more detailed discussion of difference between the living-at-risk philosophy and relational care can be found in the section "Choosing to live at risk interpreted as 'non-interference'" and in the conclusion.

PART III

Key findings from interviews and focus groups

Research participants commented on difficulties experienced by moderate- and lower-income residents in accessing the services they needed in private-pay assisted living residences.

THE INTERVIEWS AND FOCUS GROUPS CONDUCTED AS PART OF THIS STUDY highlight many of the challenges facing assisted living residents, their families and friends, and the health-care workforce. These include problems with how the living-at-risk policy is implemented, the unmet care needs of many residents, moral distress experienced by staff, and the off-loading of costs and responsibilities onto families and hospitals.

Problems with living at risk for moderate- and low-income seniors

Half of single BC seniors have incomes of $25,000 or less. [44]Additional structural inequalities mean that Indigenous seniors,[45] LGBTQ2 seniors,[46] and persons with disabilities[47] can be further economically marginalized as they age.

As the companion CCPA–BC report notes, access to public subsidized assisted living units has declined alongside a rapidly growing private-pay sector.[48] As of 2016, 42 per cent of BC assisted living residences were private-pay.[49] Across the interviews and focus groups, research participants commented on difficulties experienced by moderate- and lower-income residents in accessing the services they needed in private-pay assisted living residences. As one LPN manager

44 Ivanova, 2017.
45 Wien, 2017.
46 Coker, 2017. LGBTQ2 stands for lesbian, gay, bisexual, transgender, queer and two-spirited.
47 Ross and Khanna, 2017.
48 Longhurst, 2020.
49 Longhurst, 2020, 6.

noted, in private-pay residences, the ability to access services and make choices about whether or not to live at risk depends on the individual's personal and family resources:

> I can't tell you how many people, that their underwear was so shredded and so thin, and I actually went out to Value Village and bought them underwear or bought them clothing because a lot of times, the loved ones spend [the resident's] full pension just to live there and that's all they could afford so when you contacted the family, the family would say, "My mom's pension is going to run out, she doesn't have any more money, I can't afford to subsidize her anymore." (Ava, LPN manager, interview, December 13, 2017)

This same LPN manager talked about the pressure in private-pay residences to accept seniors who were not appropriate for assisted living (either because their needs are too high or too low):

> My role as LPN Manager, according to the Assisted Living Regulation, was to perform all intake interviews to assess the client and ensure that they were appropriate for assisted living. What I experienced was different. I was not invited to be part of the interview or invited when the client had already agreed to take the suite. The general manager designated the marketing director to do all intakes (who held no medical designation). She was strictly marketing to get all the rooms filled, based on occupancy and capability to pay. So now we've got all our rooms filled because that's their push was the bottom line, the revenue. (Ava, LPN manager, email response, November 14, 2019)

Across both private-pay and subsidized assisted living, LPNs and care aides reported residents using towels as adult diapers or for wound care, skipping meals not included in basic food packages or wearing dirty clothing because laundry detergent was too expensive or residents could not afford to buy new clothes.

In private-pay assisted living, every service a resident receives costs more money. The implications of this are captured in an interview with a resident:

> [One resident] fell outside on the patio on the fifth floor… She tripped on something and fell and she said there was something in the way… They didn't even come and see her and ask her what had happened and how she fell and what she fell on. And she has glaucoma so she smashed up her hand and couldn't put her drops in, so they charged her for putting in the drops. They charge for every little thing. (Nava, resident, interview, November 16, 2018)

There were also reports of tiered payments for medication management, representing financial incentives associated with higher use of different types of medications. Each medication is charged separately (e.g., eye drops, a blister pack, a nitro patch, inhaler, etc.) even if they were all being administered at the same time. One family member of a resident at a private-pay assisted living residence reported being told by a staff member that the residence where her mother was living liked to keep residents on more medications because it was financially lucrative. Breaking up medication administration into several sessions throughout the course of the day and night was also reported to result in more charges. Multiple participants reported substantial reductions in their relatives' prescriptions in assisted living after interventions from outside health-care practitioners.

While the issue of affordability is much less acute in subsidized assisted living, there are still challenges, particularly for low-income seniors. Across both private-pay and subsidized assisted living, LPNs and care aides reported residents using towels as adult diapers or for wound care, skipping meals not included in basic food packages or wearing dirty clothing because laundry detergent was too expensive or residents could not afford to buy new clothes. While assisted living services include "laundering of towels and linen," residents have to pay to do their personal laundry; and only "two nutritious meals" are included in their care packages.[50] In response to the fact that many seniors go without breakfast because they cannot afford to pay for meals not

50 Government of British Columbia, 2019.

covered in their care packages, one subsidized for-profit residence created a low-cost "porridge program," offering a bowl of porridge to residents for breakfast at $1 a day (Tara, manager, interview, November 22, 2018).

Workers also reported paying for residents' food or clothing out of their own wages, despite workplace policies to the contrary. One care aide participating in the study elaborated:

> Yeah, well, in our residence, there are residents who can't afford to have briefs… There are also residents who [don't] have relatives and they're just alone, and they cannot even afford to buy some personal stuff for them. So it's really very hard for them, yeah. Sometimes we just try to help, but we cannot do it all the time. (Zelda, care aide, focus group, September 25, 2018)

Choosing to live at risk interpreted as "non-interference"

Assisted living workers also noted that mandating staff to allow people to live at risk through policies of non-interference easily translates into a way for operators to cope with, or justify, low staffing levels.

A critical challenge across publicly subsidized and private-pay assisted living residences is the interpretation of "living at risk" as non-interference. A clear illustration of the limitations of non-interference is Managed Risk Agreements (MRAs), which residents are expected to sign when first entering assisted living residences. MRAs are legally codified agreements designed to limit the operator's liability by clarifying the risks that residents are expected to accept.[51] For example, rugs in living areas can be construed as a tripping hazard, and residents who have difficulties swallowing might sign a form stating their willingness to accept risks associated with eating. But what are the operators' responsibilities to provide safeguards such as pursuing fall prevention, or working with residents to identify easy-to-swallow foods that they would enjoy eating?

In some cases, MRAs do not deal with safeguards at all—the focus is entirely on limiting operator liability. In other cases, MRAs fail to realistically account for the level of care seniors require and/or sidestep significant cognitive conditions that limit a resident's ability to consciously "choose to live at risk."

More broadly, feedback from LPNs and care aides working in BC's assisted living residences points to tensions between the philosophy of residents "choosing to live at risk," their cognitive abilities, residents' and families' financial resources, and the business motivations of operators to charge additional fees for services and equipment.

Assisted living workers also noted that mandating staff to allow people to live at risk through policies of non-interference easily translates into a way for operators to cope with, or justify, low staffing levels. As one LPN manager in a private-pay assisted living residence notes, this interpretation of *living at risk* as non-interference all too often leads to situations that border on neglect:

> I was asked to assess a resident by the HCA [health-care assistant], that was refusing to leave her room, not eating anything on her tray, very little in her refrigerator, curtains never open, client sitting in the dark and had not changed her cloths for unknown period of time. Upon entrance I found a resident sitting in her chair, frail looking, clothes with holes, not wanting to move, a tray in front of her with untouched food and beverages, I asked this resident to stand, she was unable to pull herself up due to weakness, she had barely eaten in weeks according to a chart in her room, she had tattered soiled underwear with no replacements. I spoke to the General Manager stating we need to

51 Carton et al., 2015, 14.

> get involved in her care as she was deteriorating and not aware of her declining condition, I was told this was not my concern, the resident has the right to live at risk, I called her son who stated she was "fine", I continued to push anyways to finally have her case worker come in to assess, she was immediately placed in LTC and passed away within a week. She was suffering and I was helpless to intervene without putting my position at risk with the employer. (Ava, LPN manager, email response, September 23, 2019)

With the shift in BC to private-pay for-profit assisted living services,[52] policies appear to be focused on minimizing both legal liability and the staffing levels in order to maximize profits rather than on ensuring that residents are supported to live with autonomy. The trends in BC indicate a broader shift in corporate practice internationally, where risk mitigation has grown as a means to protect corporate interests while increasing risk to citizens.[53] This approach creates an uneven distribution of risk, shifting responsibility from the most powerful to the most marginalized.[54] Researchers emphasize the need for best-practice guidelines governing MRAs in Western Canada and for provincial consensus on identifying "manageable levels of risk."[55]

In assisted living, "choice" requires resources to support staff in establishing meaningful relationships with residents and facilitating their unique personal interests and social preferences—in other words, resources that support relational care with the goal of enhancing well-being and respect for autonomy.

The challenge of supporting higher-needs residents in assisted living

> "It doesn't look like assisted living to me."
>
> —Rosa, care aide, focus group, September 25, 2018

Many of the interviewees and focus group participants commented on the fact that assisted living increasingly looks like under-resourced long-term care. Prior to policy changes in the early 2000s that reduced access to long-term care beds, many residents currently residing in assisted living residences would have been assessed as more appropriate for long-term care. This report echoes the BC Ombudsperson's concerns about challenges related to inadequate staffing and lack of policy processes and oversight to reflect the reality of the complex care needs of the seniors currently in assisted living residences.

Many of the interviewees and focus group participants commented on the fact that assisted living increasingly looks like under-resourced long-term care.

An LPN reflects on the challenges of having higher-needs residents in assisted living, a shortage of beds in long-term care and rapid discharge policies in BC hospitals:

> [The] local hospital is very bad at giving them [assisted living residents] a quick assessment and sending them back, returning them back, and I spend days…every day…on the phone talking to the hospital explaining to them…that if they cannot call for help on their own, they cannot mobilize in their room on their own, they can't come back to assisted living… You can't send somebody back that's not walking anymore, that can't call for that help, that's not getting out of their room on their own… They're just arriving back in the building again with their family members or from the ambulance or the hospital transfer bus has brought them back. They're pushing them in in a wheelchair

52 Longhurst, 2020.
53 Carroll, 2011, 283.
54 Collins, 2010.
55 Edney et al., 2009, 9.

> and I'm realizing, well, if they can't walk, they can't go to the bathroom on their own… so I'm sending them back again. And then the family is going, "Well, why do you keep sending them back to the hospital?" Well, they can't care for themselves here, so again it circles and circles and circles. (Saoirse, LPN, rural focus group, October 5, 2018)

Caring for residents with higher, more complex needs puts immense pressure on families and staff. Challenges associated with dementia and palliative care illustrate why so many staff see assisted living as under-resourced long-term care.

Assisted living residents living with dementia

In 2012, almost 24 per cent of assisted living residents received a diagnosis of dementia within a year of accessing assisted living services.[56] Given the rapid growth in the Canadian population over age 85, today the number is likely higher.[57] Dementia results in progressive deterioration of cognitive, social and emotional functions. Care aides and LPNs reported increasing numbers of residents with dementia entering assisted living or, alternatively, developing dementia as they attempted to age in place. Reflecting this population change, many care aides participating in this study reported receiving specialized training for dementia in assisted living residences.

LPNs and care aides overwhelmingly reported that residents with dementia, who were unable to direct their own care, were living on their own in both publicly subsidized and private-pay assisted living.

Housing seniors with moderate to more advanced forms of dementia in assisted living contradicts the provincial requirement that assisted living residents be able to choose to live at risk. Current legislation states that assisted living operators "must not allow a person to reside in the residence if the person…is unable to make, on their own behalf, decisions that are necessary to live safely," unless they reside with someone who can make decisions on their behalf (such as a spouse).[58] Indeed, as researchers from the University of British Columbia note, "Individuals with moderate to advanced dementia were never intended to be eligible to reside in assisted living, given its requirements for the ability to make decisions and self-direct care."[59]

LPNs and care aides overwhelmingly reported that residents with dementia, who were unable to direct their own care, were living on their own in both publicly subsidized and private-pay assisted living. One care aides elaborated:

> We have a resident, he has Alzheimer's… Nowadays he cannot even follow simple instructions and we have to help him for the shower, for example. Lift your left foot. He doesn't know how to do it. Give me a cup for your milk. He doesn't know what I'm talking about. (Jasmine, care aide, September 25, 2018)

Many workers also felt that while they had the skills to care for residents with dementia, inadequate programming and staffing levels undermined their ability to support residents experiencing cognitive decline with safe and dignified care.

56 McGrail et al., 2012, 31.
57 Statistics Canada, 2019.
58 Community Care and Assisted Living Act, S.B.C. 2002, s. 26.1.
59 McGrail et al., 2012, 32.

Assisted living residents requiring palliative care

In BC, palliative care[60] aims to provide patients and their families with a holistic approach appropriate to the medical, social, spiritual and psychological needs at the end of life.[61] In 2012, researchers documented that a third of BC's assisted living residents died in place, while two-thirds moved to long-term care or hospitals before dying.[62] More recent statistics are not available, but care aides and LPNs participating in this study reported increases in the number of residents requiring more complex forms of care, including palliative care. For example, a care aide described her experience caring for palliative residents in assisted living:

> We have to provide [bathing], we have to change their briefs for them, and we have to dress and undress them. We have to make breakfast for them, everything. It's like some people are [more work] than the long-term care, it's like a possibility of like total care, but they are still living in the assisted living unit and the workload and the staffing is not matched. So that's the problem. (Jasmine, care aide, focus group, September 25, 2018)

The concerns expressed above, and by many others participating in the study, identify the challenges of caring for palliative residents in a setting that is not equipped to support end-of-life care.

The concerns expressed by many participating in the study identify the challenges of caring for palliative residents in a setting that is not equipped to support end-of-life care.

Cognition can be dramatically impacted during the process of dying and affected by a variety of factors, including the resident's level of stress,[63] their specific condition,[64] and medications such as morphine prescribed for pain management.[65] There can be an inherent tension associated with the requirement that residents direct their own care in assisted living and in experiences of dying. Workers, in turn, reported that there are not appropriate resources and regulations in place to facilitate the delivery of safe and quality palliative care services in assisted living residences in BC. For example, the need for regulations around management of opioids for pain relief was a critical challenge highlighted by LPNs:

> You need a way better system because right now, it is so awkward with medication… I'm hearing so many different things about opioids because when you have palliative people, you have a high level of narcotics on site… When I went to work, I saw fentanyl patches just laying everywhere. There was no count… There's hydromorphone all over the place… The residents couldn't remember to lock up their drawers. (Anna, LPN, focus group, September 25, 2018)

Another LPN, who reported working 60 hours a week to facilitate a single resident's death, raised the following concerns:

> If they are going to introduce that more [complex care in assisted living], how are you going to sustain it? How is that sustainable when…there's not enough staff, there's not enough resources, they don't have the training? (Alesha, LPN, focus group, September 28, 2018)

LPNs participating in the study emphasize that effectively providing palliative care to assisted living residents requires increased staffing, more support for complex medication management,

60 Canadian Nurses Association and Canadian Hospice Palliative Care Association, 2015.
61 Johnson and Smith, 2006; Kary, 2015.
62 McGrail et al., 2012, 32.
63 McEwen and Sapolsky, 1995.
64 Pereira et al., 1997.
65 Kamboj et al., 2005.

more training and equipment, and better supports for catheter and incontinence management. Palliative care services also require enhanced opiate tracking and administration procedures and oversight, hospital-style adjustable beds, and hoists and slings for resident bed transfers. A relational care approach to palliative care emphasizes patient's "values and health-care wishes by promoting autonomy, dignity and control as well as shared decision-making (as appropriate)."[66] Assessing and treating symptoms, enhancing the patient's quality of life and pursuing a reduction in suffering and pain are also critical to palliative care approaches.[67] Focus group and interview data from this study suggest that effectively supporting palliative patients in BC's assisted living residences requires a dramatic restructuring of assisted living services and additional government investments in staffing, supports, resources, training and oversight.

Assisted living residents with higher health needs fear losing their home

Family members, residents, care aides and LPNs reported that many seniors attempt to hide their deteriorating health out of fear they will be required to pay for additional services or will be relocated to long-term care.

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> There was a group of people going into…one of the rooms and there were two or three walkers, and they entangled in the process, and she [the resident] got knocked over. And in that case, there were no aides there, she did get up and somebody did help her up. But she had some damage to her knee that was painful… And she never wanted me to tell them [the staff] because she was afraid she'd get kicked out. But the fear is, if you cross that medical line, you lose your home. (Charlie, family member, interview, November 2, 2018)

Charlie also talked about the fact that "she cut her underwear… She cut it up into little pieces and put it down the toilet because she didn't want anybody to know. So if she goes over that line to incontinence, I think she'll have to move." The fact that seniors go without care in an attempt to hide changes in their health status adds further complexity to the story of assisted living in BC.

Honouring seniors' diversity, perspectives and care needs

> "Assisted living was created to be an alternative to nursing homes, but if you walk into some of the big assisted living facilities, they sure feel like a nursing home."
>
> —Doug Pace, Alzheimer's Association[68]

Interviews with family members and residents point to the need for a shift in the culture of assisted living. Positioned as an alternative to institutionalized care, there is nevertheless much about assisted living that is reminiscent of institutionalized care. The Metro Vancouver Cross-Cultural Seniors Network Society and the Council of Senior Citizens' Organizations of BC emphasize BC's "increasingly culturally and age diverse populations of seniors," requiring different group activities, diverse language supports and access to culturally appropriate foods in assisted living residence.[69]

66 Canadian Nurses Association and the Canadian Hospice Palliative Care Association, 2015.
67 Johnston and Smith, 2006.
68 Quoted in Rau, 2018.
69 Grewal and Jamieson, 2017.

As emphasized in earlier sections of this report, relational care is rooted in participatory approaches to meeting residents' care needs. These approaches also place attention on each resident's unique social and economic context. The current emphasis on autonomy and choice in consumerized models of care do not account for inequalities that shape resident "choice." Furthermore, residents can become isolated in institutional forms of care that do not meaningfully provide for physical or emotional needs.

> Charlie: I remember hearing these two gay guys being interviewed… They've created a supportive community in the world, and now they have to go back into an unsupportive community in their seniors' care.
>
> Researcher: I know a lot of folks go back in the closet at that point.
>
> Charlie: And that's what these guys were talking about… But I think that it's a social problem that's much more…that affects a lot of people… And all the cultural diversity, every kind of cultural diversity even…well, religion, gender, preference. But even little things like readers and non-readers. (Family member, interview, November 2, 2018)

Assisted living services in BC are fraught with tensions between the care seniors need and the supports they actually receive. Honouring and respecting seniors' diversity needs to be key focus in shifting assisted living philosophy from living at risk to relational care.

Quality of care is undermined when staff are undervalued and overworked

Research participants in this study had a lot to say about current working conditions for LPNs and care aides. High workloads and an undervalued workforce shape current challenges in assisted living. The workforce is disproportionately made up of female and racialized[70] immigrants to Canada, and the working conditions are impacted by these structural inequalities.[71] Care aide participants in this study reflected these workforce demographics.

An undervalued workforce shapes current challenges in assisted living. The workforce is disproportionately made up of female and racialized immigrants to Canada, and the working conditions are impacted by these structural inequalities.

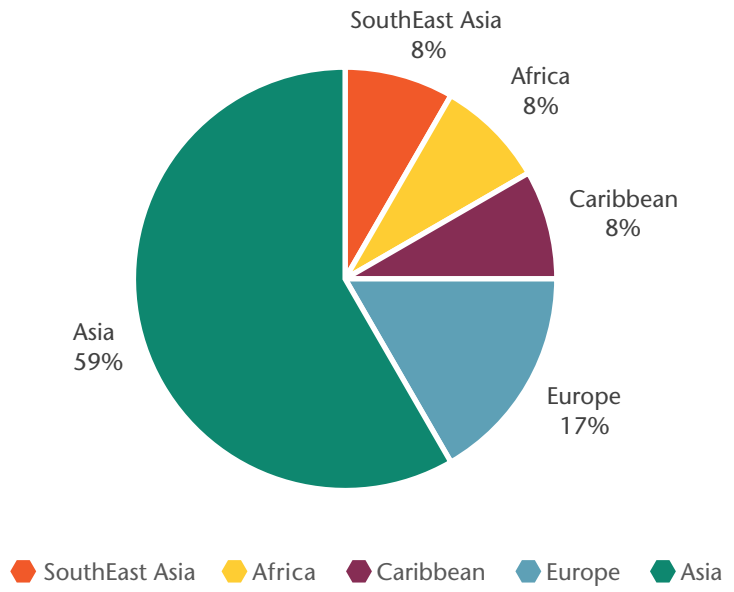
Care aides and LPNs working in both publicly subsidized and private-pay assisted living reported variations in the ratio of workers to residents, and virtually all emphasized the need for more staff to cope with the increasing complexity of resident care needs. Many workers reported missing lunch or coffee breaks; others emphasized the extreme breadth of their duties. For example, care aides reported being responsible for:

- Janitorial duties,
- Assisting with medications,
- Residents' laundry,
- Preparing dining areas for meals,
- Responding to residents' emergency calls,
- Arranging supply orders,
- Dressing and washing residents, and
- Bringing residents down to meals, among other duties.

70 City for All Women Initiative and City of Ottawa, 2016.

71 Armstrong et al., 2008. See the websites for the Philippine Women Centre of BC (https://pwcofbc.wordpress.com/) and Open Canada (https://www.opencanada.org/features/why-canadians-should-care-about-global-care-economy/) for posts and articles.

Figure 3: Global region of origin of participants who are immigrant LPNs and care aides



Many care aides experienced precarious part-time working conditions throughout their career, often working on call.

Workers from larger facilities with more beds reported marked discrepancies between the ratio of LPNs and care aides to residents. "I work for 10 years evening shift… It's over 100 residents, because there are couples living in one suite. And evening shift we have only two care aides working" (Mahalia, care aide, focus group, September 25, 2018).

Similar themes emerged during focus groups held with LPNs (focus group, September 25, 2018):

Christine: I am responsible for 60 residents at the moment. I'm the only practical nurse in the whole building at one time for the duration of my shift. So I do medications, injections in the morning, dressings—it just keeps on going. And then you've got one or two people falling through your cracks, and then there is no one else to do your job. And people fall all the time.

Anna: How many care aides?

Christine: I've got one care aide per floor, and it's 20 residents per floor.

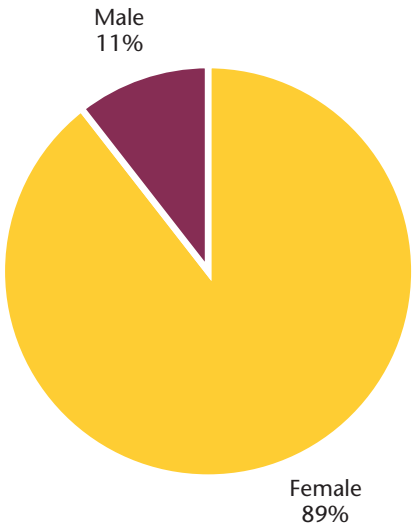
Janis: That's a heavy load.

Christine: It is. We've got tough nurses who would go home crying.

Other workers emphasized the inadequacy of wages associated with such a heavy workload, reporting that their counterparts in long-term care were paid more and valued more as workers. Many care aides experienced precarious part-time working conditions throughout their career, often working on call.

Some LPNs and care aides worked across assisted living service sectors in private-pay and subsidized models of care. One care aide said, "So we're having $18.70 an hour and dealing with over 100 residents. It's not really fair" (Teena, care aide, focus group, September 28, 2018). Ultimately, the combination of increasing care needs and low staff-to-resident ratios—particularly during night shifts and in high-occupancy residences—places additional pressures on workers, staff and families.

Figure 4: Self-identified gender of LPN and care aide study participants



Note: No participants reported self-identifying as non-binary or transgender.

A family member said:

> They need to have more staff. And all the staff there were unhappy. They were tired because they're overworked, and they're not happy with their working conditions. So they're just going through the motions… And they all have families at home that they've got to participate in as well. And for some reason, these facilities just figure oh well, they're coming here and this is all they have to do. And they work them hard. (Jen, family member, interview, November 13, 2018)

In Canada, racialized and immigrant women are disproportionately represented in "ancillary" care services and can be vulnerable to structural inequalities and racism.

Low staffing levels and heavy workloads mean that many care staff feel their work is undervalued. Of the 14 care aides interviewed for the study, 10 had immigrated to Canada, or were in the process of immigrating to Canada, from Asia, Southeast Asia, Europe and Africa. In Canada, racialized and immigrant women are disproportionately represented in "ancillary" care services[72] and can be vulnerable to structural inequalities and racism.[73] This has prompted immigrant workers in BC to organize in home and community care.[74] A family member of an assisted living resident in a subsidized for-profit residence explained:

> It's just not fair… Most of them now are from Philippines… I'm just saying it looks like a lot of other people aren't getting into that business because they don't get enough money…and they work hard for that amount of money. (Faith, family member, interview, October 26, 2018)

Stories emerged of a hierarchy in health care with care aides and LPNs at the bottom. One family member of a resident described negative comments made about LPNs by other health-care practitioners. "Oh, they made comments about it… And they looked down on her… You know, like

72 Armstrong et al., 2008.
73 Michel and Peng, 2017; Novek, 2011.
74 The Philippine Women Centre of BC (https://pwcofbc.wordpress.com/) is one example.

you're not an RN [registered nurse] or you're not a…you haven't got your bachelor of nursing or anything" (Sal, family member, interview, October 16, 2018).

Clearly multiple issues impacting the working conditions of staff and ability to provide quality care in BC's assisted living sector need to be addressed. This includes a lack of regulation of appropriate staffing levels, increasingly complex resident care needs, racism and the devaluing of a largely feminized workforce.

Concerns raised about inappropriate use of medications

Some research participants in this study also reported concerns about the overprescription of antipsychotic medications—a trend previously documented in BC's long-term care facilities. A family member who participated in this study noted:

> I noticed with the staff, as soon as a resident was maybe angry at something or just fed up with being treated like a herd and being talked down to like you're a child, they'd speak up or say something or get angry with the staff member, and the staff member would report it to the nurses, "Mr. so-and-so or Mrs. so-and-so is agitated, they need something to calm them down." And it's only because they're frustrated because it's not like what they thought it was going to be. So then the more meds they gave them, the less combative they were, the less they spoke out. (Jen, family member, interview, November 13, 2018)

Some research participants in this study also reported concerns about the overprescription of antipsychotic medications—a trend previously documented in BC's long-term care facilities.

The overmedication of seniors has been well documented in other research studies in BC.[75] In long-term care, 25 per cent of residents are currently prescribed antipsychotic medications without a supporting diagnosis, despite lower reported rates of psychiatric conditions compared with residents in other provinces.[76] This prompted BC's Seniors Advocate to raise concerns about the situation:

> There is no apparent clinical reason why our residents should be receiving more off label antipsychotics than similar populations in other provinces. In fact, the clinical information supports that it should be less.[77]

While extensive evidence is available on the use of antipsychotic medications in BC's long-term care facilities, less research has focused on their use in assisted living—a gap that requires further attention. McGrail et al. (2012) provide one of the few studies documenting antipsychotic prescriptions in BC's assisted living residences, noting "use of benzodiazepines and atypical antipsychotics in this population is high."[78]

We know from research in long-term care that antipsychotics are prescribed to "calm" residents and are also used off-label as a sleep aid without a diagnosis of psychosis.[79] Other studies point to workplace pressures for staff and the potential for antipsychotic overprescribing, especially when human support is inadequate.[80] For seniors the dangers are real. According to the Canadian Institute for Health Information:

75 Schoepflin, 2017; Morgan et al., 2016; Association of Registered Nurses of British Columbia, 2016.
76 CTV Television, 2018.
77 Quoted in Bains, 2018.
78 McGrail et al., 2012, 4.
79 Carton et al., 2015.
80 Taylor, 2016, 234.

> Use of psychotropic drugs is linked to an increased number of falls among seniors, and in the case of antipsychotics prescribed to elderly patients with dementia, may be associated with an increased risk of death.[81]

Use of psychotropic drugs is linked to an increased number of falls among seniors, and in the case of antipsychotics prescribed to elderly patients with dementia, may be associated with an increased risk of death.

The overprescription of antipsychotics has obvious implications for residents' quality of life. For example, a 2009 study that compared nine classes of drugs found that antipsychotics were strongly correlated with falls.[82] Others researchers have emphasized the long term costs to the healthcare system of over-prescribing antipsychotics, including ER visits, falls and medication expenses, noting, "$1 invested in AP [antipsychotics] reduction prevents $4.24 in healthcare costs."[83]

Approaches to clinical practice that focus on building relationships and social connections (i.e., relational care) can be a positive alternative to drug therapy. There is evidence, for example, that practitioners can effectively manage behavioural and cognitive symptoms associated with dementia by addressing residents' needs through non-drug interventions like gardening, pet therapy, music and exercise.[84] A recent report on human and taxpayer costs associated with antipsychotic overprescribing emphasizes the importance of "first determining the causal and contributing factors of the behavior" before turning to drugs.[85] Addressing the broader context of care and the social needs of residents in assisted living can help to offset the costs of ER visits, falls and medication expenses associated with the overprescription of antipsychotics. More importantly, it will enhance the quality of life for residents.

81 Vogel, 2014.
82 Woolcott et al., 2009.
83 Canadian Foundation for Healthcare Improvement, 2016, 2.
84 Fossey et al., 2006; Weeks, 2016.
85 Levinson, 2011, 6.

Assisted living care staff are experiencing moral distress

> "If we throw everything at them [care aides], they are not going to have anything right."
> —Tara, manager, interview, November 22, 2018

The increasing complexity of resident care needs and the inability of managers and front-line care staff to adequately meet those needs have created moral distress for front-line staff. Moral distress can be defined as stress that "occurs when one knows the right thing to do, but institutional or other constraints make it difficult to pursue the desired course of action."[86] An LPN manager, working in a private-pay residence, describes the moral distress she experienced when she was not able to do a simple health procedure that was within her scope as a health professional and would have prevented a resident from having to go to emergency.

Moral distress can be defined as stress that "occurs when one knows the right thing to do, but institutional or other constraints make it difficult to pursue the desired course of action."

> A resident came into my office knowing I was a nurse asking if I could test her urine as she had frequent UTI's [urinary tract infections] but was feeling too weak to go alone to the doctors and her family was not available to take her until the weekend, but the doctor was willing to issue a prescription if the Urine Analysis was positive. I said of course I would be willing to do a urine dip, to assist in mitigating a possible escalation of an infection. She also asked if I could do her vital signs. I was advised by my manager that I was NOT to do any vital signs (temperature, blood pressure, heart rate) or urine dip (which we did not have any available) as this was not my job, not my role as a nurse/manager in assisted living. The resident had to go to the doctors, I was not to get involved, this was their "home" and they would have to seek medical help on their own. This resident became ill, during the next day, and called 911 and was taken to ER, where she was diagnosed "UTI," given prescription and sent back to AL [assisted living]. I felt so helpless as a nurse having the skills, knowledge and the ethical compassion to help this resident but was not allowed and no tools to provide basic services. (Ava, LPN manager, email response, September 23, 2019)

In subsidized and especially private-pay assisted living, front-line staff are constrained from doing what they ethically know they should, but institutional constraints—including low staffing levels and a lack of resources—mean that they are unable to. As one manager states, "There is no extra funding at this time, but they are actually doing more work than they once did" (Tara, manager, interview, November 22, 2018). Another LPN manager reported extreme workloads for care aides in the private-pay sector and a lack of availability of LPN managers, who are often preoccupied with managerial duties, not assisting with resident care needs:

> You've got one care aide. You cannot do good service with one person running around and then they have to deliver room service and then on night shift you want that care aide to do all the laundry, if not set the dining room table. So not only do you have this person working all by themselves at nighttime, if you have an ambulance, and that's most of the time when people fall, it's at nighttime because they're getting up to go to the bathroom and they trip… 160 residents to one care aide… I've even talked to a lot of my colleagues before this interview. *We're all ethically challenged. We're watching this and we're going, "This is inappropriate."* (Ava, LPN manager, interview, December 13, 2017)

The need for more training, particularly for care aides, was highlighted by one manager: "Our front-line workers are the least educated and we expect the most out of them" (Tara, manager, interview, November 22, 2018). With residents requiring more supports arriving in assisted living,

86 Jameton, 1984.

our interviews with managers highlighted the need for enhanced training for staff to cope effectively, including in areas such as mental health, dementia, assisted transfers and safe operation of mechanical lifts, diabetes management, medication management and palliative care. Despite the reported need for more training, however, cuts to education were also reported. For example, one manager noted recent cuts to a health authority's funding of community college credits for care aides wishing to become certified as assisted living workers at her residence. The coursework largely covered simple medication management, and had been available for 10 years but was recently cut to reduce costs (Tara, manager, interview, November 22, 2018).

As the next section demonstrates, frequent resident falls compound moral distress for care aides and LPNs left with little capacity or resources to cope with the complexity of residents' care needs.

The cost of inadequate care is off-loaded onto hospitals and emergency services

In assisted living the costs of inadequate care are off-loaded to residents and families; however, the public health-care system also picks up the tab for frequent trips to emergency rooms and unnecessary hospitalizations—resources more wisely invested in providing care that matches seniors' existing needs and helps reduce hospital use.

The public health-care system also picks up the tab for frequent trips to emergency rooms and unnecessary hospitalizations—resources more wisely invested in providing care that matches seniors' existing needs and helps reduce hospital use.

Front-line staff participating in this study reported a high rate of ER visits by residents in assisted living, particularly due to falls. A care aide (Ted) and LPN (Saoirse) working in rural BC (focus group, October 5, 2018) described the paramedics' frustrations with frequent calls to emergency services:

> Ted: We had three falls in a matter of 45 minutes…and the same paramedics are coming back, "What's going on?" You tell us, because we don't know!
>
> Saoirse: And I've had paramedics that'll say to me, "Well, why are they still living here? Why are they still here?" Well, you tell me why they're still here!
>
> Ted: Most days we're calling an ambulance at least once a day to help somebody up.

There were also multiple reports in the interviews and focus groups of residents themselves attempting to lift other residents who had fallen. A family member of a resident explained, "She was a very helpful person and tried to help people. A guy fell and she wasn't allowed to help him, he couldn't get up" (Charlie, family member, interview, November 2, 2018). The time delay between a fall and the arrival of emergency services can also cause considerable distress to residents. In one case, an assisted living resident reported that approximately an hour passed before emergency services arrived following another resident's fall:

> He was out smoking one night, and he came in and fell on the floor and so I was there… They had lifted him up and put him in a chair and he had a heart situation, which I knew, and I'm sure everyone else knew, and his speech was becoming slurred and he couldn't hold his neck up, so I kind of stood by him and let him lean because he couldn't hold it up… I kept saying to the girls, "When are you getting the ambulance, when are you getting the ambulance?" So I don't know, finally the ambulance came. I think it was in about an hour… When the ambulance came, there was two ambulance workers and someone like a supervisor, and she said to me, "Why didn't you call sooner?" And I said, "I'm not a nurse, I'm just a person." (Dot, resident, interview, November 27, 2019)

An LPN manager participating in the study emphasized that transitional supports for residents are often needed when they return from hospital but are not always not available due to poor discharge planning and understaffing:

> If they do end up being hospitalized for whatever, most of the time it's due to a fall… Here's this person that's been hospitalized now for 10 days, sometimes even longer. Now they come back, they have that transitional shock of having all the services done in the hospital—people [at hospitals] show up [and] wash them, feed them, give them their medications. Now they're thrown back into their room and now they're trying to figure out, What do I do? Can't remember how to do the meds, can't remember how to do this, and they're waiting for some care to come. The care doesn't come because the case manager hasn't set it up or the LPN supervisor hasn't set it up because they don't have the staffing… I've seen that tons of times, I've seen failed discharges just because of that… This is a huge problem. (Ava, manager, interview, December 13, 2017)

Frequent resident falls and related hospitalizations highlight the inability of assisted living to appropriately manage complex care needs.

Ava also talked about the fact that assisted living residents often stay in hospital longer because of the lack of health-care services to support their rehabilitation (e.g., physiotherapy and occupational therapy) in assisted living residences.

Falls are the leading cause of hospitalization and injury-related death for BC seniors. The BC Injury Research and Prevention Unit estimates that "the number of bed days for fall-related hospitalizations is expected to increase from 162,562 in 2009/10 to 208,853 in 2018/2019," resulting in the need for 127 extra beds per day by 2018/2019.[87]

The evidence from front-line care providers interviewed in this study echoes research findings from BC and Alberta, as well as internationally.

In BC, a 2014 study documented higher rates of ER visits by assisted living residents compared with long-term care residents, particularly on weekends and after hours; McGregor et al. concluded that "at least some of these visits may be avoided with improved access to after-hours care and/or increased medical/nursing services on site."[88] In Alberta, a 2015 study concluded that "[assisted living] residents with dementia had a hospitalization rate almost 4-fold higher than LTC [long-term care] residents with dementia…[raising] questions about the ability of some AL [assisted living] facilities to adequately address the needs of cognitively impaired residents."[89] Another study, an evaluation of assisted living in Alberta, found 16 per cent of assisted living residents, compared with 6 per cent of long-term care residents, had one or more ER visits prior to a medical assessment.[90]

Frequent resident falls and related hospitalizations highlight the inability of assisted living to appropriately manage complex care needs. As the next section demonstrates, a critical component of complex care is the built environment needed to support resident care.

87 BC Injury Research and Prevention Unit, 2018.
88 McGregor et al., 2014, 160.
89 Maxwell et al., 2015, 568.
90 Strain et al., 2011, iii.

Assisted living residences' built environments do not safely support complex care and aging in place

> "I don't think our building is set up very well for people who have physical challenges."
> —Tara, manager, interview, November 22, 2018

LPN managers, front-line LPNs and care aides all emphasized the lack of built environments to support complex care needs in assisted living residences. Built environments can be described as the physical environments developed by engineers and planners to provide for the "health, safety, and mobility of older adults."[91] For example, one LPN manager at a subsidized for-profit residence emphasized that the building did not have the structural capacity to support ceiling lifts, "because they were trying to make it home-like" (Tara, manager, interview, November 22, 2018). Small bathrooms and doorways are inappropriate for wheelchairs and walkers. The use of carpeting instead of linoleum can hinder the mobility of residents who use mobility devices.[92] Broadening the services and supports doesn't just require additional staff and training; it requires renovations and structural adjustments to the assisted living residences themselves.

Care aides (focus group, September 28, 2018) described workplace pressures to manually lift residents even when they were not supposed to:

> Abebi: They come in saying they can transfer [out of bed themselves] and then you quickly realize they cannot… And you bring it up to…the nurse and whoever, and they'll maybe start the process of talking to the family and the employer themselves. But it doesn't really seem to get anywhere. I mean, we've had people that have been needing an assessment for their transfer for months, we've been needing them to be assessed, and same thing. I'm sure the Workers Compensation Board [WCB] would have something to say about that.
>
> Devorah: An unsafe transfer is unsafe for residents and staff. WCB looks at the staff injury part.
>
> Abebi: Yeah, WCB would have something to say about that.
>
> Devorah: But residents can be injured very badly as well.
>
> Abebi: I agree.

Across private-pay and subsidized assisted living, workers reported inaccurate and/or outdated care plans. One care aide participating in the study said, "I frequently have to lift people or assist them with their transfers when they are supposed to be independent" (Abebi, care aide, focus group, September 28, 2018). Another care aide said, "They will ask us 'Can you lift my leg, can you lift this, can you lift that,' and then 'I cannot transfer, help me to pull up my pants'" (Jessica, care aide, focus group, September 25, 2018).

According to WorkSafeBC, front-line caregivers experience the highest number of on-the-job injuries in BC at a rate of 8.7 per 100 workers—four times the provincial average for all workers.[93] Trips, falls and overexertion are all common workplace injuries experienced by BC's care aides.[94]

According to WorkSafeBC, front-line caregivers experience the highest number of on-the-job injuries in BC at a rate of 8.7 per 100 workers—four times the provincial average for all workers.

91 Kerr et al., 2012, 43.

92 Kapsin, 2008.

93 Griffin, 2017.

94 WorkSafeBC has had to publish several guides on the topic of home care (https://www.worksafebc.com/en/health-safety/industries/health-care-social-services/topics/home-care).

And while there has been considerable effort to mitigate the risk factors for injury among care aides working in long-term care, there has been much less focus on strategies to identify and mitigate these risks in assisted living residences.

At present, assisted living places both residents and workers at significant danger of transfer- and lift-related injury. It is not clear to what extent residents with significant mobility challenges are able to protect themselves in case of an emergency. This is very important because it is one of the criteria in the recent legislation (Bill 16) for determining whether an individual is an appropriate candidate to live in an assisted living residence. It is therefore critical to understand whether and to what extent the built environment represents a barrier to supporting people with significant mobility challenges from aging in place in an assisted living residence.[95]

At present, assisted living places both residents and workers at significant danger of transfer- and lift-related injury.

The built environment can also have a profound impact on the quality of life for seniors with dementia. A recent research study notes the importance of health-care environments for persons with dementia that 1) enable independence, 2) provide a sense of safety, 3) facilitate supportive social interactions and 4) promote respect.[96] Based on interviews with persons with dementia, the study documents the importance of modifications to physical environments, such as using colours instead of numbers to identify residents' rooms, adequate lighting, removing "clutter" in public areas, reducing "busy and crowded signage" and physical designs that limit noise and high traffic areas.[97] Other researchers emphasize the importance of safe access to outdoor areas, nature[98] and murals[99] to create a welcoming homelike environment. "Dementia villages" use architectural design as therapy on an even larger scale, offering residents entire communities with restaurants, theatres, stores and hair salons carefully crafted to reduce confusion and anxiety.[100] These approaches to built environments have documented therapeutic benefits and clearly contribute to the wellbeing of people living with dementia.[101]

As noted earlier, it is clear there are significant numbers of individuals currently living in assisted living with different levels of cognitive impairment, including many who should not be in assisted living because they are not able to direct their own care. How this issue will be addressed in the future depends on the development of appropriate assessment processes for individuals prior to moving into an assisted living residence, as well as a requirement that residents are reassessed if they show signs of cognitive decline. It is beyond the scope of the paper to determine precisely what improvements in staffing levels and built environment could make it possible for individuals with some forms of cognitive impairment to safely remain in the assisted living residence longer, and is an area for further investigation.

The next section talks in more depth about the challenges with care coordination and care planning across the assisted living sector.

95 Bill 16, 2016, Community Care and Assisted Living Amendment Act.
96 Hung et al., 2017.
97 Hung et al., 2017.
98 Innes et al., 2011.
99 Gnaedinger et al., 2007.
100 Glass, 2014.
101 Day, Carreon, and Stump, 2000.

Inaccurate care plans and poor communication create barriers to coordinate assisted living with other services

Inaccurate care plans and poor communication and information sharing across health-care providers and health-care settings lead to poor coordination of care for assisted living residents. LPNs, LPN managers and care aides widely reported that care plans were out of date and/or inaccurate. This increases the risk of resident falls, lowers the quality of life and influences the residence's ability to provide appropriate levels of care as required under legislation. As one care aide explained:

> [We have] residents coming into care, not accurately or adequately assessed, it happens. And to watch somebody struggle to try to get up because my co-worker is busy, like it just…I feel terrible and it shouldn't happen, but it does. And ultimately, it's the residents who suffer for it, you know, physically, [and with their] dignity. (Devorah, care aide, focus group, September 28, 2019)

Another care aide in the focus group added, "The care plan, maybe it won't be updated, or originally when they first come in, the assessments weren't exactly how the resident needs care" (Abebi, care aide, focus group, September 28, 2018). As previously discussed (see "The cost of inadequate care is off-loaded onto hospitals and emergency services"), LPNs and care aides reported that people were admitted to assisted living with medical needs that exceed the legal definition of being able to direct their own care. Inaccurate and/or out-of-date care plans compound this problem. Another contributing factor can be found in intake assessments conducted by business and marketing professionals at private-pay residences who are not trained health professionals (see "Problems with living at risk for moderate- and low-income seniors"). Residents are not being assessed by individuals with the expertise required to determine whether assisted living is appropriate based on their physical and cognitive status, allowing seniors to fall prey to the financial agendas of private-pay residences.

Out of date and/or inaccurate care plans increase the risk of resident falls, lower the quality of life and influence the residence's ability to provide appropriate levels of care.

Poor communication between assisted living residences (both publicly subsidized and private-pay) and health authority staff can create further barriers to effectively coordinate care for residents. For example, under current privacy laws, when someone returns to the assisted living residence after hospitalization and the community health-care worker (from the health authority) continues to provide support, the worker is not necessarily required to share the resident's health-care information. As a result, many LPNs and care aides working in the assisted living residence have little information regarding residents' progress or health-care needs. As an LPN participating in the study emphasized, this was particularly problematic for residents living in a private-pay for-profit assisted living residence: "When you have private—and there's a lot more of these companies—they do not cross-communicate with the health authorities. So if [the health authority] is coming in and provided services [in] a private-care facility, we don't know about that" (Anna, LPN, focus group, September 25, 2018).

LPNs (focus group, September 25, 2018) reported that in the past they sometimes had access to paper copies of health-authority care plans left on site in the resident's room:

> Janis: Oh yeah, and to add onto that now, all the authorities have gone electronic, so that folder that was on top of the fridge is no longer there…
>
> Anna: Yeah, because the care plan was available so at least we could see what the care plan was… Now, if I called that supervisor and [said], "Can we talk about the care plan?" [I get] "I can't talk to you."
>
> Janis: Right… "I'm sorry, because you are not part of health authority and your name is not written on the contact list, I cannot talk to you."

Effective coordination between the assisted living residence, the family, the resident's physician and the health authority is essential. Like other participants, LPN managers highlighted ongoing challenges in terms of communication and the coordination of services particularly in private-pay for-profit residences:

> The health authority has made up this wonderful care plan and everything. They won't talk to us. Even with the care aides that come into the facility [from the health authority] are saying, "We're told we can't talk to you because of confidentiality," but they can ask us all sorts of questions, but we can't ask them. (Ava, LPN manager, interview, December 13, 2017)

Assisted living residences operate with significantly less oversight and proactive enforcement of health, safety and quality-of-care standards.

Residents and family members also reported a pronounced lack of communication between assisted living residences, hospitals and other agencies regarding the status of residents' health and saw this as a safety concern.

Provincial legislation and regulations are clearly needed to facilitate the sharing of information for effective care coordination, in ways that still ensure an appropriate level of privacy protection for the resident. Provincial coordination is also needed to improve the care-planning processes within the assisted living sector. This would include:

- Provincially standardized and validated intake assessment tools administrated by regulated health-care professionals (e.g., a licensed nurse);
- Provincial policies to ensure timely and appropriate reassessments of care plans;
- Improved training for all staff on care planning; and
- Enhanced staffing levels in assisted living residences and in health authorities to ensure staff have the time to communicate changes in residents' health status.

Assisted living legislation is not proactively enforced

This report documents residents entering assisted living with increasingly complex care needs—many of whom in the past would have been directed to long-term care. Yet compared with long-term care, assisted living residences operate with significantly less oversight and proactive enforcement of health, safety and quality-of-care standards.

Prior to these changes, the provincial assisted living registrar worked strictly within a "complaints-driven" regulatory framework. This framework required residents to raise their concerns through their residence's internal complaints-resolution process before going to the assisted

living registry.[102] There was also no process in place for inspecting and monitoring assisted living residences to ensure compliance with provincial legislation and policies. With the changes made in the spring of 2018, the assisted living registrar now has the power to proactively inspect assisted living residences. There is, however, no requirement that these inspections occur at regular intervals (e.g., yearly).

It remains to be seen how the assisted living registry will operationalize its new monitoring and inspection powers, and whether regular inspections of assisted living residences will occur. To date, the existing operational capacity of the assisted living registry remains insufficient to adopt a proactive regulatory approach. The registry, located in Victoria, BC, within the Ministry of Health, has only two assisted living investigators for the whole province as of May 2019. It is also well documented that vulnerable populations, like those living in assisted living residences, are often afraid of the personal repercussion if they raise a concern through a complaints process.

In practice, assisted living in BC sits uneasily between a housing model with home support (i.e., independent living or a private residence) and long-term care. Further, assisted living is exempt from BC's Residential Tenancy Act. The Metro Vancouver Cross-Cultural Seniors Network Society and the Council of Senior Citizens of BC note that as a result, assisted living residents have no protection from rent increases or changes in ownership or operating practices."[103] Moreover, the assisted living registry does not have jurisdiction over the following:

Assisted living residents have no protection from rent increases or changes in ownership or operating practices.

- Tenancy disputes;
- Operating issues such as problems with staff, dissatisfaction with meals, etc., unless health and safety is compromised;
- Case manager assessments such as complaints about being assessed as ineligible for assisted living government subsidies, etc.; and
- Municipal issues such as noise complaints and criminal activity, unless health and safety is compromised.

The experiences of participants in this study demonstrate there are a number of areas where enhanced regulatory oversight is needed, including, but not limited to:

- Minimum staffing levels and appropriate training to ensure residents' needs for autonomy and care are respected;
- Intake and care-planning processes that reflect the criteria for eligibility to assisted living outlined in provincial legislation (Bill 16, now brought into force);
- Improved enforcement to ensure that assessments are conducted by a regulated health professional;
- Clear requirements on the appropriate storage and management of medications; and
- Tenancy protection related to rent increases and changes in ownership and operating practices.

102 Government of British Columbia, 2018b.
103 Grewal and Jamieson, 2017, 8.

Conclusion and recommendations

While it is in no way a comprehensive review of the sector, this study together with the companion paper have clearly uncovered a number of very serious issues that need to be further examined and addressed.

MORE THAN TWO DECADES HAVE PASSED WITHOUT a comprehensive assessment of seniors' care services in BC. The last provincial review of seniors' care was conducted in the late 1990s. Prior to the election in 2001, the Liberal Party promised to build 5,000 new long-term care beds based on the Ministry of Health's projection of the need to increase access to long-term care to support BC's aging population. Once elected, the government moved in a very different direction. In 2002, the eligibility criteria for accessing long-term care were changed, making it significantly more difficult for an individual to qualify for a publicly funded long-term care bed, and more than 2,500 mostly not-for-profit long-term care beds were closed. As a result, from 2001 to 2016, access to publicly funded long-term care beds has declined by more than 30 per cent. At the same time, the provincial government introduced an alternative to long-term care, a new housing model called assisted living, that was enshrined in legislation in the 2002 through the Community Care and Assisted Living Act. While many seniors welcomed this more home-like model of seniors' residential services, it is important to note that the funding level for this new assisted living model was approximately half of what it was for long-term care.

In 2016, the provincial government introduced (but did not pass into legislation) the Community Care and Assisted Living Amendment Act with the goal of increasing access to assisted living so that more seniors could age in place in a "home-like" environment. This legislation, however, was introduced without a review of the sector to determine if the funding, staffing and ownership model in fact ensured that BC's aging population had access to quality residential services that were affordable. As a result, many key issues were not examined, including how effective the system was at responding when the physical and/or cognitive health of a resident deteriorated; whether people who required a higher level of care were staying in assisted living because of the decline in the availability of long-term care beds; and if the funding for staffing and for new subsidized assisted living units was meeting the demand for affordable quality services.

Since that time, concerns have been raised by assisted living residents and their families, and the staff working in assisted living, about the living and working conditions in these residences. In response to these concerns, this research project focused on gaining a better understanding of the current state of assisted living in the province. And while it is in no way a comprehensive review of the sector, this study together with the companion paper have clearly uncovered a number of very serious issues that need to be further examined and addressed. These include:

- **The dramatic increase in the size of the private-pay sector,** which is largely (80 per cent) run as for-profit businesses, and the plight of the low- to moderate-income residents and their families, who can barely afford the cost of the basic service package but have no better alternative. The findings from the interviews and focus groups in this study highlight significant unmet care and personal needs for these residents—not by choice, but because they can't afford the fee structure in private-pay assisted living residences, where seniors pay more for each additional service provided. These findings point to the importance of improved funding and better planning of seniors' services to ensure that there are a sufficient number of subsidized non-profit assisted living residences and long-term care facilities to meet the needs of BC's aging population.[104]
- **The significant number of seniors living in assisted living residences who do not qualify for assisted living under provincial legislation.** This includes residents living with moderate to severe dementia, complex care needs and some of those who are palliative; who are unable to direct their own care; and/or who on a regular basis require unscheduled professional health services. To understand the scope of this problem, it is important to determine how many assisted living residents fall into this category and specifically why they are not being transferred to long-term care. It is also important to determine if some of these residents could be properly supported to age in place if there were increases in staffing levels, and more access to basic health services and equipment, as well as changes in the philosophy of care—from one of living at risk to that of relational care.
- **The significant problems created by the living-at-risk philosophy in the context of inadequate staffing levels and the private-pay for-profit provision of services.** The findings from the interviews and focus groups show very clearly that at present, across both publicly subsidized and private-pay assisted living residences, *living at risk* is interpreted to mean non-interference. This approach often leaves residents feeling isolated and vulnerable—hardly a recipe for enhancing choice and autonomy. At the same time, there is considerable evidence to suggest that supporting seniors to have positive social connections can improve their emotional well-being and enhance relational autonomy. All of which speaks to the benefits of shifting from a philosophy of living at risk to a philosophy of relational care.
- **The higher costs to the health system due to overmedication, falls and inadequate care lead to unnecessary emergency room visits and hospitalizations.** Acute care is the most costly part of the health-care system, and these resources could be better spent on increased staffing levels along with access to training and equipment to support assisted living staff to provide basic health services (e.g., services related to urinary tract infections, complex wound care and palliative care), reduce injury rates and build more meaningful relationships with residents. There is a significant mismatch between the care and social-support needs of residents and the low funding provided to ensure reasonable working conditions and remuneration for staff. Improving the working and caring conditions in assisted living could significantly reduce costs in other parts of the health system. This would include improved care coordination with health authorities to ensure that assisted living staff have accurate and up-to-date information on the health needs of residents.

The following recommendations, which are based on the key findings from the interviews, focus first on the need for a review to determine how assisted living should be reconfigured to improve access to high-quality and affordable services for all British Columbians who could benefit from them. The review would begin with information gathering to ensure that any changes are informed by current realities in assisted living and long-term care.

104 Longhurst, 2020.

The remaining three recommendations are more specific, including a strategy to support the shift from a philosophy of living at risk to a philosophy of relational care, improvements in the enforcement capacity of the assisted living registry and specific measures to address the existing and future needs of the assisted living workforce. All of the recommendations are directed to the Ministry of Health.

1. Enhance the capacity of the assisted living registry to enforce the Community and Assisted Living Act by substantially increasing the number of assisted living investigators,

and by developing policies that build on the inspection provisions in the act.[105] These policies should:

a. Mandate yearly inspections of all private-pay and publicly subsidized assisted living residences; and

b. Mandate all publicly subsidized and private-pay assisted living residences to post clear and detailed information about how and where residents, families and staff can access the complaints process of the assisted living registry, including public reporting on compliance.

2. Address existing and future needs of the assisted living workforce:

a. Adopt a process for moving the wages and benefits for health care workers in assisted living to an existing provincial standard established by the appropriate health sector bargaining association and the Health Employers' Association of British Columbia;

b. Create a workforce development plan to address the recruitment and retention challenges in assisted living, and ensure that clear training standards are developed for all staff working in front-line and health-care supervisory positions in both private-pay and publicly subsidized assisted living residences;

c. Mandate the new provincial health sector occupational health and safety organization (announced in 2019) to analyze injury levels and risk factors in assisted living, and develop an injury-prevention strategy and plan for the sector; and

d. Include in the health authorities' service contracts with assisted living residences the requirement that they collaborate with the joint occupational health and safety committee at their site to develop comprehensive processes for monitoring injury rates, identifying risk factors and preventing and reducing injuries rates over time.

A review would also address the oversight issues not covered by the assisted living registry, the need for provincial regulations or protocols for information sharing, and the need for assessment processes to determine if assisted living is the appropriate level of care for a resident.

3. Support the Seniors Advocate to work with a broad-based multistakeholder advisory committee to conduct a review of seniors' assisted living residences.

This would determine how to operationalize Bill 16 in ways that support a broad continuum of affordable seniors' residences and care services and ensure access to high-quality assisted living services for all British Columbians who could benefit from them. This review would include an outreach plan to gather input from residents in assisted living, their families and friends, assisted living staff and community members on how this sector should be reconfigured, and on the services and staffing supports required to ensure a sustainable and viable relational model of care (see recommendation two).

The review would also address the oversight issues not covered by the assisted living registry (e.g., tenancy and quality-of-care issues), the need for provincial regulations or protocols for

105 Community Care and Assisted Living Act, section 25.

information sharing, and the need for assessment processes to determine if assisted living is the appropriate level of care for a resident.

To ensure that the review reflects the current reality of both publicly subsidized and private-pay assisted living residences, the Seniors Advocate would begin by conducting three mini audits:

a. To determine the proportion of residents currently living in assisted living residences who do not qualify for assisted living (as defined by the Bill 16 amendments)[106] and identify the extent to which there are problems related to inappropriate prescribing and the lack of safeguards in medication storage;

b. To determine the percentage of current residents in long-term care who do not require this level of support and who could be more appropriately supported in an assisted living residence (instead of relying on RAI-MDS data as is currently the case); and

c. To determine the number of assisted living residents using emergency services, and the reason for and frequency of these visits and the costs to the system.

In addition, the Seniors Advocate would request a report from each health authority outlining:

a. How they are using the funding provided by the Ministry of Health (i.e., $26 million over three years)[107] to increase staffing and care coordination for assisted living residents and to identify the gaps and challenges with the implementation of Bill 16; and

b. The current pressure on the health authority for acute home support and home health resources from the assisted living sector, and the potential increased pressure on these resources moving forward.

2. Establish an expert panel of both academic and practice leaders in relational care to help shift assisted living from a philosophy of living at risk to a philosophy of relational care.

This panel's work should begin with a report for the review process (above) on how to replace Managed Risk Agreements with Relational Care Agreements. Such agreements would acknowledge both the resident's autonomy and the responsibility of assisted living operators to engage with residents and provide them with the support, education and social connections required to maintain and/or enhance their well-being and autonomy. The report would:

a. Define and apply relational care principles to an assisted living environment;

b. Outline a relational-care-planning process to be used with each resident when they enter an assisted living residence and a process for updating it at regular intervals;

c. Describe the educational materials and quality-improvement processes needed to support a relational care framework and improve practice over time;

d. Include strategies for ensuring that front-line staff and residents, and their family and friends, feel safe and respected in these processes; and

e. Recommend how to facilitate the shift to relational care and processes for monitoring progress (i.e., through the inspection processes for assisted living residences).

106 Bill 16, 2018. Note section 26.1, which defines persons deemed as not appropriate for assisted living residences.

107 BC Ministry of Health, 2019b, 53.

Characteristics of long-term care, assisted living and independent living in BC

	Definition	Services included	Staffing level and mix	Service funding model	Additional personal costs (beyond monthly charge)	Regulatory oversight	Regular inspections
Publicly subsidized long-term care	Residential long-term care (nursing home care) is facility-based care that provides 24-hour nursing supervision and care for individuals with complex medical needs.	Operators must provide: • Housing; • Hospitality services (meals; housekeeping; routine laundry services; physical, social and recreational opportunities; 24/7 emergency response system); • A personalized care plan, 24/7 nursing care, allied health professional care as identified in the care plan, general hygiene and medical supplies, incontinence management and basic wheelchair and maintenance; and • Other specialized service as needed[a]	• 24/7 nursing care (provided by a regulated nurse). • Provincial guideline (not law) of 3.36 hours per resident per day of direct care. Includes regulated and unregulated nursing-care providers and allied health professionals.	• Residents pay 80% of their after-tax income to the health authority, subject to maximum and minimum rates. • For a single client, the maximum rate is $3,377.10 per month in 2019; the minimum rate is $1,162.80 per month. • For a couple sharing a room and both in receipt of the Guaranteed Income Supplement, the minimum monthly rate is $1,616.30 per month ($808.15 per person).[b] The minimum client rate is adjusted annually based on changes to Old Age Security/Guaranteed Income Supplement. • Low-income seniors can request a fee reduction[c]	Additional charges are much more limited than in assisted living but may include personal phone and cable, hearing aides, personal transportation and additional or preferred medical equipment and supplies that are for the resident's exclusive use.	As per the Community Care and Assisted Living Act, long-term care facilities must be *licensed* by the health authority through a community care licensing office.	Yes

a "Long-Term Residential Care," Health, Government of British Columbia, accessed September 5, 2018, https://web.archive.org/web/20190605135341/https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-residential-care.

b "Long-Term Residential Care," Health, Government of British Columbia, accessed September 5, 2018, https://web.archive.org/web/20190605135341/https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-residential-care.

c In private-pay long-term care, there are no maximum or minimum rates.

d The Residential Tenancy Act does not govern any aspect of publicly subsidized or private-pay assisted living.

Characteristics of long-term care, assisted living and independent living in BC (continued)

	Definition	Services included	Staffing level and mix	Service funding model	Additional personal costs (beyond monthly charge)	Regulatory oversight	Regular inspections
Publicly subsidized registered assisted living	Type of supportive housing for people with moderate levels of disability who require daily personal assistance to live independently.	Operators must provide the following, which are included in the monthly rate: • A private housing unit with a lockable door; • Personal care services; • Two nutritious meals per day, one of which is the main meal; • Access to basic activity programming such as games, music and crafts; • Weekly housekeeping; • Laundering of towels and linens; • Access to laundry equipment for personal laundry; • Heating or cooling as necessary to maintain the safety and basic comfort level of the residence; and • A 24-hour emergency response system.	No minimum legislated staffing requirements other than there must be licensed nursing oversight of unregulated care staff.	• Residents pay 70% of their after-tax income to the health authority, subject to a maximum and minimum monthly rate. • The maximum rate is based on the market rate for housing and hospitality services for the geographic area where the resident lives, as well as the cost of personal care services. For 2019, the minimum single client rate was $1,018.90 per month and $1,552.00 for a couple living together. • Low-income seniors can request a fee reduction.	Allowable chargeable items include: • A surcharge for hydro services and a one-time charge for a damage deposit, based on half the monthly rent for the unit; • Cable connection and monthly fee; • Personal telephone connection and basic services; • Guest meals and suite rental; • Client outings or special events; • Hairstyling, foot care or other personal grooming services; • Housekeeping beyond weekly service; • Personal laundry services; • Parking and deposit on garage door opener; • Fee for pet damage and cleaning; • Transportation; • Equipment rental, at or below market rates; and • An administration or handling fee associated with the service, where reasonable, to perform a task or service that would normally be the client's responsibility.	As per the Community Care and Assisted Living Act, assisted living residences must be registered with the provincial assisted living registry (an office of the Ministry of Health).[d]	No
Private-pay registered assisted living	Same as above	Same as above	Same as above	Residents pay 100% of costs directly to operator. There are no minimum or maximum rates.	• Not regulated, therefore additional personal costs are determined by the operator and set out in the contract signed between the resident and the operator. • There is no legislated maximum housing charge, and there are no limits on increases in monthly charges in private-pay units (i.e., rent control).	Same as above	No

Characteristics of long-term care, assisted living and independent living in BC (continued)

	Definition	Services included	Staffing level and mix	Service funding model	Additional personal costs (beyond monthly charge)	Regulatory oversight	Regular inspections
Private-pay independent living	A variety of private-pay apartment-style and self-contained housing options, often with fee-for-service hospitality services (e.g., housekeeping and food services) for seniors who are functionally independent and able to direct their own care. Residents may bring in publicly subsidized or private-pay home support workers or other outside service providers to assist with personal care and daily living activities.	• Varies based on facility and private-pay options available. • Housing and services are based on a menu of optional private-pay services that are charged on top of a base rate, including meals, housekeeping, monitoring and emergency support, social and recreational opportunities, transportation, etc.	No minimum legislated staffing requirements.	• Privately funded by the resident (private-pay). • Not subsidized by a health authority.	Varies based on facility and private-pay options available.	• Limited oversight under the Community Care and Assisted Living Act (with the changes brought into force in 2018). • Must meet basic municipal health and safety standards, and standards of maintenance requirements. • Depending on the legal type (i.e., strata ownership or rental), must meet legal requirements under the Strata Property Act (owner-occupied) or Residential Tenancy Act (rental).	No

Appendix B

Research participants across assisted living sectors of care

Number	Type of participant	SECTOR EXPERIENCE		
		Private-pay*	Subsidized non-profit	Subsidized for-profit
Practitioners				
1	LPN	•	•	•
2	LPN	•	•	•
3	LPN			•
4	LPN		•	
5	LPN	•		
6	Care aide		•	
7	Care aide			•
8	Care aide			•
9	Care aide			•
10	Care aide		•	
11	Care aide		•	
12	Care aide		•	
13	Care aide		•	
14	Care aide		•	
15	Care aide	•		
16	Care aide			•
17	Care aide		•	
18	Care aide (community health worker)	•	•	•
19	Care aide (community health worker)		•	
20	Manager			•
21	Manager	•		
22	Manager			•
Participants with experience navigating assisted living services				
23	Resident			•
24	Resident			•
25	Family member	•		
26	Family member	•		
27	Family member	•		•
28	Family member	•		

* Private pay includes private-pay assisted living and independent living.

Appendix C: Focus group questions for care aides and LPNs

1. Do you feel you have the time you need to do your job in assisted living?
2. Have you ever felt conflicted about the level of care formally documented for residents in assisted living versus the level of care they actually need? For example, the resident is listed as capable of self-administering medication but in practice cannot reliably self-administer medication; or they are listed as capable of basic self-care but struggle to get dressed or feed themselves.
3. Are policies at your workplace designed to support residents' ability to choose to live at risk? If yes or no, please elaborate.
4. How do residents with high needs impact your workload in assisted living? For example, dementia or mobility problems.
5. Have you seen assisted living residents negatively impacted by their lack of income and ability to pay for services or supports?
6. Do you have recommendations for assisted living policy, practice or law?

Appendix D: Individual interview themes

Managers

Professional background (including training, education and current role)

Staff (including roles, worker-to-client ratios, and minutes of personal care services)

Living at risk (including definition in assisted living, cognitive impairments of residents, physical disabilities of residents, and health and safety of residents)

Care conditions (including complex care needs, the impact of income on quality of care, health-care providers from outside agencies, falls, and hospitalizations and emergency-room visits)

Operational and capital funding (including arrangements with health authorities, capital funding opportunities and associated challenges)

Improvements to assisted living (including recommendations and current needs of the residents and families)

Participants with experience navigating assisted living services

The assisted living resident's background (including health status and factors contributing to entering assisted living)

The intake process and assessment of the resident (including professional background of the intake worker, assessments and care plans).

Staff (including roles, worker-to-client ratios, and minutes of personal care services)

Quality of care (including health outcomes, access to services, ability to pay, and aging in place)

Living at risk (including definition in assisted living, cognitive impairments of residents, physical disabilities of residents, and health and safety of residents,)

Care conditions (including complex resident care needs, the impact of income on quality of care, health-care providers from outside agencies, falls, and hospitalizations and emergency-room visits)

Improvements to assisted living (including recommendations and current needs of the resident and family)

Appendix E: General demographic information collected from participants

Note: Information was also collected on the health status of residents; the professional background of health-care providers; and whether the assisted living being accessed or provided was private-pay, for-profit or non-profit.

Age:

Self-identified gender:

Self-identified cultural or ethnic background:

If you identify as an immigrant to Canada, Indigenous or as a member of LGBTQ2 communities we would like to know a little bit more about you. We ask because historically public policy researchers have neglected the needs of these populations in public policy advocacy.

Note: provide only if the participant is comfortable self-identifying***

- Yes, I identify as an immigrant from _____
- Yes, I identify as Indigenous from the following First Nation(s)/Inuit/Métis communit(ies) _____
- Yes, I identify as a member of LGBTQ2 communit(ies). I identify as _____

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The Hospital Employees' Union represents more than 50,000 members working for public, non-profit and private employers in B.C. HEU members work in all areas of the health care system — acute care hospitals, residential care facilities, assisted living facilities, community group homes, outpatient clinics and medical labs, community social services, and First Nations health agencies — providing both direct and non-direct care services. HEU has a long history as a strong, democratic, social justice union and a passionate defender of Canada's universal, public health care system.

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BC Health Coalition

The BC Health Coalition is a democratic, inclusive and consensus-based community of individuals and organizations that span the province of British Columbia. Together we advocate for evidence-based improvements to our public health care system, stimulate public education on health care issues, and drive positive change to our health care system through campaigns across the province.

bchealthcoalition.ca

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The Canadian Centre for Policy Alternatives is an independent, non-partisan research institute concerned with issues of social, economic and environmental justice. Founded in 1980, it is one of Canada's leading progressive voices in public policy debates.

The CCPA–BC is located on unceded Coast Salish territory, including the lands belonging to the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh (Squamish) and səl̓ílwətaʔɬ /Selilwitulh (Tsleil-Waututh) Nations.