SUMMARY

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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.

THE EVOLUTION OF ASSISTED LIVING IN BC

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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).

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

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.

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.

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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

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 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.

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).

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.

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> 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.

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

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.

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.

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.

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 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 səl̓ílwətaɁɬ /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 publically-funded health-care at a time when it is needed the most.

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This report is dedicated to the memory of Frances Belich (1927–2016) and of Carol Pearlstone (1940–2019).

CO-PUBLISHERS

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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.
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The opinions and recommendations in this report, and any errors, are those of the author, and do not necessarily reflect the views of the publishers and the funders of this report.

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