IMPROVING QUALITY OF LIFE IN LONG TERM CARE – A WAY FORWARD

Abstract

This paper explores the following:

- Our current situation in LTC including quality of facility care, staffing, and resources
- What contributes to quality of care/quality of life, how staffing/routine impacts this
- How well policy, regulation, and monitoring processes support quality of life (QOL) in LTC.
- Recommendations for a paradigm shift that detail a model of care, staffing requirements, work force stabilization, standards/monitoring processes that address residents' and families' need for QOL.

Action for Reform of Residential Care (ARRC)

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Dedication

This work is dedicated to all the residents of long-term care in British Columbia—you deserve better—and to family and facility staff who shared their stories.

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EXECUTIVE SUMMARY

Introduction

Long-Term Care (LTC) is neither structured nor resourced to ensure quality of care/life for residents, or a quality work environment for staff. Over the years, LTC systems have trimmed staffing resources and reduced access to quality of life (QOL) supports to manage shrinking budgets. Systems with lean resources cannot adapt to stressors such as pandemics, and band aids can no longer cover the wounds to the system illuminated by COVID-19. Long before COVID-19 there were stories in the media exposing problems in LTC, for example, neglect, aggression and abuse, all problems fueled by a chronically short-staffed workforce working within a custodial care culture. A paradigm shift, embedded in an ethical framework, is needed that recognizes and addresses the systemic/structural factors that continue to hold British Columbia back from developing a high quality LTC system that enables each resident to live their best life possible.

This document, grounded in evidence, is being presented by the Action for Reform of Residential Care (ARRC), a group of citizens with expertise, professional and lived experience, committed to working with the Province to reform long-term care (LTC), to better meet the needs of residents. The B.C. government has acknowledged its moral obligation to seniors in LTC. It has taken some important steps to stabilize the workforce and has indicated its commitment to improving the care and quality of life in LTC. Our reason for putting forward this paper is to support the Province, Health Authorities and LTC facilities to make the shift from an institutional model of care to one that supports residents' quality of life, and a quality work environment for staff.

This paper explores the following:

- Our current situation in LTC including quality of facility care, staffing, and resources
- What contributes to quality of care/quality of life; how staffing/routine impacts this
- How well policy, regulation, and monitoring processes support quality of life (QOL) in LTC
- Recommendations for a paradigm shift that detail a model of care, staffing requirements, work force stabilization and standards/monitoring processes that address residents' and families' need for QOL

Current Situation

Current conditions in LTC are not providing residents with the dignity and quality of life they deserve or are promised. Many facilities in our province are older, have a poor layout, and are overcrowded. Layout of older facilities, combined with lack of equipment, upkeep and overcrowding, contributed to the spread of

COVID-19. Beyond the physical conditions, staff are increasingly expected to care for seniors with a wide variety of needs, such as those with dementia, debilitating illnesses, mental health issues, challenging behaviours, substance use and severe psychiatric illnesses, as well as those who are young, strong and significantly cognitively impaired. COVID-19 has amplified the inadequacy of mental health support for residents living with dementia-related responsive behaviours or with psychiatric illness, and for the staff caring for them. Many facilities in BC, especially in rural areas, do not have adequate access to consulting seniors' mental health teams or clinical educators to support assessment, care planning and to provide education related to care of residents with mental health and substance use challenges. An additional concern is that even though many individuals die in LTC, facilities lack adequate numbers and appropriate mix of staff with specialized training to provide adequate palliative care.

Quality of Life: Staff matter

The staff who provide direct care have a significant impact on the quality of care/services available and quality of life for residents. Care aides, who provide the most direct care, are ill equipped through their training to manage the specialized needs of the diverse and complex LTC population and have little access to relevant ongoing learning, skill development or to mentoring once employed.¹ Registered Nurses (RN), who formerly provided leadership, mentorship and supervision may not be on site, or may be focussed on administrative duties. The Royal Society of Canada (Royal Society) in a review of front-line staffing issues in Canada pre COVID-19, (equally applicable to BC), notes care aides have needed to patch together hours to create a living wage, usually without benefits. Over-use of casual staff and failure to replace staff over burden those working and jeopardize team work and continuity of care. Chronic short staffing makes it difficult to provide quality care or to meet residents' relational needs, as this takes time. Relational care is the difference between care that is mechanistic and care that recognizes and relates to the whole person — not just the body — and creates connection. Many staff experience moral distress related to their inability to take enough time with residents to provide quality individualized care.

More front-line nursing staff, well supported and consistent, would result in greater capacity to respond to basic care needs such as taking residents to the bathroom, changing continence products, providing assistance to eat meals, and building relationships with residents. Not only would this improve the residents' quality of care, it would also engender a sense of being cared about – a key component to quality of life. Although there is evidence that therapists' work links directly with quality of care and quality of life, the Royal Society notes that across Canada there has been a systematic reduction of staff providing medical coverage, and physical and occupational therapy, with social and spiritual care nearly non-existent.² Maintaining physical functioning is important for health and to enable residents to be as independent as possible, supporting self-esteem, but therapy services are too often unavailable. Nutritional status, including deficiencies and imbalances, may affect a resident's wellbeing, health status and level of functioning, but access to assessments by Registered Dietitians is also limited.

Good physical/clinical care is an essential component of quality of life, but QOL also comes from the way one spends one's days, the number and quality of interactions with others and the comfort/security the social environment provides. A strong recreation program can provide residents with purpose, enjoyment

¹ MacCourt P., Wilson K. & Tourigny-Rivard M-F. (2011). "Guidelines for Comprehensive Mental Health Services for Older Adults in Canada." Calgary, AB: Mental Health Commission of Canada. Retrieved from: http://www.mentalhealthcommission.ca

² Estabrooks CA. et al. *Restoring trust: COVID-19 and the future of long--term care.* Royal Society of Canada. 2020 p 14

and meaning but almost half of all residents in 2018/19 had a low sense of social engagement. Recreation staff have an important role to play but have little time to spend one-to-one with the many who do not benefit from, or are distressed by, group activities. Social workers are not mandated in LTC although emotional and mental wellbeing are important components of QOL. Social workers, if integrated into the care team, could provide support to residents and families experiencing emotional and mental health challenges and to staff members experiencing work-related moral distress, trauma and burnout. Food has cultural, emotional and relational aspects, and mealtime could be the highlight of the day, but not when inadequate staffing prohibits a pleasant dining experience. As well, quality may suffer when food costs are reduced by contracting out, often to the lowest bidder³, compromising residents' appetites.

Life in LTC facilities, greatly exaggerated by restrictive visiting policies, is largely institutionalised, representing loss of social relationships, privacy, self-determination and connectedness.⁴ COVID-19 has revealed long standing limitations in the care of residents in LTC that arise from the staffing issues and a culture in which there is minimal or no attention to, or resources, for residents' QOL. Institutional influences on work routine such as significant documentation and standardized care routines mean that staff may spend more time documenting their work and completing checklists than providing individualized quality care. The result is a regimented, routinized, daily life over which residents have little control and that does not promote QOL.

Policy, Regulation, Monitoring

Health Authorities are responsible for the quality of care and quality of life for seniors in residential care even when services are contracted out to private operators. There is, however, no formal system in place to monitor resident QOL in the way Licencing monitors facility operation.⁵ Criteria to assess care, such as "appropriate staffing to meet need" are vague and subjective. Tools designed to monitor facilities, and for facility self-assessment, lack emphasis on QOL indicators and need to be strengthened and augmented. Enforceable staffing levels, care and quality of life standards, adequately monitored, would ensure the best life possible for our seniors.

Families of residents in LTC prior to and during COVID-19 have been instrumental in exposing inadequate care, negligence, and abuse in LTC, leading to several for-profit corporate homes being placed under Health Authority administration. While families' voices have proven crucial in monitoring the care provided in facilities, many families are reluctant to take their concerns to facility administration for fear of repercussions. Further, if families or Family Councils take concerns forward, the administration is under no obligation to address them. Many of the concerns of families relate to QOL and do not "fit" either the Patient Quality Care Office (PQCO) or the Licencing frameworks. If the role of families as partners in care, and of Family Councils as facility monitors, was written into the Residential Care Act, they could become highly effective advocates for resident quality of care and life. Regional Family Council Facilitators could support Family Councils and communicate directly with Licencing and Health Authorities as needed.

³ Key informant interview operator in for profit private facility.

⁴ Drageset J. et al (2009) "The impact of social support and sense of coherence on health-related quality of life among nursing home residents—A questionnaire survey in Bergen, Norway." Int J Nursing Studies 2009; 46: 66–76.

⁵ Key Informant interview with HA Director

Recommendations for a paradigm shift

It is not enough to make small, piecemeal changes to the current model of long-term care. Without a complete paradigm shift to replace the current institutional/custodial model our government will not be able to meet its moral obligation to the wellbeing of residents in BC LTC facilities. A shift to a philosophy of person-centred care that focusses on holistic care and quality of life, with physical/clinical care as background, is paramount and will enable residents to live their best possible lives, rather than simply existing. The following are recommendations necessary to support the province with making this transition.

1. Person Centred Care Model

We recommend that:

- the provincial government mandates, implements, and funds a person-centred care model in all LTC facilities and that each facility is staffed and organized to implement unit-based primary care and team approaches
- training be made available to all facilities' Directors of Care to prepare them to lead the implementation of person-centred care
- the provincial government provide infrastructure funding to enable facilities to adapt or modernize their physical environments to better meet residents' needs, such as outdoor spaces, single rooms, ceiling lifts, etc.

2. Staffing Levels and Mix

We recommend that:

- the MOH set a <u>standard</u> of actual direct care nursing hours worked per resident per day as 4.1 hours and facilities be funded and monitored effectively to ensure they meet this standard
- each facility be provided with sufficient Registered Nursing hours to address infection prevention and control, best practice care standards, quality improvement, staff education and orientation, and team leadership.⁶
- the MOH set a <u>minimum standard</u> .5 direct care hours worked by allied professions per resident per day and facilities be funded and monitored effectively to ensure they meet this standard. There must be access to:
 - Physical and occupational therapist hours based on performance indicators that support the goal of maintaining physical independence
 - Registered dietitian hours for nutrition care/resident/month based on acuity levels of residents in the facility

⁶ Nursing Home Basic Care Guarantee RNAO Submission to the Long-Term Care Staffing Study Advisory Group June 9, 2020

- Recreation staffing sufficient for day, evening, and weekend programming, and for one-one activities
- A social worker fully integrated into the care team, for each facility, to support person-centred care, address emotional and mental health needs of families, and to provide support to care giving staff.
- regional volunteer coordinators be funded to develop volunteer teams that can support recreation and other therapies and develop relationships with individual residents.

3. Staffing levels and delivery of direct care hours

We recommend that the provincial government

- fund LTC facilities to the level required to meet enforceable staffing level standards
- develop a clear definition of direct care hours as actual worked hours of direct care delivered and enforce it
- implement the following Senior Advocate's recommendations: (1) funding for direct care must be spent on direct care; and (2) monitoring for compliance with funded care hours must be more accurate
- limit the growth of corporate for-profit long-term care facilities and develop a buy-back program for existing facilities.

4. Work Force Issues

We recommend that:

• the provincial government develop a recruitment strategy for Care Aides that trials and evaluates different recruitment, training and retention strategies.

We recommend, in concert with the Royal Society of Canada, that the provincial government:

- "maintain appropriate pay (not limited to the timespan of COVID), and implement benefits, including sick leave, for the large and critical unregulated workforce of Care Aides. Pay and benefits must be equitable across the LTC sector, and between the LTC and acute care sectors for regulated and unregulated staff.
- make available permanent full-time employment with benefits to all unregulated staff and regulated nursing staff. They should also evaluate the impact on LTC facilities of "one workplace" policies, and the further impact on adequate care in other LTC settings such as retirement homes, hospitals and home care. Provincial governments must assess the mechanisms of infection spread from multi-site work practices and implement a robust tracking system.
- make mental health supports available to all LTC staff." ⁷

⁷ Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. *Restoring trust: COVID-19 and the future of long-term care.* Royal Society of Canada. 2020, p 28

We recommend that the provincial government

• create a task force that includes relevant stakeholders to review the curriculum for Care Aides and ensure; (1) it equips them to meet the complex needs of residents, including mental health, behavioural and palliative care needs, relationship building skills, culturally safe care practices, and (2) students' physical and psychological suitability for work in the LTC sector is assessed at entry and during the program.

5. Staff Training/Education

We recommend, in keeping with the Royal Society's recommendations,

- that the provincial government establish and implement (a) continuing education for the direct care workforce in LTC, and (b) proper training and orientation for anyone assigned to work at LTC through external, private staffing agencies.
- that the provincial government achieve these education and training objectives by supporting educational reforms for specializations in LTC for all providers of direct care in LTC facilities, Care Aides, health and social care professionals, managers and directors of care.

We recommend that

- RNs with responsibility for leading the care team and supervising staff be on site days and evenings.
- Social workers support front line staff in developing active listening, communication and relationship building skills.
- MOH optimize access to advance practice nurses in long term including Clinical Nurse Specialists and Nurse Practitioners.

We recommend that the provincial government

- support the best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care⁸ through staff education and access to specialized mental health consultants.
- mandate that facilities provide support for staff to become certified in *Building a Strong Foundation for Dementia Care*.⁹
- support quality mental health and palliative care for residents through funding of staff continuing education and facility access to in-house social workers and mental health and palliative care consultants.

https://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf

⁸ B.C. Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care. A Person-Centred Interdisciplinary Approach. B.C. Government, October 25, 2012.

⁹ Alzheimer Society of British Columbia (n.d.) Building a Strong Foundation for Dementia Care <u>https://alzheimer.ca/sites/default/files/files/bc/bsfdc%20guidebook.pdf</u>

6. Standards to Support QOL and Monitoring

We recommend that the provincial government

- implement, monitor, and enforce staffing and QOL standards related to person-centred care, nutrition, recreation, and mental health (as presented in the full document).
- create a mechanism/process/role, or expand the role of Licensing Officers, to monitor the QOL standards.¹⁰
- ensure the designated QOL monitors are trained to assess QOL and that there is an adequate number to monitor the standards effectively.
- ensure monitoring/complaint investigations are performed with enough frequency and without notice so that reviews accurately represent the day to day quality of care that residents are receiving.
- mandate Family Councils in all LTC facilities in the CCALA Regulations, require that all publicly funded facilities support them, and ensure that they do so.
- create regional Family Council Coordinators to help develop Family Councils, and to provide education to families and Family Councils to become effective advocates.
- ensure that the Regional Family Council Coordinators have direct lines of communication for taking Family Council concerns to Licensing, QOL monitors and the Health Authority.

7. Policy Context for LTC

We recommend that the provincial government:

- develop a provincial strategy for the care of seniors in LTC, embedded in a multi-sectoral continuum encompassing health promotion through end-of-life and with attention to transitions between various care settings.
- develop a funding model that ends reliance on for-profit corporations.

8. Research - A Pilot Program to Demonstrate Impact of Reforms in LTC

We recommend that the provincial government engage Health Authorities, universities, and other partners in care (e.g., residents, families, seniors, front line and allied staff)

- to review successes in specific care facilities in relation to person-centred care and integrating a palliative approach to care, and to articulate potential province wide initiatives.
- to implement a pilot program to evaluate the impact of these recommendations on residents and staff.

¹⁰ Appendix B presents indicators/measures for monitoring evidence and expert informed standards, designed to promote and protect residents' quality of life in LTC facilities and to support the recommendations made throughout this document

Further Reading

Funding decisions are political choices that have real consequences for the availability and quality of seniors' health care services. The level of provincial health care spending significantly influences whether there will be improvements in seniors' health. Never has there been more urgency and public support to reform and improve the way care is provided and quality of life is supported in LTC facilities. Doing so requires boldness, a conviction that seniors matter and a commitment to funding a system that (1) supports seniors' health while enabling them to live their lives to the fullest, and (2) supports a quality work environment. Implementing the recommendations contained in this report will accomplish this and firmly situate BC as a national and international leader in the care of one of the most vulnerable populations in society. Further reading on our research and recommendations is available in the full version of this report.

REPORT

I – Introduction

The year 2020 has been a watershed moment in human history. COVID-19 has shone a bright light on the pervasive, systemic and structural weakness in how care is provided in long-term care (LTC) facilities, and how these practices have left residents vulnerable to the impact of COVID-19.

Eighty percent of COVID-19-related deaths in Canada have occurred in Long-term Care (LTC) facilities¹¹.

- Canada's hardest-hit LTC facilities lost 40% of residents in just three months of the pandemic.
- The Canadian Military was called in to take over the management of four senior care homes in Ontario and 25 care homes in Quebec.
- Military personnel, families, care workers, and others have exposed appalling conditions in LTC facilities, including:
 - Health care workers being absent from the facility for extended periods while on active duty
 - Lack of attention to the most basic of needs for bedridden residents, including:
 - Deprivation of basic nutrition and hydration
 - Lack of skin care leading to infected breaks in skin integrity
 - Poor hygiene and poor sanitary care.¹²

COVID-19 is simply the canary in the coal mine. COVID-19 may have been listed as cause of death, but the real killer was the systemic breakdown of humane and responsible care of seniors. COVID-19 illuminated an existing, systemic breach and betrayal of our trust in institutionalized senior care. This moral crisis offers an opportunity for government and the community to restructure the LTC system so that residents' safety, security, and quality of life are maximized in an ethical environment that supports residents and staff and welcomes their families.

The system in place to protect our most vulnerable seniors has failed residents, families and society at large and has been doing so for many years. This problem is well-known. Our¹³ purpose in preparing this document, built on evidence, expertise, lived experience and key informant interviews with diverse stakeholders, is to support the provincial government, health authorities and LTC facilities to meet our moral obligation to seniors living in LTC facilities in British Columbia today and in the future.

We begin with a discussion about the current situation in long-term care facilities in BC that identifies residents' care needs, issues related to staff and care provision, and the culture of care. We then look at what contributes to quality of life (QOL) from the perspective of residents in LTC and how the staffing level and organization of work affect this. Next, we look at how well policy, regulations, and monitoring processes

- http://s3.documentcloud.org/documents/6928480/OP-LASER-JTFC-Observations-in-LTCF-in-On.pdf
- Bugs, bedsores and burnout: Observations on five distressed LTC homes. Joanne Laucius, Ottawa Citizen, May 26 2020. https://ottawacitizen.com/news/local-news/bugs-bed-sores-and-burnout-observations-on-five-distressed-ltc-homes/
- 13 Action for Reform of Residential Care (ARRC) is a British Columbia citizen's group made up of families, clinicians, seniors and researchers concerned about seniors' care and quality of life in LTC.

¹¹ https://www.cbc.ca/news/canada/nursing-home-covid-19-deaths-1.5641266

¹² Letter from C.J.J. Mialkrowski, Brigadier General, Commander, May 20, 2020.

support QOL in LTC. We end with recommendations for a paradigm shift that encompasses a model of care, staffing, work force stabilization, standards, and monitoring processes that together address residents' and families' need for quality of life. Suggestions are made for provincial policy and research.

Moral Considerations¹⁴

"Our policy decisions are moral decisions. They are issues of care and responsible citizenship".¹⁵

"The COVID-19 pandemic shone a light on the significant gaps in the long-term care (LTC) system as never before. COVID-19 has precipitated, in the worst circumstances, high levels of physical, mental, and emotional suffering for our older adults"¹⁶.

The COVID-19 pandemic has highlighted our longstanding policy and practice challenges and failures in delivering ethical and effective health care, particularly to older, vulnerable adults and their families. While in Canadian society we have often emphasized our high ideals, we have too often fallen short in achieving them, as the pandemic has laid bare. Hence, it is now imperative that we engage in a thorough rethinking and restructuring of the ethical foundations of the health care system in relation to older adults.

This rethinking and restructuring can begin by supporting a person-centred paradigm shift in LTC and other practice areas, guided by a moral compass of core foundational values, including autonomy, justice and beneficence. These values ought to lead the development of policies at all levels--from individuals through to organizations and larger health care systems. All older adults deserve ethical and effective health care delivery, and "now is time to make a commitment to change from complacency with the status quo and create our preferred future".¹⁷

II – Addressing the Issue in BC

The purpose of this document is to support the provincial government, health authorities and LTC facilities to meet our moral obligation to the wellbeing of seniors living in LTC facilities in BC today.

The Action for Reform of Residential Care (ARRC) is a citizen's group made up of families, clinicians and researchers with considerable expertise and experience in the long-term care system. We believe that:

- Quality of life is important across the lifespan
- Quality of life requires quality of care and both are non-negotiable
- Quality of care is linked to quality working conditions for care providers

¹⁴ For full discussion see Appendix D $\underline{\textit{Considering A Moral Compass for LTC}}$

¹⁵ Kenny, N. P. (2002). What Good is Health Care? Reflections on the Canadian Experience. Ottawa, ON: CHA Press.

¹⁶ Estabrooks, C. A., Straus, S., Flood, C. M., Keefe, J., Armstrong, P., Donner, G., et al. (2020), p. 9. *Restoring trust: COVID-19 and the future of long-term care: A policy briefing by the Working Group on Long-term Care. Royal Society of Canada*. Retrieved September 20, 2020 from https://rsc-src.ca/sites/default/files/LTC%20PB%20%2B%20ES_EN.pdf.

¹⁷ Levitt, D. (2020), Pandemic exposes need to revamp seniors care. *Vancouver Sun*. Published September 8, 2020, p. A9. Retrieved September 9, 2020 from <u>https://vancouversun.com/opinion/op-ed/dan-levitt-it-is-time-to-transform-</u>

agedcare/wcm/0197d0cc-7819-40f7-bd0e-28d9e7b2b67a/.

- Care is a relationship between those receiving and providing care, and meaningful and sustainable relationships between seniors and care providers are imperative for quality of life
- LTC facilities must support seniors' health and wellbeing/mental health, enabling them to stay as active as possible and to participate in meaningful activities and relationships
- The current institutional model is dehumanizing and must be replaced by a person-centred model of relational care.

The BC government has made a commitment to ensure "our senior citizens are able to live their final years with dignity, and ... to improve and strengthen services to ensure seniors receive dignified and quality care".¹⁸ We are proposing a way to meet this commitment that is underpinned by an ethical framework and principles of person-centred and relational care, and that is guided by the rights to dignity, choice, respect and security for residents and for those providing care.

We believe that the BC government has the reputation, opportunity, and motivation to become a leader in the development and implementation of ethical standards that support quality of life for residents living in LTC facilities and a quality work force. The BC government has an enviable reputation for containing COVID-19 in our communities and LTC facilities by taking decisive action to level wages, implement a one site rule, and to lock down facilities early in the outbreak. Further, given the rapidly growing seniors' population in BC, especially those over 80, and the likely addition of aging retirees from other provinces, it is in BC's best interest to build the best, most stable and sustainable LTC system possible.

Our goal is to support the government, health authorities and LTC facilities to (1) make a broad sociocultural shift that facilitates good care, safety, security and quality of life for residents in LTC, (2) in an environment embedded in an ethical framework (3) that supports care providers and families, and (4) is buttressed by strong, effectively monitored and enforced standards that protect the wellbeing of residents and promote quality of life.

III – Framing the Issue

COVID-19 has exposed and amplified well known and long-standing problems in the organization and delivery of adequate and humane care for those living in LTC facilities. LTC is neither structured nor resourced to ensure quality of care and life for residents, or a quality work environment for staff. COVID-19 swept in on a stripped down, "lean and mean" system that lacks the capacity to respond effectively to any extra stressors. The system is built on minimum standards and lowest common denominators. Regulations and standards meant to protect the health, safety and wellbeing of residents were too weak and too poorly enforced to prevent the carnage of COVID-19.

A plethora of reports document the challenges and limitations of the LTC system. The media has shone a light on aggression, negligence, misery, abuse, and deaths in LTC facilities many times, even prior to COVID-19. Over time, recommendations have been made about how to improve LTC, and while the "deck chairs on the Titanic" have been moved around, the problems remain, and the ship is still sinking. Rather than minor "fixes", a complete paradigm shift is needed that recognizes and addresses the systemic/structural factors that continue to keep us from moving forward to support residents, their families and care providers.

 $^{18\ {\}rm https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/premier-cabinet-mlas/minister-letter/dix-mandate.pdf$

Because COVID-19 has made the deficits in the LTC system highly visible to the public, there is an unprecedented demand and opportunity at this time for decision makers to make things better. Trust in LTC care and providers has never been lower, and the fear that most seniors and their families already feel about having to go into an LTC facility has been magnified.¹⁹

I am a nurse in Long-term Care and will fight like hell to keep my parents out of this situation²⁰

It will take the voices of all British Columbians – seniors, their families, care providers and the public – to demand that politicians make real/fundamental changes to the LTC system and provide the funding to do so. Politicians have never been more aware of the imperative for change in LTC but need the courage, will, and moral fortitude to act. At issue is whether British Columbians think that our most vulnerable citizens "deserve" lives worth living, and are willing to pay for it, or will soon turn their attention elsewhere and sink back into denial. As a society we need to have a hard conversation about how we value seniors and what we are willing to do (or not do) to support them.

Not only am I concerned about the unsatisfactory conditions our seniors have to contend with– especially those with no family nearby to speak for them – but now in my nineties, I am afraid what I will have to put up with when I have to be a resident there. Let's hope that if enough of us complain, it will force our government to once again be responsible for the wellbeing of their seniors. And I hope all those who voted for a government that privatized so many of our vital corporations such as Hospitals, Ferries and Seniors homes, rather than be responsible for them, will realize how tragic the results are.²¹

The systemic cracks that contributed to the pandemic's course in LTC facilities were there before COVID-19 and will remain.²² However, we can never again say that we don't know about the shocking inadequacies of the LTC system, the misery experienced by residents and their families, and the moral distress of care providers. If we fail to take bold action now, we are demonstrating that our most vulnerable seniors don't matter and are in fact "throw away" people. If left unaddressed, the systemic cracks that contributed to the pandemic's course in LTC facilities will remain.

Background in BC

The same urgency for change applies to BC as elsewhere in Canada. Long before COVID-19 the previous and current BC governments have been made aware of similar concerns about the care and quality of life experienced by residents in LTC facilities, about how care/services are provided, and about the precariousness of the workforce. These concerns have been expressed by seniors and their families, by seniors' organizations, by professional organizations/associations, by relevant work force unions, by the BC

¹⁹ Not scared of dying but of dying scared. Kelli Stajduhar and Denise Cloutier. Healthy Debate Opinions, June 16, 2020 https://healthydebate.ca/opinions/not-scared-of-dying-but-of-dying-scared

²⁰ Personal communication by family member

²¹ Personal communication – BC senior citizen

²² When COVID ends a great deal of effort will necessarily go into preventing and containing it if/as it reoccurs, and into facilitating safe family visiting. These are not our focus but we do support the Royal Society recommendation that provincial governments establish and implement standards to address preventing and managing COVID outbreaks. We also support the Canadian Foundation for Health Care Improvement guidance on steps that can be taken now to ensure that long-term care facilities are better prepared for future waves of COVID-19.

Care Providers Association (BCCPA), by policy groups such as the Canadian Centre for Policy Alternatives, by the BC Ombudsperson and by the BC Seniors Advocate. Relatively little attention has been paid to these concerns or to the many recommendations made. For example:

- In 2012 the Ombudsperson identified issues of quality of care "fundamental to a person's physical and mental well-being" and made specific recommendations about the need to establish measurable standards for residential care, most of which remain unimplemented.²³
- In 2017 many of the same quality of life concerns were identified in the BC Seniors Advocate report "Every Voice Counts: Provincial Residential Care Survey".²⁴
- In 2019, the BC Ombudsperson reported that the BC government and health authorities had failed to act on the most important of the recommendations and that fewer than half had been implemented.²⁵

The BC Ombudsperson and the Seniors Advocate have illuminated ongoing issues in LTC and made recommendations for improvement. Implementing their recommendations would be an immediate first step for this provincial government in addressing long standing issues in LTC that affect residents' quality of care and life.

The importance of quality of care is recognized under the statues regulating long-term care facilities: the Hospital Act and the Community Care and Assisted Living Act, in the Residential Care Regulation ⁽Regulations), and in Health Authority policies, including in their contracts with non-profit and for-profit operators. The Community Care Facility Licensing program (Licencing) monitors compliance with regulations and is the front line of protection for residents in LTC facilities. Concerns about care can also be taken to the Patient Care Quality Office (PCQO).²⁶ Neither of these bodies, however, address quality of care or quality of life.

Prior to COVID-19, in 2018/19, the Seniors Advocate reported there were 853 complaints received by the Patient Care Quality Office (PCQO). Fifty-six per cent (56%) of complaints were about care:

- direct care (34%) e.g., inappropriate type of care, or delayed or disruptive care
- accommodation (11%) e.g., dissatisfied with placement or preferred accommodation not available
- communication (10%) e.g., relatives/carers not informed or given inadequate/incorrect information (p 35)²⁷

In the same time period, the Seniors Advocate reported that:

²³ Office of the Ombudsperson (2012). The Best of Care Getting it Right for Seniors in British Columbia (Part2)

²⁴ Office the Seniors Advocate (2017). Every Voice Counts: Provincial review of Care Survey Results

²⁵ Times Colonist, February 25, 2019. *Recommendations on Seniors Care not implemented 7 years after report: ombudsperson* 26 Where residents or families have complaints about care not resolved at the facility, they may take their concerns to the PCQO which will register the complaint with the Health Authority and work with the resident/family towards a resolution. If the issue remains unresolved the resolution Patient Care Quality Review Board (PCQRB) which reports directly to the Minister of Health, may carry out an independent assessment.

²⁷ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary.

- Eighty-nine percent of long-term care facilities had at least one Licencing inspection during the fiscal year²⁸. There were 765 inspections conducted with 1,103 licensing infractions found. The number of infractions ranged from to 27.4 to 119.6 infractions/ 1,000 beds. Most of the infractions found related to care and supervision (21%), records and reporting (19%), the physical environment (19%), and staffing (13%).
- Licensing offices in BC received 18,007 reportable incidents²⁹, or 15.8 per 100 beds, in long-term care, which represents a 3% increase over the previous year.
- Four hundred and sixty-seven (or 16.2/1,000 beds) complaints about care and services in long-term care facilities were received by Licencing, of which 167 (36%) or 5.9/1,000 beds were substantiated and resulted in a licencing violation.³⁰

Investigations are lengthy and there is often an inordinate amount of time and effort by Licencing to bring facilities into compliance, meanwhile leaving residents at risk.³¹

Before COVID-19, between September and December 2019, inadequate and negligent care of seniors was identified by the Community Licencing Program officers (Licencing) in four BC long-term care facilities owned by one operator. Following lengthy efforts by the Licencing Officers to bring the four facilities into compliance, and following assistance from Health Authorities, the Chief Medical Officers reported that the Licensee did not meet the standard to ensure the health, safety and dignity of persons in care, and did not have sufficient staff to provide adequate and safe care. In one facility, the following was noted: "failure to mobilize residents and to provide adequate wound care, and that there were delays or omission of medications".³² The Chief Medical Officers took the highly unusual steps of imposing Health Authority administration of the facilities for at least six months, citing lack of response to the concerns, failure to respond with a feasible plan to remedy the situation, and the evidence of ongoing and current risk to the health and safety of residents. Had the provincial government acted on the recommendations to improve long-term care made in the related reports the pain and suffering of the residents and their families, would likely have been avoided.

It was a nightmare—we all knew that the staff were too short staffed to do the work---my mother's bath was two weeks behind---the housekeeping was appalling.... It took ages to get Licensing to act and all this while the facility was accredited and deemed low risk! It is a travesty and I have lost all faith in the system.³³

In spite of the failure to address the many concerns about LTC articulated in reports and submissions to governments by so many seniors and by those who care for/ about them over the years, we must continue to demand improvements. As Kane has stated:

- 31 Medical Health Officer Report to the Board of the Vancouver Island Health Authority
- $\underline{https://www.islandhealth.ca/sites/default/files/nanaimo-seniors-village-mho-report-to-board.pdf}$
- 32 Medical Health Officer Report to the Board of the Vancouver Island Health Authority

²⁸ Office of the Seniors Advocate British Columbia (2019) Monitoring Seniors Services, p 37

²⁹ Reportable incidents include falls with injury, resident to resident aggression, abuse or neglect, disease outbreak and missing and wandering residents

³⁰ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary. p 2

 $[\]underline{https://www.islandhealth.ca/sites/default/files/nanaimo-seniors-village-mho-report-to-board.pdf\ p5$

³³ Personal communication – family member

"Trying to improve QOL is ethically superior to creating a societal institution that is often seen as worse than death.... and then suggesting, as sometimes is done with the concept of quality-life adjusted years, that living in nursing homes is de facto a dependent and devalued form of life" (p 29).³⁴

IV – Defining the Problem

Providing Care in LTC

The Physical Context of LTC

Congregate living has provided a ripe breeding ground for COVID-19 among residents and staff in older buildings. These facilities are often characterized by shared rooms and small spaces for congregating, making them spaces where people are especially vulnerable to infection. Many care facilities are long overdue for major renovation, if not demolition and replacement. Building age and outdated design can affect the safety of residents, staff and visitors by contributing to the spread of COVID-19. Four, or even two bedded rooms with one shared toilet and sink make infection control and hygiene measures challenging, as do "tub rooms" where residents must travel far down the hall to have a bath or shower. Old buildings also often lack hygiene stations to support hand washing by direct caregivers. "Sick bays", "quiet rooms," and palliative care suites have been converted to office and storage space. Many older buildings lack ceiling lift systems and other installations that enable care to be more safely and comfortably carried out.

The physical environment is an important component of quality care and quality of life. Older buildings are often described as "warehouses" for the elderly because they do not provide personal, comfortable and familiar spaces. Older buildings house large numbers of people together, e.g., thirty residents in the "east" wing. Most no longer have on-site kitchen and laundry facilities, so meals and food become institutional, and personal clothing is often lost. Housekeeping is often contracted out and in short supply, leading to frequent complaints by families about lack of cleanliness regardless of the age of the facility.

I brought my sister back to her room and, when I went to wash her up, I found a pile of feces in the middle of her bathroom floor. It was obvious it had been there for a while. I could not find anyone to clean it up, so I did it myself.³⁵

In many facilities there are not adequate areas in which to carry out physical therapies or recreational activities. Commodes, lifts, and wheelchairs are often in short supply, causing inconvenience and extra work. Safe outdoor space is often not available. The result is an institutional hospital like environment with medical/care equipment scattered throughout the hallways and little to do throughout the day. The space lacks home-like qualities that people in LTC need and deserve for QOL.

³⁴ Kane, RA. (2003). Definition, Measurement, and Correlates of Quality of Life in Nursing Homes: Towards a Reasonable Practice, Research, and Policy Agenda. *The Gerontologist*, 43 (Special Edition II), 28-36

³⁵ Personal communication - family member

It does not have to be this way. There is a brilliant example in Holland of what can happen when we are able to imagine an environment that promotes *living* in the context of being well cared for, regardless of cognitive limitations.³⁶ The founders of this non-profit facility created a "town" within the same constraints that the long-term care facilities around it work in. Hogeweyk is a town where the residents, all living with dementia, are encouraged to roam freely; to stop by the grocery store, to sit at the bar with friends, have their hair done, or take a stroll through the park. Each of the 23 houses is home to a small group of individuals matched together by interest, increasing the likelihood of forming meaningful friendships. And the homes are where life is still life: dishes are done, there is the smell of food cooking on the stove, and the laundry gets folded.

The Resident Population in LTC

The Office of the Seniors Advocate reported that on any given day there are about 27,380 residents (about 3% of BC seniors) living in 1 of 294 publicly funded long-term care homes.³⁷ The resident population in LTC facilities is a vulnerable one with complex needs. The average age of residents in long-term care facilities is 85 years, with 60% aged 85 or older and 5% younger than 65; 65% of residents are female.³⁸ With efforts to keep seniors in the community as long as possible the acuity and care needs of residents at admission is high and increasing.³⁹ A large percentage (41%) of Canadian seniors, many of them in LTC, have two or more chronic illnesses such as diabetes, respiratory issues, heart disease, and depression, and many are experiencing a decline in physical and/or cognitive functioning.⁴⁰

The Seniors Advocate identified the following care needs for 2018/19 across BC⁴¹:

- Thirty-one per cent of residents are totally dependent on staff for their Activities of Daily Living (ADLs)⁴², such as bathing, getting dressed, going to the bathroom and getting out of bed. These activities often require two staff members.
- Twenty-three per cent of residents are diagnosed with depression.
- Twenty-four per cent of residents are prescribed an anti-psychotic without a supporting diagnosis of psychosis.
- Sixty-four per cent of residents have a dementia diagnosis and 29% of residents have severe cognitive impairment.
- The average Case Load Mix (CMI) is 0.580⁴³

³⁶ Burns, S A Beautiful Look at the Future of Eldercare! <u>https://everwideningcircles.com/2019/11/16/dementia-village-hogeweyk/</u>

³⁷ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary.

³⁸ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary p 1

³⁹ Kary, M (January 2017). Strengthening Seniors Care- Supporting Pape: BC Health Care Providers Association

⁴⁰ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary p 7

⁴¹ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary.

⁴² The Activities of Daily Living (ADLs) refer to essential self-care tasks, such as bathing, dressing, and going to the bathroom.

Impairment in ADLs is measured on a seven point scale, where a higher score indicates greater degrees of impairment." Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary, p 5

⁴³ The Case Mix Index (CMI) is a standardized method for calculating the intensity of resources required to meet the needs of a resident and reflects a measure of clinical complexity of the resident population as a whole. A higher score indicates that a greater intensity of resources is required to meet the needs of the resident population Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary, p 5

- Nine percent of residents exhibit physically abusive behaviour (easily altered and not easily altered).
- Almost half of all residents have a low sense of social engagement.
- The average length of stay in long-term care is 832 days.

Resident Issues

Special populations

Residents in LTC are heterogeneous, with diversity in culture, gender identity and race, necessitating the practice of culturally safe care⁴⁴. As well, long-term care facilities in British Columbia have seen growing numbers of residents admitted with special needs, particularly those who are not yet seniors but have severe mental health challenges. Staff members without the required knowledge and experience must increasingly care for younger adults with disabilities and persons with developmental challenges who are aging into care. As well, seniors with severe psychiatric challenges such as personality disorders and substance use disorders (which involve a risk of violence) are being admitted because they are aging and are no longer able to live independently. Other populations requiring specialized care planning and resources are those middle aged, cognitively intact persons with advanced physical illnesses such as Multiple Sclerosis and Parkinson's Disease. Standard facility recreation programming is seldom of interest to these individuals and they may require physical and psychological treatment modalities not provided by the facility. Of particular concern are persons with early onset dementia such as young onset Alzheimer's disease and Fronto-Temporal dementia. These persons require individualized care planning because they are young and strong. The care team may be less comfortable and less skilled in caring for someone who has fluctuating behaviour patterns because of preserved memory, fluid cognitive ability, and responsive and protective behaviours.

Mental Health

COVID-19 has exacerbated the long standing inadequacy of mental health support for residents living with dementia and mental health disorders (long-term, disease produced and late-onset) that require skilled and knowledgeable care, which is often unavailable.⁴⁵ Depression, the most common mental health problem, is associated with a significant burden of illness that affects seniors and their families.⁴⁶ COVID-19 has increased staff and resident stress and many residents suffer from a lack of family contact that they may not understand. Many facilities in BC do not have adequate access to consulting seniors' mental health teams in the community for support with assessment, care planning and education related to care of residents with responsive and protective behaviours associated with dementia or care of persons with other mental health and substance use.⁴⁷ Further, the availability of mental health supports is very uneven

⁴⁴ Estabrook CA, Straus S, Flood CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. restoring trust: COVID-19 and the future of long-term care. Royal Society of Canada. 2020.

⁴⁵ MacCourt P., Wilson K. & Tourigny-Rivard M-F. (2011). Guidelines for Comprehensive Mental Health Services for Older Adults in Canada. Calgary, AB: Mental Health Commission of Canada. Retrieved from: <u>www.mentalhealthcommission.ca</u>

⁴⁶ Canadian Coalition for Seniors' Mental Health. National guidelines for seniors' mental health: The assessment and treatment of depression. Toronto,

ON: Canadian Coalition for Seniors' Mental Health; 2006. Accessed at www.ccsmh.ca/en/guidelinesUsers.cfm.

⁴⁷ Antifeau, E., Ward, C., & British Columbia. Ministry of Health. (2012). Best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care: A person-centred interdisciplinary approach. Victoria, B.C.: Ministry of Health.

throughout the province with rural areas in particular disadvantaged. Mental health challenges and issues are often dealt with by medications alone rather than being complemented by holistic, non-medical supports and care. There are however pockets of excellence upon which we can build, notably the development of regional knowledge co-ordinators who assist in the creation of behavioural care plans for long-term care residents in Interior Health.⁴⁸

Palliative Care

Although many individuals die in LTC facilities they do not receive expert palliative care due to lack of staff and lack of training. Nevertheless, these residents are not eligible to be transferred to a hospice or palliative unit when they are dying because they are already "in care". The death of seniors in LTC is not insignificant. Families experience grief, as do the staff persons who may have known the deceased resident for years. All these issues were amplified when COVID-19 ravaged care facilities, with people dying alone and most without family support. It is imperative that these situations do not reoccur, and that the families of residents and staff all have the support they require.

It's not about if my loved one is going to die, it's about them living a life as best as they can till that day comes.⁴⁹

Given the complexity and acuity of the LTC population, it is clearly untrue that 'anyone' one can care for today's seniors in long-term care facilities. It is imperative that facilities operate with well trained and well supported staff in adequate numbers to meet the needs of this complex population and to facilitate residents' quality of life.

The Role of Care Providers in LTC

All Health Authorities define direct care hours to include Registered Nurses (RNs), Licensed Practical Nurses (LPNs), Health Care Aides (HCAs)⁵⁰ and allied health disciplines (e.g., occupational therapists, physical therapists, speech therapists). For 2017/18 the Seniors Advocate reported that, in aggregate, 67% of direct care is provided by HCAs, 17% by LPNs, 8% by RNs, and 8% by allied health disciplines.⁵¹

Care Aides

Relational care – Foundation of Quality Care

Nursing staff spend the most time with residents and provide most of the direct care. How this care is provided is crucial to the well-being of residents and to their quality of life. Results from research with residents of long-term care facilities confirm this:

⁴⁸ Improvements in regional geriatric care outlined, February 2019

www.kelownadailycourier.ca/news/article_5a7a5adc-30e7-11e9-a0aa-6f5fa51d81af.html

⁴⁹ Personal communication - family member

⁵⁰ Throughout this document we use care aide to refer to Health Care Aides, Residential Care Aides, Nurse Aides.

⁵¹ Office of the Seniors Advocate. (2020) A Billion Reasons to Care

Residents stressed their need for connectedness or belongingness with the nurses highlighting the relationships to their caregivers as essential for wellbeing. Frustration, suffering, hopelessness, meaninglessness and depression result from not being attended to or being treated with indifference, and thereby violating individuals' sense of worthiness which negatively impact residents' mental and physical symptoms.⁵²

While doing their best, care aides and nurses on the front line of physical/body care have been burdened by large caseloads of residents with ever increasing acuity and mental and physical care needs. Strict timelines for task completion, and large and demanding caseloads, leave little room to engage in quality conversation, learn about residents' life histories or to discover and accommodate people's values, ideas, wants and interests, in the context of prioritizing body care. While some frontline care staff may have been formally educated about the psycho-social and spiritual needs of older residents, they seldom have time or direction to integrate this into their work. To address the relational needs of residents nursing staff need to feel supported by colleagues and management to do so.

It is truly awful. If I stop to try and figure out why Mrs. J is weeping, I get behind and I get into trouble for not getting the work done. It makes me feel terrible when I have to ignore what I see.⁵³

Quality Care and Working Conditions on the Front Line Matter

Quality care requires quality working conditions for care providers. The OECD long-term care quality framework identifies direct contributors to quality resident care as staffing ratios per resident, consistency of caregiving staff, staff turnover, length of employment, education and training, and staff response times.⁵⁴ Similarly, the Canadian Health Coalition notes that an unstable workforce without adequate staffing levels, proper training and supports has serious consequences for residents in LTC:

- Quality of care and working conditions are both negatively impacted by funding cuts, contracting-out, privatization, inadequate staffing levels and reduced care services.
- Short-term measures such as hiring temporary workers to address inadequate staffing levels affects the continuity of care residents receive and prevents care workers from familiarizing themselves with residents and work environments.
- The development of meaningful relationships between care workers and residents is eroded and limited by the prevalence of casual, part-time and contract staff.⁵⁵

⁵² Haugan G, Kuven B, Wenche E, Tasen S, Rinnan E Nurse-Patient Interaction and Self-Transcendence: Assets for a Meaningful Life in Nursing Home Residents? (2019)Geriatrics & Gerontology (preprint) DOI 10.21203/rs.2.13599/v1

https://www.researchsquare.com/article/rs-4308/v1 p 15

⁵³ Personal communication - care aide

⁵⁴ OECD/European Commission 2013a, A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care, OECD Publishing, Paris

⁵⁵ Canadian Health Coalition (November 2018) Policy Brief: Ensuring Quality Care For All Seniors, p10

In the evenings, it was common to see casual staff completely unfamiliar with the dietary routine of residents who would feed special meals designated for one resident to another, placing them at risk.⁵⁶

There has been so much inconsistency with care aides – so many new faces over the years with varying degrees of care practices and skills and a real problem with not enough staff and not enough eyes overseeing the whole situation. It's been heartbreaking and exasperating to witness the inconsistencies of staff and their varying levels of care practices negatively impacting my father – heartbreaking and exasperating because so much of it is preventable.⁵⁷

Can A Devalued/Disempowered Frontline Provide Quality Of Care And Facilitate Quality Of Life?

Care aides provide the bulk of direct care for residents in LTC. This workforce is gendered and racialized – about 90% are women, approximately 60% speak English as a second language, and about half of those in urban centres are immigrants⁵⁸. The Royal Society of Canada (Royal Society) in a review of front line staffing issues in Canada pre COVID-19, (equally applicable to BC), notes:

- No groups of care aides are regulated or licensed in Canada and few are registered.
- Care aides receive the lowest wages in the healthcare sector and rates vary considerably between facilities.⁵⁹
- Care aides work at the bottom of a rigid hierarchy with little input into decision-making about resident care even though they may know the resident best.
- There is chronic short staffing in LTC facilities that predates COVID-19. To piece together a livelihood care aides often work in more than one job and in healthcare settings other than long-term care facilities.
- Many care aides cannot get full-time or regular part-time work with benefits because some employers choose to rely on casual staff.
- Casual staff exacerbate challenges in providing care as they may not be well oriented to LTC, making team work more difficult and increasing the work of already stretched staff.
- Many LTC facilities routinely do not fill positions or back fill for illness/leaves etc., further contributing to working short staffed. In one study up to 65% of care aides per shift reported that have insufficient time to complete necessary care tasks and must rush essential care.⁶⁰
- Care aides receive variable and minimal formal education. They are generally not required to complete any continuing education and are often not offered it. Most in house education focuses on mandatory

⁵⁶ Patrick Dudding Class action suit No. VIC-S-S-182236 Victoria Registry <u>https://drive.google.com/file/d/1mJKhIhD-</u> PGqnIf2nFcoBAWZenIdxI7eU/view

⁵⁷ Personal communication- family member

⁵⁸ Estabrook CA, Straus S, Flood CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. Restoring trust: COVID-19 and the future of long-term care. Royal Society of Canada. 2020, p 14.

⁵⁹ According to the BC Seniors Advocate prior to wage levelling in BC wages ranged from \$16.85 to \$23.48/hour

⁶⁰ Song Y, Hoben M, Norton P, et al. Association of Work Environment with Missed and Rushed Care Tasks Among Care Aides in Nursing Homes. *JAMA Netw Open*. 2020;3(1).

workplace safety regulations, for example, and on physical aspects of care such as maintaining skin integrity.

- When there is an immediate need to fill vacancies regulated hiring practices may not be followed with criminal and reference checks foregone. Similarly, new hires may receive minimal or even no orientation to the facility and residents prior to beginning work.⁶¹
- Staffing Levels and Mix Matter for Quality Care and Quality of Life

In 2009 the Ministry of Health developed a staffing framework for LTC facilities that included a target of an 'average' daily minimum of 3.0 hours (or 180 minutes) of nursing care (delivered by registered nurses, licensed practical nurses and care aides) and .36 hours of allied health care.⁶² The Seniors Advocate reported in 2018-19 that 70% of long-term care homes in B.C. did not meet the Ministry of Health's recommended staffing guideline, with the average number of funded direct care hours 3.25.⁶³ (This is even less nursing care than it appears as the 3.25 includes allied health disciplines.) Staffing levels for nursing need to be updated urgently as acuity has doubtless increased since 2009. Additionally, researchers have identified that long-term care residents are at risk when the ratio of nursing staff to residents is below the minimum total of 4.1 direct care hours worked per resident day⁶⁴.

What I have seen at this facility is nothing I would wish on anyone. These vulnerable seniors become statistics to politicians, doctors, care home administrators. We hear about the 3.36 hours of care per day they are allocated to receive. This is a false narrative – I am 3 years into our LTC story, and this is NEVER the reality.⁶⁵

Resident acuity affects the staffing needed to provide adequate and appropriate care. Nursing researchers have recommended ratios of residents to staff and hours per resident day for care aides, LPNs and RNs for each shift, based on six levels of resident acuity.⁶⁶ The researchers have also provided a method that facilities could use to assess whether minimum staffing levels are sufficient to meet the needs of their residents. For 2018/19, the Seniors Advocate reported the average case mix index (CMI)⁶⁷ for BC facilities was 05.80.⁶⁸

⁶¹ Estabrook CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. *Restoring trust: COVID-19 and the future of long-term care.* Royal Society of Canada. 2020

⁶² British Columbia Ministry of Health 2017, *Residential Care Staffing Review*, British Columbia Ministry of Health, Canada pp. 40-1. 63 Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary.

⁶⁴ Eagar K, Westera A, Snoek M, Kobel C, Loggie C and Gordon R (2019) *How Australian residential aged care staffing levels compare with international and national benchmarks*. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong

⁶⁵ Personal communication - family member

⁶⁶ Harrington C, Dellefield ME, Halifax E., Feming ML, Bakerjian D. (2020) Appropriate Nursing Staff Levels for US Nursing Homes. Health Services Insights Vol 13: 1-14 <u>https://journals.sagepub.com/doi/full/10.1177/1178632920934785</u> See table of staff ratios

https://journals.sagepub.com/na101/home/literatum/publisher/sage/journals/content/hisa/2020/hisa_13/1178632920934785/202 00629/images/large/10.1177_1178632920934785-table4.jpeg

⁶⁷ The Case Mix Index (CMI) is a standardized method for calculating the intensity of resources required to meet the needs of a resident and reflects a measure of clinical complexity of the resident population as a whole. A higher score indicates that a greater intensity of resources is required to meet the needs of the resident population

⁶⁸ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary. p 5

Many policies in long-term care facilities such as when to get up, to eat, to bathe, to go to bed, have been instituted in response to inadequate staffing levels and the organizational expectation that the work be completed efficiently. Yet the "work" is with vulnerable humans who have more than physical needs. Imagine having your most intimate needs met by a virtual stranger who focuses only on the task, and barely exchanges a personal word with you.

I don't blame the staff. They did double shifts, going home in the evening, and coming in again first thing in the morning - hand feeding for those who could not feed themselves was inadequate, calls for bathroom assistance often ignored, call bells from those in bed often ignored. Baths were supposed to be once a week but sometimes that didn't work because of being short staffed. A lot of diaper rashes because of poor cleaning practices. They are not as clean as they should be ... again due to staff shortages.⁶⁹

Results of a survey of residents in long-term care facilities (n 9,605) by the BC Office of the Seniors Advocate found that 49% of residents only, sometimes, rarely or never, have the same care aide on most weekdays, and that less than half (46%) of staff regularly make time for friendly conversation with the resident.⁷⁰ If the resident is not "known" as a person by care aides the care can only be custodial, even if kindly carried out, and the resident's sense of being valued/mattering is undermined.

Having more front line nursing staff, and more consistency in staffing patterns would result in greater capacity to respond to basic care needs such as assisting residents to the bathroom, changing of incontinence briefs, and providing help at meal times, and more time to converse with and relate to the resident. Not only would the resident's quality of care improve –more thorough cleaning for example – but it would also engender a sense of being cared about - a key component to quality of life.

Care aides are at high risk for burn out and for injury. An ongoing longitudinal study reported by the Royal Society describes the front line work force as women who are mostly middle-aged or older, newcomers/immigrants with English as a second language, and as noted above, often have more than one job. This vulnerable and marginalized population has little voice and is easily exploited by unscrupulous employers.⁷¹ Given the aging work force, workplace injuries are likely to increase with concurrent negative effects on staff retention, recruitment, and job satisfaction.⁷²

This work is nothing like I was trained for—there is no time to do anything well and always we are rushing the residents—never time to stop. I will leave as soon as I can.⁷³

Professional Nurses

Over the past 10-20 years, issues related to care delivery have been exacerbated by the reduction of regulated nursing staff. The role of the Registered Nurse for example, has been stripped of mentoring, support, supervision and leading care, and an RN is no longer required to be physically on site 24/7 in BC.

⁶⁹ Personal communication - family member

⁷⁰ Office of the Seniors Advocate British Columbia (2017) Every Voice Counts: Residential Care Survey Provincial Results

⁷¹ Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. *Restoring trust: COVID-19 and the future of long-term care.* Royal Society of Canada. 2020

⁷² Kary, M (January 2017). Strengthening Seniors Care- Supporting Pape: BC Health Care Providers Association, p80

⁷³ Personal communication – care aide

These positions were previously responsible for orientation of new staff, ongoing continuing education, supervision of nursing students, hands-on support to nursing staff at the bedside, and with implementation of best practice guidelines such as fall prevention, frailty assessment, maintenance of skin integrity, pain management, continence care and provision of high quality palliative care. Although access to advance practice nurses such as Clinical Nurse Educators and Nurse Practitioners is associated with improvements in measure of heath status and patient responsive behaviours, these services are not routinely available in LTC facilities.⁷⁴

Non-Direct Care / Documentation

There is a time consuming demand on staff at all levels for numerical documentation to meet quotas and other reporting requirements that takes time away from residents. How useful is this to quality of care and quality of life?⁷⁵ For example, the RAI-MDS 2.0 (Resident Assessment Instrument-Minimum Data Set), designed to assist care providers to develop and individualize residents' care plans based on the assessment of the resident's strengths, limitations, and their personal preferences, is only as useful as the information entered and if there is time and expertise to use the results. The loss of RAI coordinators has left the responsibility with RNs who do this work off the corner of their desks, often with minimal RAI training or time to make substantive use of facility results. Without a true understanding of its benefits, coupled with the lack of trust in the accuracy of the data submitted - (staff have shared that during the 7 day observation period that colleagues, either untrained or uncertain, often copy information from the previous shift thus impacting its validity) - many go through the motions of manually submitting data into the software 'as a means to an end'. Regardless, completing forms and documenting what is being done and when may be prioritized over the care/intervention that is being provided. For example, RNs spend most of their time on such administrative functions and care aides spend significant time entering information about nutrition/dining rather than relating to/focusing on the resident of concern.

Try to find someone—they are all busy on their computers or iPads writing stuff but not doing what should be done!⁷⁶

They (activity workers) bring anyone they can, whether they want to or would benefit or not, to activities so they can tick off their boxes and have the numbers.⁷⁷

Allied Professional Care

The Royal Society asserts that the work by therapists links directly with both quality of care and quality of life but "across Canada there has been a systematic reduction of regulated staff, including staff providing medical coverage, and all other regulated health professionals such as physical and recreational therapists. Social and spiritual care are too often nearly non-existent(p14)."⁷⁸ This is true in BC.

⁷⁴ www.anfiide-gic-repasi.com/wp-content/uploads/2014/07/Donald et al-2013-Journal of Advanced Nursing.pdf

⁷⁵ For discussion see Appendix D Data Collection and Interpretation in LTC Facilities—Issues with the RAI-MDS 2.0

⁷⁶ Personal communication – family member

⁷⁷ Personal communication – family member

⁷⁸ Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. *Restoring trust: COVID-19 and the future of long-term care.* Royal Society of Canada. 2020, p 14.

Health Authorities, through their contracts, require that facilities provide .36 hours of direct care per resident by allied health care providers, which includes dieticians, social workers, recreational staff, physio and occupational therapists, and others. There is no requirement in BC about which allied professions are to be allocated the hours. The BC Seniors Advocate reported that on average 11% of residents received physical therapy, 29% of residents received recreation therapy and 7% of residents received occupational therapy in 2018-19. Over the past five years there has been a reduction in physical and occupational therapy.⁷⁹ The availability of allied professional services varies between facilities and is determined by each facility based on an assessment of residents' needs and on the availability of therapists.

Most allied professionals work under contract, are not protected by union agreements, and often work at multiple facilities a few hours at a time. Due to the task-oriented culture of many care homes there can be consistent pressure on these allied professionals to integrate their practices into an institutionalized culture, sometimes creating ethical conflicts between facility demand and professional standards/codes of ethics. For example, Registered Dieticians (RD) are bound by their College to report deficiencies in nutrition care in facilities, which can cause tension with employers. There needs to be a process identified for how issues can be reported and addressed without repercussions, especially for contracted professionals. The benefit that allied professionals bring to the quality of life of residents in long-term care should be guarded by careful planning to ensure their continued engagement.

Registered Dietitians⁸⁰

Nutrition is a major factor regarding a resident's wellbeing, health status, level of functioning, and in the presence and duration of wounds. A resident may have swallowing difficulties, low energy, or other issues often requiring a special diet, and/or assistance in eating. Registered Dietitians can assess a resident's nutritional status and identify nutritional deficiencies and imbalances that may be contributing to a resident's wellbeing, health status, and level of functioning. They are also responsible for monitoring facilities. They audit facilities for food quality/presentation, dining environment, nourishment delivery, and hydration. As well, Registered Dieticians monitor the nutritional adequacy of menus, menu substitutions etc., and communicate gaps and collaborate with facility staff to resolve problems. Too often Registered Dieticians are not provided with enough hours to carry out the full scope of their role.

Occupational Therapy and Physical Therapy

Occupational therapy and physical therapy services are critical in long-term care facilities, as they improve physical function and occupational well-being, resulting in an improved quality of life for residents. Access to consistent occupational therapy and physical therapy services in long-term care facilities has been shown to improve residents' function and quality of life.^{81,82} Areas of therapeutic intervention might include, but are not limited to: enhancing mobility, appropriate seating, fall prevention, safe transfers, pressure wound management, activities of daily living, feeding and swallowing, adaptive equipment, pain reduction,

Facilities? A Cross-Sectional Study. *Physiotherapy Canada*, 67(2), pg. 113-121.

⁷⁹ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary, p 15. 80 For discussion see Appendix D The Importance of Registered Dieticians in LTC

⁸¹ McArthur, C., Hirdes, J., Berg, K., and Giangregorio, L. (2015). Who Receives Rehabilitation in Canadian Long-Term Care

⁸² https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2015/09/PlacementReport.pdf

incontinence reduction, cognitive activities, post-hospital rehabilitation, and splinting.⁸³,⁸⁴ Therapist assistants work under the supervision of occupational therapists and/or physical therapists, making more time available for therapists to assess and plan resident programs, and to advocate for residents as required. The process of task assignment to assistants is clearly described in the relevant BC Regulatory College practice standards.⁸⁵ Few LTC residents have access to physical or occupational therapies. Without appropriate staff to assess resident' ADL functioning, and to teach front line staff how to maintain or improve these functions—and give them the time to do so-- there is often a sharp drop in physical functioning (e.g., mobility, independent eating, continence) that occurs soon after admission to LTC, often with devastating effects.

... although he had no serious mobility issues before he was taken to the hospital, he failed quickly upon his return as there was no one able to help him recover properly. He couldn't walk because he became weakened and although some of the staff tried to help him, there were those who would not by, more or less, indicating it was not their job.⁸⁶

Staff, when rushed, may routinely feed residents who are able to feed themselves so that they can get on to the next tasks. Passivity and learned helplessness become a way of life.

It is not uncommon for a single care aid to be responsible for providing mealtime eating assistance to 9-12 individuals within a short period of time 20-30 minutes. This resulted in some of the most challenged and vulnerable residents being deprived of food. This included my mother who without assistance could not eat fast enough before the end of the allotted mealtime.⁸⁷

Physical Care and Quality of Life

Even if physical care is adequate and residents physically safe in a physical-care based environment, it is not enough for quality of life. Good physical/clinical care is an essential component of quality of life, but it is not the whole picture. QOL in a facility comes from the way one spends ones' day, the number and quality of interactions with others, and the comfort/security the social environment provides. Quality of life is neither trivial nor frivolous- it is only the focus on clinical/physical care in the context of a custodial/medical/institutional model that leads to its neglect. A day that involves interludes of nothing meaningful, punctuated by mealtimes that provide limited enjoyment, being taken to the bathroom and assisted with personal care needs by virtual strangers on their time schedule, is unlikely to be satisfying or to make life worth living.

⁸³ Health Association of Nova Scotia. (2015). The Role of Physiotherapy in Long-term Care. Retrieved from:

https://www.healthassociation.ns.ca/res/base/documents/library/research%20and%20policy/continuing%20care%20council/prese ntations%20to%20council/the%20role%20of%20physiotherapy%20in%20long%20term%20care%20march%2012%202015.pptx 84 Ontario Society of Occupational Therapists. (2012) *Occupational Therapy in Long-term Care*. Retrieved from:file:///C:/Users/User/Downloads/OT in Long Term Care handout.pdf%20(1).pdf

⁸⁵ College of Physical Therapists of British Columbia. (2018). *Standard 18: Supervision*. Retrieved from: https://cptbc.org/wpcontent/uploads/2019/04/CPTBC_Standards_2018_Dec14_singles_18.pdf

⁸⁶ Personal communication - family member

⁸⁷ Patrick Dudding Class action suit No. VIC-S-S-182236 Victoria Registry <u>https://drive.google.com/file/d/1mJKhIhD-</u> PGqnIf2nFcoBAWZenldxI7eU/view

Psycho-Social-Emotional and Mental Health Care

Emotional and mental health are as important as physical health to individuals' health, wellbeing and quality of life. Our long-term care system through its funding mechanisms, policies and practices has, to date, focused almost exclusively on 'body care', which is not true of other vulnerable populations where the needs of the whole person are emphasized (e.g., children), suggesting institutional ageism. Government funding and regulation has prioritized the bodily care of residents with an almost total neglect of their psychological, emotional, relational, cultural and social well-being and the need to make specialized support available to address complex needs. The long-term care system has come to rely almost exclusively on family members to fill this significant gap in psycho-social care. The central role of families in providing for the psycho-social needs of residents is a necessity borne out of austerity and governmentality, which has resulted in the denial of residents' ongoing and daily access to psycho-social supports and mental health professionals, including, most notably, social workers.

Social Work

Social workers are not mandated in long-term care facilities and yet social workers are best-placed to attend to the psycho-social well-being of residents and their families.⁸⁸ Social Workers complement the provision of physical and body care by front-line care staff by:

- providing a personal, relational, educational and advocacy role, (for example, ensuring all staff are aware of the perspectives, needs and values of individuals and their families)
- engaging in family counselling and support
- organizing and supporting family and resident councils
- assessing the psychosocial needs of residents through the transition to their residency and as their needs evolve
- advocating for institutional and systemic change.

Social workers are trained to recognize and honour individual and collective identity across the life course, give voice to vulnerable and marginalized people, advocate for inclusion and belonging, and to advance for the human rights and citizenship of residents through their daily practice. Given that funding limitations have resulted in a lack of prioritizing social work in long-term care, and the absence of the voice of social workers at the policy decision-making table, it is no wonder that the mental health of residents and their families took a drastic turn for the worse during the COVID-19 pandemic and that responses to improve the situation have focused almost exclusively on physical safety/body care. The devastating effects of social isolation and loneliness have been ignored, as have the mental health impacts of restricted visiting on residents and their families.

Recreation

Residents, like all of us, have the need to have enjoyment, feel like they matter and are cared about, feel connected, and to have meaningful activities. Recreational therapists design group activities and programming for a facility and may also provide individualized recreation-based treatments. Recreation staff develop and adapt programs to meet the needs of diverse groups and individuals for activity and social

⁸⁸ For discussion see Appendix D Ensuring the psychosocial health and human rights of long-term-care residents and their families: A social work perspective

connection. With resident variation in function, cognition, and culture, a large repertoire of approaches is needed (1 to 1 for residents who cannot tolerate groups or who may be bedridden, challenging and ageappropriate activities for younger disabled residents, etc.). Given the importance of recreation to quality of life, it must be available on days, evenings, and weekends. Recreation staff are usually responsible for bringing in community groups and supervising volunteers.

Often residents have no significant other and/or no visitors and facility staff are their only human contact, which makes how they provide care crucial to residents' emotional wellbeing. If the resident is not known to recreation staff, then programming cannot be appropriately individualized and may lack relevance or meaning for the resident.

Being lonely and socially isolated is possible and very likely in an institutional setting such a LTC facility. For the 2018/19 period the Seniors Advocate reported that almost half of all residents had a low sense of social engagement.⁸⁹ Social isolation and loneliness are associated with:

- higher risk of mortality
- twice the negative effect on health as obesity
- development of chronic illnesses
- depression, cognitive decline, and increased risk of dementia^{90 91 92}

Alongside relevant activities, strategies that encourage residents to engage with each other and with staff, and that welcome visitors, will contribute to people feeling connected.

Mealtimes — An Opportunity for Pleasure and Socialization

Food and the dining experience can be the highlight of a resident's day. If, however, food is unappetizing, meals, which have cultural, emotional and relational aspects, are only a biological function rather than a source of enjoyment.

Some care aides rushing to feed the residents would grossly stir all of the food on their plates together into a pile of grey mush and expected residents to eat it.⁹³

This is especially true when staff are rushed or preoccupied with documentation, or when table mates are not congenial. Staffing allocations at meals need to be sufficient to provide quality and enjoyable food services to residents, including those who eat slowly. Residents' mental health is supported when

- 91 Loneliness twice as unhealthy as obesity for older people, study finds. The Guardian. Ian Sample.. Accessed at:
- http://www.theguardian.com/science/2014/feb/16/loneliness-twice-as- unhealthy-as-obesity-older-people.

⁸⁹ Office of the Seniors Advocate British Columbia (2017) **Every Voice Counts:** Residential Care Survey Provincial Results

⁹⁰ Social isolation, loneliness, and all-cause mortality in older men and women. Proceedings of the National Academy of Sciences of the United States of America. Andrew Steptoe et al. Accessed at: http://www.pnas.org/content/110/15/5797.fulll

⁹² Steptoe, A., Shankar, A., Demakakos, P., and Wardle, J. (2013). Social isolation, loneliness, and all-cause mortality in older men and women, p. 5797. Accessed at: http://www.imfcanada.org/sites/default/files/Growing_Old_Alone.pdf

⁹³ Patrick Dudding Class action suit No. VIC-S-S-182236 Victoria Registry <u>https://drive.google.com/file/d/1mJKhIhD-</u> PGqnIf2nFcoBAWZenIdxI7eU/view

consideration is given to creating socially appropriate groupings and when staff facilitate conversation in the dining room.

Mealtimes were horrible, food dished out, then residents left alone to eat in silence. Often, I'd see residents after a meal, alone, food taken away and they'd be asleep at the table.⁹⁴

Care aides would always place this blind resident next to the one that was territorial about her food. The blind resident would commonly run her hand along the edge of the table for orientation. When this occurred towards the other resident who was territorial she would physically strike at her. Instead of placing the blind resident elsewhere for her safety, nothing was ever done to make a simple change as there was no staff oversight. It was sad and disgraceful.⁹⁵

The Seniors Advocate reported that for 2018/19 the actual cost of raw food per day per bed⁹⁶ in LTC facilities is \$8.11 (range \$5.21-\$19.88).⁹⁷ In some facilities food costs are reduced by contracting out, often to the lowest bidder, and quality may suffer⁹⁸. Given the level of acuity and the number of altered consistency/therapeutic diets the Meal Day Budget allocation spent should at minimum reflect the most recent cost of a Nutritious Basket of food/person/day for the region of residence, indexed for inflation (CPI for food) and reviewed at least annually.

The quality of foods served was an ongoing issue as well, and let me just describe it this way ... it was often so bad "it wasn't even fit for dogs," and as just one of many examples of that, was when she got served a tuna sandwich that had been pureed to the point that it poured out of the container as cold gray water, and I have pictures to show. ⁹⁹

Life in LTC facilities today is largely institutionalised, representing loss of social relationships, privacy, selfdetermination, and connectedness, all dramatically increased by restricted visiting policies.¹⁰⁰ Without being aware of or honouring resident's individuality and providing care/culture/environment that supports more than the physical body, we are only ware-housing people until they die. This is why one so often hears from people that they'd rather die than go to a long-term care facility, and even more so since the deplorable conditions revealed by COVID-19.

Culture/Social Environment and Quality of Life

⁹⁴ Personal communication - family member

⁹⁵ Patrick Dudding Class action suit No. VIC-S-S-182236 Victoria Registry <u>https://drive.google.com/file/d/1mJKhIhD-</u> PGgnIf2nFcoBAWZenldxI7eU/view

⁹⁶ The raw food cost includes the daily food and dietary supplements for the residents of care facilities and is calculated per bed per day. The cost of preparing and serving the food is not included.

⁹⁷ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary. (p 12)

⁹⁸ Key informant interview - facility operator

⁹⁹ Personal communication - family member

¹⁰⁰ Drageset J, Eide GE, Nygaard HA, Bondevik M, Nortvedt MW, Natvig GK. The impact of social support and sense of coherence on health-related quality of life among nursing home residents—A questionnaire survey in Bergen, Norway. Int J Nurs Stud 2009; 46: 66–76.

The horrors related to COVID-19 are only exaggerations of the limitations in the care of residents in LTC that arise from staffing issues and the resulting culture in which physical care is often inadequately provided and there is minimal or no attention/resources for residents' quality of life. For example, when short staffed, priority is given to basic needs such as eating and drinking, while call bells and assistance to the bathroom are overlooked.¹⁰¹

Care aides barely have enough time get the residents up in the morning, take them to eat, sit them in a different chair, take them to eat, sit them in a different chair, take them to eat, get them ready for bed, and hopefully they sleep through the night. Repeated day in and day out---what a life! This is "warehousing" and it's wrong.¹⁰²

My experience in Long-term Care for my 99-year-old veteran father is best described as a nightmare. My father was routinely ignored by staff largely because of a staffing shortage. He rapidly lost weight because of substandard food. He was routinely given medications of other residents and he slept on a decrepit mattress which could not support his frail body. After 2 years of attempting to correct these issues with management, I gave up and moved him back to his home, providing my own care team, which saw a rapid recovery in his body weight, his physical ability, his spirit and his desire to live. The fact that appropriate care could sustain him so readily demonstrates the inadequacy of long-term care in a facility supported by the provincial government.¹⁰³

Because of the shortness of staff, there was a lack of activities, the rehab room was usually empty and none of the staff had time to chat with the residents on a more personal level. It just seemed like – "I have a job to do, I need to get all this stuff done before I leave, something always comes up, bing, bang, boom... no time for chit chat or personal attention" – how you would think a factory was run but with living people.¹⁰⁴

The current institutional/custodial delivery of care is "necessitated" by the effects of staffing issues on residents' lives, outlined above. How and when personal/physical care is delivered is driven by staff and organizational/institutional need, not by resident preferences—a bath once a week at a time determined by the unit schedule/staffing; incontinence products changed at set times per shift rather that as required. As well, standardization of tasks to promote efficiency removes autonomy from the care aides and provides little or no space to address the individual needs and preferences of residents/families - instead the focus is on tightly scripted timelines, quantification, documentation and ordering of tasks.¹⁰⁵ This contributes to a physical care-based environment that is unlikely to achieve quality of life:

- aging experience becomes medicalized
- performance indicators focus on "functioning"

¹⁰¹ University of South Australia & Flinders University. 2016. *National Aged Care Staffing and Skills Mix Project Report 2016.* Adelaide : Australian Nursing & Midwifery Federation

¹⁰² Personal communication - family member

¹⁰³ Personal communication - family member

¹⁰⁴ Personal communication - family member

¹⁰⁵ Baines D., Armstrong P. (2018) *Can work organizations treat both residents and providers with dignity*. Social Work and Policy Studies: Social Justice, Practice and Theory

- clinical outcomes are constantly tracked and monitored
- front-line staff focus on tasks, rather than outcomes
- risk mitigation and demonstrating accountability for funds are prioritized.¹⁰⁶

The current culture of care and the resulting social environment create a regimented, routinized daily life, over which residents have extraordinarily little control, and that does not address/promote their quality of life, all magnified by restricted visiting during the pandemic.

The results from the Seniors Advocate's survey asking residents (n 9,605) how well their needs are met found:

- more than half (62%) of residents say they do not get to bathe or shower as often as they want, with a full 50% saying it rarely, or never happens as often as they want.
- One in four residents only sometimes, rarely, or never get help to the toilet when needed—which may mean a humiliating and demeaning accident.¹⁰⁷

Periodically, I found her left in bed for days, or the weekly bath could be postponed for weeks. Also, at times she was left for hours wet, soiled and with developing sores, and occasionally I could find her with bruises that were never explained. On at least two occasions, as I came in at noon, I found her in her wheelchair left out in public view having her face and neck caked with dried and hardened breakfast for all to see.¹⁰⁸

The roots of today's institutional model run deep, and "care" is largely equated to physical/body care including safety—somewhat like the Romanian orphanages we heard of over 30 years ago. Care of destitute/ill elderly started with the Elizabethan Poor Laws/work-house model that was eventually replaced by a medical model/hospital-like environment we largely see today.

Institutional/Custodial Care and Human Rights

Comparison to a custodial prison model, however, where civil liberties and human rights take a back seat to security, is not farfetched and particularly apropos at the time of writing this document, when LTC residents have been locked in and without visitors for over seven months, followed by limited and restricted visits. The Justice Centre warns that:

"this forced isolation and prohibition on meaningful visitation to elderly Canadians amounts to breaches of section 7 of the Canadian Charter of Rights and Freedoms, which protects the right to life, liberty and security of the person. As well, it is a violation of the Residents' Bill of Rights as protected in section 7 of British Columbia's Community Care And Assisted Living Act."¹⁰⁹

¹⁰⁶ BC Health Care Providers Association (May 2019) Quality of Life Framework for Seniors Care in BC. Retrieved. https://bccare.ca/qualityoflife/ p 3

¹⁰⁷ Office of the Seniors Advocate British Columbia (2017) **Every Voice Counts:** Residential Care Survey Provincial Results 108 Personal communication - family member

^{109 &}lt;u>https://www.jccf.ca/legal-warnings-issued-to-long-term-care-homes-who-continue-to-isolate-</u> seniors/?fbclid=IwAR1q46TGuDqu81JoxblnSET_p7yP-uIk_KHi1U9gef9RyZfNsb1aItUS2LY

The Council of Senior Citizens Organizations of BC (COSCO)¹¹⁰ asserts that the violation of seniors' human rights seen during COVID-19 is not new and is likely based on pervasive ageism and sexism, both of which are deeply entrenched in Western society.¹¹¹ They note that the *UN Conventions on Human Rights* and the *Canadian Charter of Rights and Freedoms* explicitly prohibit both. With more waves of COVID-19 expected, and the relatively short time seniors in LTC have left to live, it is crucial that a humane balance is struck between protecting institutionalized seniors from infection and the needs of residents and family for connection.

Currently, the only contact for a few of the luckier elders, are brief video and phone calls and if your loved one happens to be napping you miss your visit until the next week! Even as we hear of other care homes starting to allow family visits, those visits are far too short and too distant. A half hour a week will inflict even more mental harm on loved ones as they are reconnected to family then denied access again. How could anyone believe it is acceptable to ration human contact? You are wrong if you believe this isolation is saving more lives than it is harming, it is inflicting long lasting untold mental and emotional harm on thousands and thousands of families.¹¹²

Living in a long-term care facility is, for most people, like living in a poorly resourced hospital, but for the rest of your life. One day we will look back at how we care for our seniors with disbelief, in the same way we look back at the old mental hospitals and orphanages, as inhumane.

The European Centre for Social Welfare Policy and Research states:

"There is growing consensus that long-term care services should look beyond a medical model of 'care' to take a broader, more holistic view in which older people's wellbeing and quality of life and their preferences regarding care and support are central to the design of services in line with existing human rights standards (p. 5)"¹¹³

V – Towards Quality of Life in LTC

What Makes a Life Worth Living?

Quality of life is intrinsically linked to quality care but is a much more subjective and personal concept. Based on extensive observations and interviews with residents (with and without dementia), their families, and staff in 100 LTC facilities, researchers have identified the following domains as important to resident quality of life:¹¹⁴

111 Submission to the Select Standing Committee on Finance and Government Services by COSCO BC June 2020

¹¹⁰ COSCO BC is a non-profit umbrella organization of about 80 seniors' organizations in BC, affiliated with the National Pensioners Federation, that advocates for the rights and well-being of all seniors in BC.

¹¹² Personal communication - family member

¹¹³ Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V. & Schulmann, K. (2019). From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people. Vienna: European Centre for Social Welfare Policy and Research.

¹¹⁴ Kane, RA. (2003). Definition, Measurement, and Correlates of Quality of Life in Nursing Homes: Towards a Reasonable Practice, Research, and Policy Agenda. *The Gerontologist*, 43 (Special Edition II), 28-36.

- <u>Autonomy/Choice</u> refers to the perception that one is making decisions and choices and directing one's own life.
- <u>Dignity</u> embedded as a requirement in nursing home regulations, refers to the perception that one's dignity is respected rather than the important but different notion that each person is treated with dignity regardless of whether he or she can perceive indignities.
- <u>Food/Enjoyment</u> food that they are used to and that meets cultural needs e.g., a vegan going into care is in trouble, likewise a person who wants kosher food. Food that is cooked on site and not pre-packaged. Family style dining.
- <u>Functional Competence</u> as an outcome, functional competence means that within the limits of the person's physical and cognitive capacities, the LTC consumer is as independent as he or she wants to be.
- <u>Individuality</u> refers to the consumer's sense of being known as a person and being able to continue to experience and express his or her identity, and to have desired continuity with the past.
- <u>Meaningful Activities</u> need to perceive that their lives are replete with interesting and meaningful things to do and see. What is meaningful will differ according to the physical status of the individual.
- <u>Physical Comfort</u> being free from physical pain and discomfort, including shortness of breath, nausea, constipation, joint pain, and so on. It includes being comfortable in terms of temperature and body position. To some older people, it even includes crisp, freshly laundered sheets.
- <u>Privacy</u> being able to be alone when one wishes, to be together in private with others when one wishes, and to be in control of information about oneself.
- <u>Relationships</u> make life worth living, whether they be relationships of love, friendship, or even of enmity and rivalry. Reciprocal relationships where the LTC consumer is able to give as well as receive support, advice, and confidences are best of all.
- <u>Safety/Security/Order</u> a sense of security about oneself in one's world. A person needs to be able to trust that he or she is living in a benign environment where people are well intended, and where the ordinary ground rules of life are understood.
- <u>Spiritual Well-Being</u> may incorporate but go beyond and can be independent of religiousness. Spirituality can be defined as "A dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practice."¹¹⁵

These domains are congruent with how older adults conceptualize the joy of life - positive relations, a sense of belonging, sources of meaning, moments of feeling well, and feeling accepted - which correspond to the concept of flourishing mental health.¹¹⁶

¹¹⁵ Puchalski, C., Vitillo, R., Hull, S.K. and Reller, N. (2014). Improving the spiritual dimension of whole person care: Reaching national and international consensus. *Journal of Palliative Medicine*, 17(6), 642 – 656.

¹¹⁶ Rinnan, E., et al. (2018). Joy of life in nursing homes: A qualitative study of what constitutes the essence of Joy of life in elderly individuals living in Norwegian nursing homes. *International Journal of Caring Sciences*, 32: 1468 – 1476.

Standards for Ensuring Quality of Life

Quality of life requires quality of care. Health Authorities are responsible for the quality of care and quality of life for people in residential care, even when they have contracted out service delivery to private operators. There is, however, neither a formal nor funded system in place to monitor quality of life in the way Licencing monitors physical care.¹¹⁷ Some Health Authorities require that long-term care facilities are accredited by Accreditation Canada, which does look at quality of care and quality of life. However, the rigour of accreditation structure and process is called into question when all four BC facilities placed under government administration in 2019 had been accredited only a few months prior.¹¹⁸ BC has a Residents' Bill of Rights¹¹⁹ that is required to be on display in every LTC facility. The Bill of Rights is a comprehensive set of rights that is grouped into four main themes: commitment to care; rights to health, safety and dignity; rights to participation and freedom of expression; and rights to transparency and accountability. If these rights were operationalized and monitored, quality of care and life would not be at issue in LTC facilities.

Australia has recently (2019) developed a comprehensive approach to quality of life that included an overhaul of their (equivalent) Licencing body, what it monitors, and how. This project was initiated because of public outcry following revelations of abuse and neglect in a large facility. Aged Care Quality Assessors, trained in assessing QOL, carry out two day investigations that focus on eight quality standards that are described broadly in terms of intent. Each of the Standards is expressed in three ways: a statement of outcome for the consumer; a statement of expectation for the organisation; and organisational requirements to demonstrate that the standard has been met. Qualitative information is gathered through observation, discussion with residents and family, interviews with floor staff and administrators, and from documentation.¹²⁰ This model, once fully implemented and evaluated, could be considered for adaptation to British Columbia.

Policy, Regulations and Monitoring

BC lacks an overarching provincial strategy related to seniors' care and quality of life. A review of policies in BC, using Kane's QOL domains/indicators (discussed earlier as a lens), examined how policy supports or undermines residents' quality of life in LTC.¹²¹ Of 274 policies identified related to seniors in LTC, only 11 were found to support quality of life to any extent.¹²²

¹¹⁷ Key Informant – Health Authority official

¹¹⁸ Key informant - Health Authority official

 ^{119 &}lt;u>https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/policy-and-standards</u>
120 <u>https://www.agedcarequality.gov.au/sites/default/files/media/Guidance %26 Resource V9.pdf</u>

¹²¹ Keefe J, Hande M J, Aubrecht K, Daly T, Cloutier D, Taylor D, et al (2020). Team-Based Integrated Knowledge Translation for Enhancing Quality of Life in Long-term Care Settings: A Multi-method, Multi-sectoral Research Design. International Journal of Health Policy and Management Apr; 9(4): 138-142.

¹²² Key informant—policies that support QOL: Community Care and Assisted Living Act Residential Care Regulation 96 2009; Home and Community Care Policy Manual Ch 6 Residential Care Services 2016; Mental Health Act RSBC 1996 c288;Model Standard for Continuing Care and Extended Care Services 1999; Pharmacy Operations and Drug Scheduling Act SBC 2003 c 77; Representation Agreement Act RSBC 1996 c 405; Residents' Bill of Rights pursuant to Community Care and Assisted Living Act and Hospitals Act; Seniors Advocate Act SBC 2013 c 15; Workers Compensation Act 1996; Occupational Health and Safety Exposure Control Plan Regulation 296 97; Workers Compensation Act Reports of Injuries Regulation 713 74; Workers Compensation Act 1996.

We reviewed the Community Care and Assisted Living Act Residential Care Regulation (Regulations) using Kane's QOL indicators as a lens. The Community Care and Assisted Living Act Residential Care Regulation is:

"a regulatory framework established to protect optimal quality of life and promote the development, individuality, autonomy, and well-being of persons in care. Licensing staff monitor the services provided by Licensees to ensure that the requirements of the Community Care and Assisted Living Act (CCALA) and regulations are being met." (p.4) ¹²³

We found that many of the regulations relate to the physical environment and building. Only one regulation related to cleanliness, a frequent concern of families. There are regulations related to care provision, but these focus only on tasks related to physical care, and how they are to be carried out is vague. For example:

(b) assist persons in care with the activities of daily living, including eating, moving about, dressing and grooming, bathing and other forms of personal hygiene, in a manner consistent with the health, safety and dignity of persons in care.

Food and nutrition, important to both physical wellbeing and to quality of life, are one of the areas of greatest concern to families. Using Kane's QOL domains we found no clear regulations identifying that a Registered Dietitian must be contracted or hired to ensure adequate nutrition is provided to residents. There is nothing in the Regulations that identifies a ratio of Registered Dieticians to be employed to perform nutrition audits for facilities. Complaints must be filed for specific aspects in nutrition care to be reviewed by Licencing. It is unlikely that Licencing officers have the specialized skills and in-depth understanding needed to assess nutrition, nor the understanding about the implications of non-compliance with nutritional standards for residents.

We found no regulations that focus on resident quality of life directly, or that compel attention to residents' relational, spiritual, or mental health needs. These limitations in policies and regulation are reflected in the criteria that Licencing uses to monitor the health, safety and dignity of persons in care.

We reviewed the *Residential Care Inspection Checklist,* designed for self-monitoring by facilities and as a set of measures for formal compliance inspections by Licencing in one Health Authority, using Kane's QOL indicators.¹²⁴ The *Checklist* consists of nine categories, with *Physical Facility* divided into two subcategories. Each of the category sections consist of compliance indicator items. These compliance items are the standard measures used to monitor residential care facilities. Licencing inspections are primarily paper based, for example reviewing charts, care plans etc. for 10% of a facility's resident population.

The review of the *Residential Care Inspection Checklist* using a QOL lens demonstrates a high degree of deficiency in relation to quality of care and QOL across all indicators. Clearly, articulated measures are consistently absent across all items of the Checklist. Two issues emerge as primary deficiencies:

- Staff and Licensing officers do not have a common language to measure success or respond appropriately to inadequacy.
- Little of the person in care's QOL is incorporated into the compliance items.

^{123 &}lt;u>https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/child-day-</u> care/a guide to community care facility licensing in british columbia update spring 2018.pdf p4

¹²⁴ See Appendix A for discussion of methodology

A distinct lack of balance privileges the "safety" of persons in care and does little to safeguard QOL. The impact of this approach is likely to contribute to the poor QOL experienced by many people in care.

Role of Families in Monitoring Residents' QOL

Families of residents in LTC have been crucial in the exposure of inadequate care, negligence, and abuse in LTC facilities. Families are well positioned to observe care and how it is provided, the facility environment (physical and social), and staffing levels, not only for their relative but for residents generally. Families may take their concerns to facility administration but are often reluctant to do so for fear of repercussion.

There was no respectful consideration for human dignity. And at that point, what was I able to really do? I felt so angry. Do I make waves and possibly he would be treated worse when we weren't there? Do I grovel hoping they will be good to Dad? There was no trust, no confidence, no one to talk to. ¹²⁵

Where there is a Family Council (FC) they may also take concerns forward. If concerns are not resolved at the facility level families may take them to the PQCO (which only acts in response to complaints), or to Licencing. Many of the families' concerns relate to QOL and do not "fit" the Licencing framework. Of the 467 (or 16.2/1,000 beds) complaints about care and services in facilities received by Licencing in 2018/19, only 167 (36%), or 5.9/1,000 beds, were substantiated and resulted in a licencing violation. The Seniors Advocate noted that complaints increased by 33% compared to the previous year, while substantiated complaints decreased by 21%.¹²⁶

The discrepancy between the number of complaints made to Licencing, and those that are substantiated suggests that many family's concerns are discounted, or not legitimatized/recognized as important/relevant by the system in place for complaints. Further, even when investigated the complainant only hears the final decision – whether or not the identified issue is verified. Families can file a Freedom of Information request, however the report provided to the family is almost all redacted.¹²⁷

Licencing said that my complaint about my husband's care was not substantiated but wouldn't tell me what information they used to make the decision. I went through FOI to get the report, but it was so blacked out I learned nothing! Where is the accountability and transparency?¹²⁸

The following story is illustrative of the challenges families experience in having their concerns heard in the current system for monitoring facilities and ensuring residents' health, safety and quality of life in LTC.¹²⁹ For over 2 years families of residents in one BC facility expressed concerns about resident care to administration directly and through the administered Family Council, to no avail. In the same period Licensing identified at least 22 separate contraventions through routine inspections for a range of issues

¹²⁵ Personal communication - family member

¹²⁶ Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary. p 36

¹²⁷ Reported by several family members

¹²⁸ Personal communication – family member

¹²⁹ Summarized with permission, COL, <u>https://decafnation.net/2019/09/30/island-health-takes-control-of-comox-valley-seniors-village-to-ensure-residents-safety/</u>

from substandard wound care to lack of fall prevention planning. Families believed that many of their issues of concern were not evident during Licensing investigations, speculating this was related to unreliable records. Taken in their totality, these issues suggested to them that there was endemic problems with how the facility was operated and that health and safety of the residents was not of paramount concern.

In March 2019, following the death of three residents during Norwalk virus, the families advised the Health Authority of their concerns about the facility's failures to follow outbreak protocols and provide appropriate care, and asked them for an investigation and better oversight of the facility. It was only when their concerns were framed in risk management language by a retired risk management professional that the Health Authority met with families and instituted some corrective actions, reassuring them that all would be well. However, after several months with no evidence of improvements the families asked the Health Authority to assume full operational responsibility, which they were reluctant to do. In May 2019 a five month letter writing campaign was initiated that finally led to a full investigation by Licencing Investigators who found a "multiplicity of deficiencies" related to care plans, which, "are critical to ensuring the health and safety of persons as they enable the facility staff to appropriately know, provide and respond to unique needs for those in care." There were multiple examples of lack of documentation and "no apparent intention to implement a corrective action plan", which was termed a "serious systemic failure." Insufficient experienced staff put residents of the facility "at significant risk of harm." They found that "there has been high turnover of staff, and few employees have attended education and training events".

On September 30, 2019, the Medical Health Officer recommended that the Health Authority appoint its own administrator to oversee the facility saying a "lack of timely responses to address the contraventions and the duration of the contraventions were unacceptable" and "I do not have confidence this Licensee is either willing, or able to come into compliance with the (Care Act) on their own accord".

In this instance, the failures in the system/process for monitoring resident health, safety, and quality of life, are evident and point to the power differential/relations between families and those charged with residents' care.

- Individual families were unable to get the administration to address concerns—they felt discounted.
- When the Family Council (FC) brought concerns to administration they were minimized and mediated by the staff FC chairperson.
- It was difficult to make effective complaints—to whom and how to frame?
- Time between making a complaint and it being investigated was lengthy.
- Many of the family concerns were not evident to Licencing or didn't fit into their criteria and were not substantiated.
- The Health Authority, once engaged, believed that the facility was remedying issues, but the families disagreed.
- It took coordinated pressure from the community to instigate a comprehensive investigation by the Health Authority.

VI – Changes Needed: Recommendations

Shifting the Paradigm to Support Quality of Life

It is not enough to make small, piece meal changes to the current model of long-term care. Without a paradigm shift to replace the current institutional/custodial model there will be no real improvement in the care of residents or to their quality of life. If we are to meet our moral obligation as a society to the well-being of residents in BC LTC facilities, care must be underpinned by an ethical framework that attends to the needs of residents and those who care for them. This paradigm shift will create a culture/environment that allows and enables quality of life for residents and in which they flourish and live their best lives possible. Making the shift requires the immediate implementation of a principle and value based model of care, with strong leadership, appropriate staffing and organization of care, mandated staff continuing education, supported by strengthened standards, enforceable and effectively monitored, to support health, safety and quality of life for residents in LTC. The following recommendations are crucial to reforming the long-term care system so that quality of life for residents is ensured in an environment that supports living life, not just existing.

Person Centred Care Model

We recommend that:

- the provincial government mandates, implements, and funds a person-centred, relational care model in all LTC facilities and that each facility is staffed and organized to implement unit based primary care and team approaches.
- training be made available to all facilities' Directors of Care to prepare them to lead the implementation of person-centred care.
- the provincial government provide infrastructure funding to enable facilities to adapt or modernize their physical environments to better meet residents' needs, such as needs for outdoor spaces, single rooms, ceiling lifts etc.

"Person-centred" care means humane care

"that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect and to participate fully in their environment."¹³⁰

It can be viewed as a moral concept and philosophy that envisions health-care providers

"as demonstrating person-centred-care attitudes and behaviours that are respectful of the whole person and their preferences, are culturally sensitive, and involve the sharing of power within a therapeutic alliance to improve clinical outcomes and satisfaction with care."¹³¹

^{130 &}quot;Guidelines for care: Person-centred care of people with dementia living in care homes." Alzheimer Society of Canada. January 2011.

¹³¹ Registered Nurses' Association of Ontario. (2015). *Person- and Family-Centred Care.* Toronto, ON: Registered Nurses' Association of Ontario. P. 7

Improving Quality of Life in Long Term Care – A way forward

There are many care models and frameworks that seek to guide organizations and staff to adopt the person-centred philosophy of care through a process of culture change – for example, the Eden Alternative and Pioneer Network. There are pockets of excellence in BC where person-centred care has been implemented that can be shared and built upon¹³² as well as a planned dementia village¹³³ The Registered Nurses' Association of Ontario has developed evidence-based best practice guidelines for implementing person and family centred care for care providers, educators and policy makers.¹³⁴

Most person-centred care models share common values, which are related to the right of each person in care to be:

- treated with respect and dignity, regardless of cognitive and communication abilities, physical capacity, and social connections.
- empowered and supported to be in control of their own life.
- fully supported to live the life that they choose including engaging in activities that are meaningful, give purpose to life, bring joy, and those that may involve some risk.
- viewed, first and foremost, as a person with strengths and talents.

The Alzheimer Society of Canada has developed an evidence-based framework for strengthening the capacity of care home staff to implement person-centered care by influencing the culture of care and encouraging recognition of each resident's individuality (reproduced below). Implementing person-centred care would support the mental health of any long-term care resident, not only those living with a dementia.

- Ensure that people who work in care homes understand what a person-centred philosophy of care means and can put it into practice.
- Ensure that relationships and interactions with residents are respectful.
- Focus on maintaining, supporting, and/or restoring the independence of the person.
- Develop strong bonds with family members of residents and engage them in activities whenever possible.
- Provide quality care to all residents, regardless of their cultural background, age, or mental ability.
- Anticipate the needs and reactions of residents and adjust individual, social and environmental factors to support positive behaviours and well-being.
- Encourage and support residents to make choices in keeping with their lifelong values, preferences, and interests.¹³⁵

Person-centred care supports and facilitates relational care, where staff form relationships with residents whom they know and can personalize/individualize care based on their knowledge. There is not a "one-size-fits-all" approach to care. For example, a resident who prefers to sleep in later can do so. Those who

https://rnao.ca/bpg/guidelines/person-and-family-centred-care

¹³² Czorny Alzheimer Centre <u>https://vancouversun.com/news/local-news/seniors-care-in-b-c-dementia-wave-set-to-make-institutions-more-responsive-to-residents</u>

¹³³ Planned Dementia Village – Comox Valley <u>http://thedailyscan.providencehealthcare.org/2020/06/dementia-village-philosophy/</u> 134 Registered Nurses Association of Canada (2015). Best Practice Guideline for Person-and Family-Centred Care.

¹³⁵ Alzheimer Society of Canada (2011) *Guidelines for Care: Person-centered care of people with dementia*. Available: http://www.alzheimer.ca/english/care/executive-summary.pdf p3

are afraid of the tub and shower are given bed baths instead, preventing re-traumatization. The "bath schedule" can be altered for those who have always enjoyed an evening bath.

Relational care is supported by continuity of staffing. A primary care model where the same staff persons are always assigned to the same residents enables relational care, particularly when coupled with a team approach¹³⁶—one group of care aides attached to one unit, so that they all come to know all the residents, and are able to share information/strategies and problem-solve together. For example, knowing that a resident becomes anxious and disoriented when tired in the later afternoon, staff may encourage a rest after lunch.

Staff members are supported to facilitate residents' quality life through ongoing continuing education, so they can:

- Develop positive relationships with residents
- Provide compassionate palliative care at the end of life.
- Prevent skin breakdown and falls and manage pain effectively.
- Interact effectively with residents who live with serious mental health challenges such as substance use disorders, PTSD or BPSD.
- Respond therapeutically to behaviours associated with dementia.

The successful implementation of a culture of person-centred care demands strong leaders who demonstrate commitment to the principles of person-centred care in every aspect of facility life, including organizing the work as above and supporting staff education. Policies, procedures, and protocols are developed that support and empower staff to always be respectful and provide dignified care. Staff feel valued by the leaders and participate in care planning. Families are made to feel welcome in the facility.

The physical environments of newer models of care reflect attention to the emotional and quality of life needs of residents in their building designs. Care facilities purpose built as "homes", based on these models, utilize best practice design, such as small "pods" of ten – twelve residents living and eating together with their own outdoor and garden spaces.¹³⁷ Some of these design practices could be implemented in older buildings through renovation but many facilities in BC may not have the capital to improve or modernize their physical infrastructure.

1. Staffing Levels and Mix

We recommend that

• the MOH set a <u>standard</u> of actual direct care nursing hours worked per resident per day as 4.1 hours and facilities be funded and monitored effectively to ensure they meet this standard.

¹³⁶ Primary care and team approaches may not be possible in small facilities with few staff but the principle of continuity of staffing can be implemented in other ways.

¹³⁷ Senior living and long-term care in a post-pandemic world: Part I. IBI. June 11, 2020. Part II, June 16, 2020. https://www.ibigroup.com/ibi-insights/senior-living-and-long-term-care-in-a-post-pandemic-world-part-1/

- additionally, each facility be provided with sufficient hours for a Registered Nurse to address infection prevention and control, best practice care standards, quality improvement, staff education and orientation, and team leadership.¹³⁸
- the MOH set a <u>minimum standard</u> .5 direct care hours worked by allied professions per resident per day and facilities be funded and monitored effectively to ensure they meet this standard. There must be access to:
 - Physical and occupational therapist hours based on performance indicators that support the goal of maintaining physical independence.
 - Registered Dietitian hours for nutrition care/resident/month based on acuity levels of residents in the facility.
 - Recreation staffing sufficient for day, evening, and weekend programming, and for 1-1 activities.
 - A social worker fully integrated into the care team, for each facility, to support person-centred care, address emotional and mental health needs of families, and to provide support to care giving staff.
- regional volunteer coordinators be funded to develop volunteer teams that can support recreation and other therapies and develop relationships with individual residents.

Nursing

A review of 150 studies (from the US, Canada, UK and northern Europe) that had been documented in systematic reviews of nursing home staffing levels, found a 'strong positive impact of nurse staffing on both care process and outcome measures'.¹³⁹ Further, several studies reviewed highlighted the importance of organisational factors to care quality, such as having a high professional staff mix (ratios of RN to total staffing levels).¹⁴⁰

Investments in long-term care facility staffing levels can result in better quality in care and increased quality of life for residents. The New Brunswick Department of Social Development conducted a pilot project to evaluate the effects of enhanced staffing levels in five long-term care homes. The five long-term care homes received funding to increase staffing levels to 3.5 hours per day, above and beyond the provincial standard of 3.1 hours per day per resident.¹⁴¹ They found that increasing hours of care resulted in:

- Greater attention and care to residents with improvement in some aspects of the residents' quality of life and quality of care for example, residents were not being rushed through their day especially in relation to hygiene, grooming, and meals.
- Residents were also assisted to get up every day and, in most instances, more than once per day (if they wish) and able to participate in more recreational activities.

¹³⁸ Nursing Home Basic Care Guarantee RNAO Submission to the Long-Term Care Staffing Study Advisory Group June 9, 2020 139 Harrington, C, Schnelle, JF, McGregor, M & Simmons, SF 2016, 'Article Commentary: The Need for Higher Minimum Staffing Standards in U.S. Nursing Homes', *Health Services Insights*, vol. 9, pp. 13-9.

¹⁴⁰ Eagar K, Westera A, Snoek M, Kobel C, Loggie C and Gordon R (2019) *How Australian residential aged care staffing levels compare with international and national benchmarks*. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

¹⁴¹ New Brunswick. 2014. Evaluation of 3.5 Hours of Care Pilot in Nursing Homes: Summary Report. Fredericton: Government of New Brunswick, Department of Social Development. P 5, 6

- Staff members got to know the residents better, provided greater choice and dignity to residents, and developed meaningful relationships with the residents.
- Residents received more attention from staff and were more engaged in recreational activities.
- Skin integrity improved as staff had more time to change residents' position and to facilitate better feeding/nutrition and hydration.

Researchers have identified a ratio of nurses to residents where long-term care residents are at risk if staffing falls below the threshold as a minimum total of 4.1 hours worked (246 minutes) per resident day of direct care, comprising 0.75 hours (45 minutes) of RN time, 0.55 hours (33 minutes) of Licensed Practice Nurses, and 2.8 hours (168 minutes) of care aides^{.142}

Additionally, the Registered Nurses Association of Ontario (RNAO) recommends one additional nursing staff member (preferably an RN) to support the functions of infection prevention and control, quality improvement, staff education, on-boarding and orientation.¹⁴³ The RNAO contends that these nursing allocations would provide each resident with safe care and quality of life.¹⁴⁴

Allied Professionals

Residents' quality of life is enhanced when long-term care facilities have adequate recreation/therapeutic programs and activities.¹⁴⁵ There are no standards for the number or mix of allied professionals required for good care quality, or quality of life identified in the research literature. The best evidence comes from Ontario's Sharkey Report, which recommends 0.5 hours of care per day be delivered by allied health care professionals. This is higher than an average of 0.36 hours (or 22 minutes) of allied health care per resident (including physiotherapists, occupational therapists, activity workers, social workers, and others) currently suggested by the BC Ministry of Health.¹⁴⁶

Volunteers can be an important resource for supporting residents' quality of life. They can be trained to assist physio and occupational therapists, recreation staff, and to act as friendly visitors for those who are socially isolated.

2. Staffing Levels and Delivery of Direct Care Hours

We recommend that the provincial government

- fund LTC facilities to the level required to meet enforceable staffing level standards
- develop a clear definition of direct care hours as actual (worked) hours of direct care delivered and enforce it

¹⁴² Eagar K, Westera A, Snoek M, Kobel C, Loggie C and Gordon R (2019) *How Australian residential aged care staffing levels compare with international and national benchmarks*. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong

¹⁴³ Nursing Home Basic Care Guarantee RNAO Submission to the Long-Term Care Staffing Study Advisory Group June 9, 2020 144 Nursing Home Basic Care Guarantee RNAO Submission to the Long-Term Care Staffing Study Advisory Group June 9, 2020 145 New Brunswick. 2014. Evaluation of 3.5 Hours of Care Pilot in Nursing Homes: Summary Report. Fredericton: Government of New Brunswick, Department of Social Development. P 5-6

¹⁴⁶ British Columbia Ministry of Health 2017, Residential Care Staffing Review, British Columbia Ministry of Health, Canada pp.40-1

- implement the following Senior Advocate's recommendations: (1) funding for direct care must be spent on direct care; and (2) monitoring for compliance with funded care hours must be more accurate
- limit the growth of corporate for-profit long-term care facilities and develop a buy-back program for existing facilities.

The Seniors Advocate reported in 2018-19 that 70% of contracted long-term care homes in B.C. did not meet the Ministry of Health's recommended staffing guideline (established in 2009)¹⁴⁷ of a minimum of 3.36 hours of direct care per day (nursing and allied professionals), suggesting that funding levels may not be enough to meet the guideline.¹⁴⁸ She also reported that the average number of funded direct care hours for these facilities was only 3.25,¹⁴⁹ but these might not be actual hours of care delivered.

Based on a systemic review of the funding and expenditures in the contracted long-term care sector, the Seniors Advocate identified several important issues related to staffing levels and resident quality of life, including that:

- The for-profit sector failed to deliver 207,000 hours of funded care and spent only 49% of its revenue on direct care.
- Some operators do not use their allocated funding to fully staff the facility to the 3.36 direct care hour staffing level, or do not replace some or all of the care staff when they are absent due to illness, vacation, training, or other types of leave.
- The not-for-profit sector spent 24% more (almost \$10,000) per resident, per year.¹⁵⁰

These practices have implications for both resident quality of life and staff working conditions, as the number of direct care hours delivered are significantly less than a BC <u>average</u> of 3.25 (nursing and allied professionals) suggest. Inadequate staff time seriously compromises capacity to provide quality care, impacting the residents' well being and the safety and integrity of the staff.

Research on private ownership of long-term care homes shows that

"Private, for-profit services are necessarily more fragmented, more prone to closure, and focused primarily on making a profit. The research demonstrates that many homes run on a for-profit basis tend to have lower staffing levels, more verified complaints, and more transfers to hospitals, as well as higher rates for both ulcers and morbidity."¹⁵¹

The first business of profit-making operators is to create a return for owners/investors/shareholders. If profit is prioritized over care by not delivering the services that facilities are funded for, we can only conclude that resident quality of care and quality of life suffer, and staff are over-burdened. Is this morally defensible in a publicly funded LTC system where the government has made a commitment "to ensure our senior citizens are able to live their final years with dignity, and.... to improve and strengthen services to

¹⁴⁷ British Columbia Ministry of Health 2017, *Residential Care Staffing Review*, British Columbia Ministry of Health, Canada 148 Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary.

¹⁴⁹ This number included nursing and allied professionals so actual nursing time is even less

¹⁵⁰ Office of the Seniors Advocate British Columbia (2020) A Billion Reasons to Care: A Funding Review of Contacted Long-Term Care in BC, p 6

¹⁵¹ Armstrong, Pat; Armstrong, Hugh; Choiniere, Jacqueline; Lowndes, Ruth and Struthers, James. April 2020. Re-imagining Long-term Residential Care in the Covid-19 Crisis. Canadian Centre for Policy Alternatives (CCPA). Toronto.

ensure seniors receive dignified and quality care"?¹⁵² We think not. We object to the commodification of our seniors, and the financialization of the long-term care sector on international markets.

The Seniors Advocate has recommended:

Funding for direct care must be spent on direct care

Financial incentive for operators to do anything other than provide as many care hours as possible with the public money they receive to deliver direct care must be removed. If an operator can find staff who will work for lower wages than their funded rate, they should use their surplus funds to provide more hours of care or return the funding. Anything short of this will not provide operators with the incentives we need in today's labour market to ensure residents have consistent and sufficient care staff to meet their needs.

Monitoring for compliance with funded care hours must be more accurate

Tighter standardized reporting is needed for direct care hours. All beds need to be counted at 100% occupancy and we need to verify self-reported worked hours. Consideration needs to be given to regulation changes that will empower licensing to monitor staffing levels similar to the current regulatory and licensing practices in licensed day care."¹⁵³

3. Work Force Issues

We recommend that the provincial government develop a recruitment strategy for care aides that trials and evaluates different recruitment, training and retention strategies.

We recommend, in concert with the Royal Society of Canada, that the provincial government:

- "maintain appropriate pay (not limited to the timespan of COVID-19), and implement benefits, including sick leave, for the large and critical unregulated workforce of care aides. Pay and benefits must be equitable across the LTC sector, and between the LTC and acute care sectors for regulated and unregulated staff.
- make available full-time employment with benefits to all unregulated staff and regulated nursing staff. They should also evaluate the impact on LTC facilities of "one workplace" policies, and the further impact on adequate care in other LTC settings such as retirement homes, hospitals and home care. Provincial governments must assess the mechanisms of infection spread from multi-site work practices and implement a robust tracking system.
- make mental health supports available to all LTC staff." ¹⁵⁴

We recommend that the provincial government create a task force that includes relevant stakeholders to review the curriculum for care aides and ensure; (1) it equips them to meet the complex needs of residents, including mental health, behavioural and palliative care needs, relationship building skills, culturally safe care

¹⁵² https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/premier-cabinet-mlas/minister-letter/dixmandate.pdf

¹⁵³ Office of the Seniors Advocate British Columbia (2020) A Billion Reasons to Care p40

¹⁵⁴ Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. *Restoring trust: COVID-19 and the future of long-term care.* Royal Society of Canada. 2020, p 28

practices, and (2) students' physical and psychological suitability for work in the LTC sector is assessed at entry and during the program.

The Royal Society contends that a "high-quality, resilient and supported workforce is, without doubt, the major component of quality care."¹⁵⁵ A well supported workforce is likely to have less sick time and fewer injuries, be more easily recruited and retained, thereby increasing continuity and resident quality of life. Monies saved could contribute to improving care in LTC facilities.

There is evidence that quality of care in LTC is affected by staff vacancy, turnover, and retention rates for all levels of staff.¹⁵⁶ It has been the norm, even before COVID-19, for nursing to be short staffed in many LTC facilities, especially over weekends and in summer. Where casual staff are used extensively, relational care, continuity and quality of care, as well as quality of life are undermined while slowing down the regular staff. For 2018/19 over one-third of care home operators contracted with another company to provide some or all the direct care they are charged with. These practices, which undermine resident care and quality of life, are often the result of deliberate policies by operators to save money.

There is an industry wide shortage of care aides, in large part due to wages and working conditions, which will be exacerbated by the negative image of long-term care facilities exposed by COVID-19 horror stories. The portrayal of care aides as overburdened, under-appreciated, and at the bottom of the hierarchy needs to change. One strategy might be to "professionalize" the work by recasting "workers" as nursing assistants and facilitating development of a Care Aide association through which all must be certified.

Some operators provide the direct care hours they are funded for at a cost less than they are funded for by paying below industry standard wages and benefits, and/or have training, overtime, and vacation/sick relief costs that are very low. The Seniors Advocate reported, prior to wage levelling, that care aides in the for-profit sector were paid as much as 28% below the industry standard, contributing to challenges some facilities have had in recruitment and retention of staff. It seems likely that the lowest paying facilities would have the most difficulty attracting any staff (let alone the most qualified and experienced people) and would be least able to provide quality care. The Seniors Advocate notes that employers who fully participate in the wage and benefit scales of the master collective agreement, according to the Health Employers Association of British Columbia, have better rates of overall retention and successful recruitment of both new and experienced care aides.¹⁵⁷ Maintaining the wage leveling established during COVID-19 where all RCAs are paid the wage provided through the master agreement, and conditions such as the one-site rule that make work less precarious and include benefits, will facilitate recruitment of care aides to the field.

Given that the front line is aging, easier and less costly access to training programs for care aides would be beneficial. For example, training could be provided at no cost to recruits in return for working a certain number of months for the funding facility in return. Alternatively, Health Authorities could estimate the number of new hires needed annually and recruit, train, and hire their own people on an ongoing basis. The provincial government has announced the development of an assistant position to "fetch and carry"

¹⁵⁵ Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. *Restoring trust: COVID-19 and the future of long-term care.* Royal Society of Canada. 2020, p 28

¹⁵⁶ New Brunswick. 2014. Evaluation of 3.5 Hours of Care Pilot in Nursing Homes: Summary Report. Fredericton: Government of New Brunswick, Department of Social Development. P 5, 6

¹⁵⁷ Office of the Seniors Advocate British Columbia (2020) A Billion Reasons to Care: A Funding Review of Contacted Long-Term Care in BC

and visit with residents for example, while training these individuals as a care aide on-the-job. A contracted facility is providing care aide training to their housekeeping staff at no cost to them, on their own time.¹⁵⁸

A consequence of relational care for staff is grieving, which unmanaged can affect mental health. The stress and circumstances of working in the face of COVID-19 amplifies this. The Royal Society points out that LTC staff experience deaths among the older adults they have known for months and years, and during the pandemic, among colleagues as well.¹⁵⁹

4. Staff Training/Education

We recommend, in keeping with the Royal Society's recommendations,

- That the provincial government establish and implement (a) continuing education for the direct care workforce in LTC and (b) proper training and orientation for anyone assigned to work at LTC through external, private staffing agencies.
- That the provincial government achieve these education and training objectives by supporting educational reforms for specializations in LTC for all providers of direct care in LTC facilities, care aides, health and social care professionals, managers and directors of care.

We recommend that

- RNs with responsibility for leading the care team and supervising staff be on site days, evenings and nights.
- Social workers support front line staff in developing active listening, communication and relationship building skills.
- Access to advance practice nurses including Clinical Nurse Specialists and Nurse Practitioners be optimized.

We recommend that the provincial government

- support the best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care¹⁶⁰ through staff education and access to specialized mental health consultants.
- mandate that facilities provide support for staff to become certified in *Building a Strong Foundation for Dementia Care*.¹⁶¹
- support quality mental health and palliative care for residents through funding of staff continuing education and facility access to in-house social workers and mental health and palliative care consultants.

- 159 Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. *Restoring trust: COVID-19 and the future of long-term care.* Royal Society of Canada. 2020
- 160 B.C. Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care. A Person-Centred Interdisciplinary Approach. B.C. Government, October 25, 2012.

¹⁵⁸ Key informant interview - profit making private facility

https://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf

¹⁶¹ Alzheimer Society of British Columbia (n.d.) Building a Strong Foundation for Dementia Care

https://alzheimer.ca/sites/default/files/files/bc/bsfdc%20guidebook.pdf

Increased staffing levels alone will not create improvement in quality care and quality of life for residents in LTC. Front line staff, once employed, require access to in-service education and/or support and supervision. All direct care staff working in LTC need ongoing training to provide care to the complex resident population in LTC today, especially related to dementia care, behavioural support, mental health needs and end-of-life care. Front line staff, including casual staff, need to be oriented, supported, and supervised. Leadership and staff supervision must be part of the RN duties, and there should be an RN in this role, onsite, days and evenings.

While care aide training teaches skills such as bathing, transferring, lifting, feeding etc., there is much less focus on how to meet the social and emotional needs of residents, or on how to respond effectively to responsive behaviours and other mental health needs. In most professional curricula little attention is paid to gerontological education or to LTC care. The Alzheimer Society of BC has developed a modular curriculum for health care providers *Building a Strong Foundation for Dementia Care¹⁶²* that addresses this gap. The modules, focusing on understanding dementia, communication, behaviours and what families experience, can be provided virtually or in person.

Across Canada there is a shortage of nursing staff at all levels, as well as physicians and allied health care professional/therapists to work in LTC facilities. LTC facilities are the 'poor sister' in health care continuum, and not many people choose this area of practice. Changing this image and engaging the interest of future health care providers as students is important.

5. Strengthen Standards to Support QOL and Monitoring

We recommend that the provincial government

• implement monitor and enforce the following quality of life standards related to person-centred care, nutrition, recreation, mental health and palliative care (*See Appendix B for full standards with indicators*)

Person-Centred Care

- All residents are treated with respect and dignity.
- All residents are empowered and supported to be in control of their own life to have autonomy and make choices.
- Each resident is fully supported to live the life that they choose.
- Residents are viewed as persons with strengths and talents.
- Organizational leaders demonstrate commitment to principles of person-centred care in every aspect of organizational life.
- Leaders and members of the interdisciplinary team role model the importance of making families feel that they are welcome in the facility.

<u>Staffing</u>

¹⁶² Alzheimer Society of British Columbia (n.d.) Building a Strong Foundation for Dementia Care https://alzheimer.ca/sites/default/files/files/bc/bsfdc%20guidebook.pdf

- The facility has a system in place to ensure required positions are always in place on all shifts, without over reliance on casuals.
- All staff, casual and new hires, are oriented to the facility/unit prior to working.
- Front line staff are supported to provide quality care, and quality of life.
- A system is in place to support staff's mental health.
- There is evidence of an effective ongoing continuing education program.
- Care team communication is supported.

Allied Professions

- Allied profession positions to reach the staffing level of .5 hours of direct care per resident/ day recommended here, are filled and allocated based on resident need.
- Residents' needs for meaningful activity and social connection are met.
- Trained volunteers support recreation and other therapies and develop relationships with individual residents.
- Resident diversity is recognized and addressed.

Equipment/Supplies

• Enough equipment to carry out care, as well as to support and provide meaningful activities is available to staff.

Specialized Mental Health Supports¹⁶³

- Residents will receive appropriate supports for the symptoms and signs of mental health conditions, and these will be recognised and recorded in the resident care plan.
- Health professionals, therapists, and care aides will participate in the development of mental wellness plans for residents.
- Staff will deepen their knowledge of mental health, with an emphasis in Alzheimer's and other dementias, through education and training provided by the care home.
- Staff will be supported to work one-on-one with residents in an ongoing process to aid in the identification of resident's needs regarding mental well-being.
- Staff will have the knowledge and training to identify triggers and implement the appropriate support and non-punitive solutions focused on the mental well-being of residents.
- Communication with and about residents, their behaviours, or mental wellness will not be reductionist, and will maintain each individual's dignity and right to confidentiality.
- Access to external mental health supports will be provided to residents when the appropriate mental health professionals are not available within the care home.

¹⁶³ Antifeau, E., Ward, C., & British Columbia. Ministry of Health. (2012). Best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care: A person-centred interdisciplinary approach. Victoria, B.C.: Ministry of Health.

We recommend that the provincial government:

- create a mechanism/process/role, or expand the role of Licencing Officers, to monitor the QOL standards.¹⁶⁴
- ensure the designated monitors are trained to assess QOL and that there is an adequate number to monitor the standards effectively.
- ensure monitoring/complaint investigations are performed with enough frequency and without notice so that reviews accurately represent the day to day quality of care that residents are receiving.

As outlined above, the current Community Care and Assisted Living Act regulations standards are meant to *"protect optimal quality of life, and promote the development, individuality, autonomy, and well-being of residents".* The Licencing program is the only body that proactively monitors facility compliance with the regulations, but this is primarily a paper process that is not designed to reveal poor quality care or quality of life. While Heath Authorities are responsible for quality of care, they lack a process for routine monitoring.

Implementation of the standards in Appendix B will strengthen the effectiveness of and monitoring of QOL and could be used by Licencing or a new body. Some of the indicators are reflective in nature and require that staff articulate their knowledge and understanding of key concepts. This means those monitoring will need to speak directly to front line staff and may need training in the area of QOL and quality of life assessment to make an adequate appraisal.

We recommend that the provincial government:

- mandate independent Family Councils in all LTC facilities in the CCALA Regulations and require that all publicly funded facilities support them, and ensure that they do so.
- create regional Family Council Facilitators to help develop Family Councils, and to provide education to families/Family Councils to become effective advocates.
- ensure that the Regional Family Council Facilitators have a direct line of communication for taking Family Council concerns to Licencing, designated Quality of Life monitors and the Health Authority.

A Role for Families in Monitoring Quality of Life

Families and Family Councils can be a potent voice for seniors in LTC. Families are those with the most investment in residents' well being, and most likely to see issues in care and the facility environment. They need to be empowered to advocate to, and be heard by, the appropriate authorities, and to be informed of investigation results. As noted by the BC Seniors' Advocate, their voices, along with strengthened standards and more effective monitoring, will increase LTC facility accountability for quality care and quality of life for residents.

We support the Vancouver Island Association of Family Councils' proposal that the Ministry of Health develop and adopt regulations and policies that define Family Councils as independent, self-determining,

¹⁶⁴ Appendix B presents indicators/measures for monitoring evidence and expert informed standards, designed to promote and protect residents' quality of life in LTC facilities and to support the recommendations made throughout this document

democratic groups of family members, representatives, or persons of importance to individual residents, who advocate for residents in care and work to advance the quality of their lives.¹⁶⁵

Not every facility has a Family Council given the constant turn over of family as residents die. Although Health Authorities are required by the Ministry of Health to support the development of resident/family councils,¹⁶⁶ not all facilities encourage the development or functioning of Family Councils, and they can be co-opted. All publicly funded facilities should be required at minimum to promote the Family Council to new residents, distribute information for them, provide space to meet, appoint a staff liaison, and establish an on-site process for addressing concerns.

The voice of families would be strengthened by investment in the development of Regional Family Council Facilitators to: develop Family Councils; to represent families where no Family Council exists; and to provide education about rights and advocacy. This requires a direct line to Health Authorities and Licencing to resolve issues not addressed by facility Family Councils.

6. Policy Context for LTC

We recommend that the provincial government

- develop a strategy for the care of seniors in LTC facilities as part of a continuum of care encompassing health promotion through to end-of-life and that recognizes and addresses transitions between various care settings.
- develop a funding model that ends reliance on for-profit corporations.

The Royal Society of Canada¹⁶⁷) notes that

"Improving the quality of life in LTC facilities thus requires change on many fronts and in many jurisdictions. Healthcare policy, improvements in quality measures and monitoring, working conditions for staff, prioritizing financial investments, and broad socio-cultural shifts are among the areas where change is necessary¹⁶⁸."

A provincial strategy is needed to bring coherence to the existing fragmented policy picture for seniors' care in BC, and to consider seniors' quality of life, the work force, funding models, accountability and other over-arching issues.

https://rsc-src.ca/sites/default/files/LTC%20PB%20%2B%20ES_EN.pdf

¹⁶⁵ See Appendix D for full proposal Vancouver Island Association of Family Councils (2020) Proposal for Change - Supporting Residents in Care 2020

¹⁶⁶ BC Home and Community Care Manual policy 6H July 2019, p 35 <u>https://www2.gov.bc.ca/assets/gov/health-safety/home-community-care/accountability/hcc-policy-manual/6_hcc_policy_manual_chapter_6.pdf</u>

¹⁶⁷ Established by the President of the Royal Society of Canada in April 2020, the RSC Task Force on COVID-19 was mandated to provide evidence-informed perspectives on major societal challenges in response to and recovery from COVID-19. The Task Force established a Working Group on Long-Term Care to support policy makers with evidence to inform their decisions.

¹⁶⁸ Royal Society of Canada. Restoring Trust: COVID-19 and the Future of Long-term Care. A Policy Briefing by the Working Group on Long-term Care. June 2020. Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M.

Improving Quality of Life in Long Term Care – A way forward

7. Research - A Pilot Program to Demonstrate Impact of Reforms in LTC

We recommend that the provincial government engage Health Authorities, universities, and other partners in care (e.g., residents, families, seniors, front line and allied staff)

- to review recent successes in specific care facilities in relation to person-centred care and integrating a palliative approach to care, and to articulate potential province wide initiatives.
- to implement a pilot program to evaluate the impact of reforming LTC facilities on residents, their families, and staff.

There are pockets of innovative approaches and practices across BC that can be models for improving residents' care and quality of life, and that provide a foundation for a better LTC system.

We have made recommendations based on the best available evidence and expert opinion. At the same time as the recommendations, standards, and monitoring process described above are initiated, we propose the government implement a phased three year pilot program to demonstrate how the impact of reforming LTC facilities supports resident QOL and a stable workforce.¹⁶⁹

The goal of the pilot program would be:

- To reform care in five publicly owned and five privately owned B.C. LTC facilities over a two year period (two facilities in each health authority.)
- To conduct research, analyze findings, publish, extend the plan throughout B.C., work with resident, family and care provider feedback, and disseminate findings across Canada and internationally.

Conclusion

Funding decisions are political choices that have real consequences on the availability and quality of seniors' health care services. The level of provincial health care spending significantly influences whether there will be improvements in seniors' health.¹⁷⁰

Never has there been more urgency and public support to reform and improve the ways care is provided and quality of life is supported in LTC facilities. The reforms and improvements require boldness, a conviction that residents matter, and a commitment to funding a system that supports not only seniors' health holistically but living their lives to the fullest as well. Implementing the recommendations here will accomplish this and firmly situate BC as a national and international leader in the care of one of the most vulnerable populations in society. The time for change is now.

Let's be leaders in BC, not only on COVID-19 but in responding to the cracks that are now wide open in the long-term care system. Talk to us, talk to families, stop keeping us out of the conversation. We need to work together to make the lives of our residents in care as meaningful and filled with quality as possible.¹⁷¹

¹⁶⁹ See Appendix C for an outline for proposed research

¹⁷⁰ Longhurst A. (2017) Privatization and Declining Access to BC Seniors' Care: An Urgent Call for Policy Change for the Canadian Centre for Policy Alternatives p 5

¹⁷¹ Personal communication - family member

APPENDICES

Appendix A: Methodology for Examining CCALA Regulations and Residential Care Inspection Checklist in relation to Kane's QOL Indicators

QoL Indicators: A=Autonomy/Choice, D=Dignity, FD=Food/Enjoyment, FC=Functional Competence, I=Individuality, MA=Meaningful Activities, PC=Physical Comfort, P=Privacy, R=Relationships, S=Safety/Security/Order, Sp=Spiritual Well-Being, UN=Undetermined purpose for compliance item

Method: The Residential Care Inspection Checklist used in one Health Authority was reviewed using Kane's QoL indicators. The stated purpose of the Residential Care Inspection Checklist is both as a self-monitoring tool for facilities and a set of measures for formal compliance inspections. The Checklist consists of nine categories, with Physical Facility divided into two subcategories. Each of the category sections consist of compliance indicator items. These compliance items are the standard measures used to monitor residential care facilities. For this review, each compliance item was counted as one or more of the QoL indicators, or as undetermined. Very few of the compliance items had an absolute correspondence with a QoL indicator. The use of terms such as "dignity", or "privacy" determined the categorization. Use of the term "activity" within the compliance item checklist resulted in a categorisation under the QoL indicator "Meaningful Activity", however it is notable that "activity" is never qualified as meaningful or otherwise within the Residential Care Inspection Checklist. It is noted in the comments when the "rights" of a person in care were referenced, however this is not linked to QoL within the Residential Care Inspection Checklist. The large majority of the compliance items were included under the QoL indicator of "Safety/Security/Order"; however, it should be noted that these compliance items do not create clear linkages with, "a sense of security about oneself in one's world. A person needs to be able to trust that he or she is living in a benign environment where people are well intended, and where the ordinary ground rules of life are understood", for the person in care. Compliance items could be counted as more than one QoL indicator.

Appendix B: Quality of Life Standards and Indicators

Following are evidence and expert informed standards, with indicators, designed to promote and protect the quality of care and quality of life in LTC facilities and to support the recommendations made throughout this document.

Person-Centred Care

> All residents are treated with respect and dignity.

Indicators:

- gentle physical care and touch observed
- addressing the resident in the way s/he prefers is observed
- no evidence of infantilizing language
- a social history is documented in the care plan
- staff can describe individual residents holistically with physical, emotional, social, and spiritual components

All residents are empowered and supported to be in control of their own life – to have autonomy and make choices,

Indicators:

- food preferences are honoured
- can choose between a bath or shower and when
- requests for alone time/privacy are respected
- resident and/or family participate in care conferences and are given a copy of the care or treatment plan developed
- staff can describe resident's life and treatment goals
- > Each resident is fully supported to live the life that they choose

Indicators:

- engage in activities that are meaningful, give purpose to life, bring joy and those that may involve some risk
- staff can describe activities that are meaningful to a resident

Residents are viewed as a person with strengths and talents.

Indicators:

- limitations are accommodated- letting a resident finish eating slowly, on his or her own, instead of spoon feeding
- staff can explain the concept of strength based and ways they help the resident build on success

> The dining experience is positive

Indicators:

- Residents have a minimum of 30 minutes to eat
- Food is served at the appropriate temperatures and reheated as needed
- Residents are grouped in such a way as to facilitate sociability
- Staff interact with residents

Organizational leaders demonstrate commitment to principles of person-centred care in every aspect of organizational life

Indicators:

- each new resident, family, and staff member is given written information on principles and values of person-centred care
- ongoing education to empower staff and give them practical skills is offered to and attended by staff
- staff are scheduled and the work organized to facilitate relational care
- supportive environments, meaningful activities, fulfilling relationships and respecting cultural diversity are operationalized
- staff can explain how to engage a person in the later stages of dementia when they wander
- staff can explain cultural diversity and how they address it with residents
- Leaders and members of the interdisciplinary team role model the importance of making families feel that they are welcome in the facility

Indicators

- families feel they are viewed as partners in care
- Family Council is supported with space and administrative staff attend on request.

Staffing

Front line/Nursing

> The facility has a system in place to ensure required positions are in place at all times on all shifts without over reliance on casuals

Indicators:

- front line nursing staff levels, as identified by the Health Authority/Ministry of Health standards are filled 24/7 through permanent positions/lines
- operator has a recruitment plan
- interview guide is used to assess suitability
- > All staff, casual and new hires, are oriented to the facility/unit prior to working.

> Front line staff are supported to provide quality care and quality of life

Indicators:

- RN is in the building 24/7
- RN provides clinical leadership and supervises care
- Clinical Nurse Educator is available for consultation and staff continuing education
- staff are scheduled to enable continuity of care and relationship building
- staff have enough time to complete tasks and build relationships
- a primary nursing team model is in place

> A system is in place to support staff's mental health

Indicators:

- staff are provided with critical debriefing when indicated.
- options are made available for individualized choice of mental health support

- There is evidence of an effective ongoing continuing education program Indicators:
 - operator provides in house education and/or pays for outside education
 - staff attend education offered on paid time
 - staff are certified in Building a Strong Foundation for Dementia Care
- Care team communication is supported

Indicators:

- paid time for change of shift communication is in place
- front line staff attends case conferences on paid time

Equipment/Supplies

Enough equipment to carry out care is available to staff

Indicators:

- there are enough commodes/wheelchairs etc./resident on each unit
- staff have enough supplies available to support resident basic needs/hygiene
- a purchasing system is in place that anticipates needs
- staff are free to access supplies as needed for each resident

Allied professions

> Allied profession positions to reach the staffing level standard recommended (.5 hours of direct care per resident per day) are filled and based on resident need

Indicators:

- physical and occupational therapist support the measurable goal of maintaining the physical • independence of residents. Family and volunteers are enabled to assist residents to maintain optimal functioning—walking, eating etc.
- social workers support person-centred care, address emotional and mental health needs of families, and to provide support to care giving staff
- recreation therapists develop and implement an individualized recreation plan for each resident

Nutritional needs/care are addressed

Indicators

- nutrition care plans are developed/assessed by a Registered Dietician
- Registered Dietician gives input into menu development for all diets.
- Registered Dieticians assist in the creation of menu rotations for residents on specialized diets that are nutritionally adequate
- standardized recipes are in place for all menu items and evidence of their use to ensure consistency and high quality nutritious food preparation
- appropriate Meal Day Budget allocations are made that reflect the current cost of a Nutritious Basket of Food/Person/day for the region of residence, indexed for inflation (CPI for food) at least annually
- appropriate resources are available for development and electronic nutrient analysis of menu

Resident's needs for meaningful activity and social connection are met Indicators:

Improving Quality of Life in Long Term Care – A way forward

- every resident has at least one 15 min contact daily with recreation/volunteer or family
- activities are scheduled every evening and on the weekends
- community is engaged and provide activities/programs
- recreation staff can describe activities with residents that are individualized and that address diversity

> Trained volunteers support recreation and other therapies and develop relationships with individual residents.

Indicators:

- a strategy is in place to recruit volunteers
- volunteers are trained and supervised and have access to support/advice when needed

> Resident diversity is recognized and addressed

Indicators:

- each resident has a comprehensive social history completed by a social worker
- diversity is incorporated into staff education/practices cultural safety training
- food choices reflect cultural preferences
- activities reflect diversity
- diverse communities are invited into the facility
- staff can describe various forms of diversity and how they address

Specialized Mental Health Supports

- Residents will receive appropriate supports for the symptoms and signs of mental health conditions, and these will be recognised and recorded in the resident care plan. Indicators:
 - evidence of appropriate charting specific to resident's symptoms and signs of mental health conditions in care plans
 - all staff can demonstrate a familiarity with the *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care.*¹⁷²
- Health professionals, therapists, and care aides will participate in the development of mental wellness plans for residents.

Indicator:

- Evidence of completed plans specific to mental health and well-being for each resident.
- Staff will deepen their knowledge of mental health, Alzheimer's and other dementias, through education and training provided by the care home. Indicators:

¹⁷² Antifeau, E., Ward, C., & British Columbia. Ministry of Health. (2012). Best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care: A person-centred interdisciplinary approach. Victoria, B.C.: Ministry of Health.

- evidence that staff have successfully completed additional and ongoing training specific to dementia, mental health and well-being for the population of older adults living in the residence of their employment
- professional staff are trained in use/scoring of the Mini-Mental State Exam (MMSE), Montreal Cognitive Assessment (MoCA) and the Geriatric Depression Scale
- mental health and well-being plans are updated annually and as necessary
- Staff will be supported to work one-on-one with residents in an ongoing process, to aid in the identification of resident's needs regarding mental well-being.

Indicator:

- staff will contribute to the mental health and well-being plan in a manner that demonstrates knowledge of the individual residents
- Staff will have the knowledge and training to identify triggers and implement the appropriate support and non-punitive solutions focused on the mental well-being of residents. Indicator:
 - staff will have been trained in the Behavioural and Psychological Symptoms of Dementia, (BPSD) algorithm
 - written documentation in reports will be professional and not contain opinions or value statements from staff
 - the public (visitors) or family will not report evidence of inappropriate responses to resident behaviour from staff
- Communication with and about resident's, their behaviours or mental wellness will not be reductionist and will maintain the individual's dignity and right to confidentiality. Indicator:
 - staff will not be heard speaking with or about residents in a manner that reduces their identity or sense of self.
- Access to external mental health supports will be provided to residents when the appropriate mental health professionals are not available within the care home. Indicator:
 - where it is determined by health professionals attending residents that specific mental health support is not available within the care home, professional support such as the Seniors Outreach Team (SORT) will be made accessible.

Specialized Palliative Care

- Residents will receive appropriate palliative care. Indicator:
 - evidence that staff have training in principles of palliative care
 - staff can explain the principles of palliative care and how they provide it
- Health professionals, therapists, and personal support workers will participate in the development of palliative care plans for residents.

Indicator:

• evidence of completed plans specific to palliative care needs of the individual resident.

- > Emotional and grief support will be made available to residents, families and staff Indicator:
 - evidence that staff are trained to, and expected to, acknowledge and respond to residents' families' and colleagues' grieving
 - emotional support is offered to residents and families proactively
 - options are made available to staff for individualized choice of support
- > Access to external palliative care expertise will be provided to residents when the staff do not have the appropriate skills within the care home.

Indicator:

where it is determined by health professionals attending residents that sufficient palliative care • expertise is not available within the care home, consultants will be made accessible.

Appendix C: A Pilot Program to Demonstrate Impact of Reforms in LTC

To address the need for immediate improvement in LTC we have made recommendations based on the best available evidence and on expert opinion. At the same time as the recommendations, standards and monitoring process described above are initiated, we propose the government implement a phased, three year pilot program to demonstrate how the impact of reforming LTC facilities supports resident QOL and a stable workforce.

The goal of the pilot program would be to:

- Reform care in five publicly owned and five privately owned B.C. LTC facilities over a two year period (two facilities in each health authority.)
- Conduct research, analyze findings, publish, extend plan throughout B.C., and disseminate findings across Canada and internationally.

The project plan would include:

- Goals and objectives, roles and responsibilities, communications, deliverables, resources, evaluation, research/publication/dissemination parameters.
- Establishment of an interagency communication system to facilitate facility result- sharing, joint problem solving, etc.
- A long-term plan for best practice sustainability and funding for project expansion throughout rest of B.C.
- Plan for choosing the pilot facilities:
 - Ask for facility interest. Facilities requesting consideration would be able to demonstrate efforts over time to offer person-centred care, have adequate compliance with existing standards in past, have committed leaders and managers and be able to show evidence of staff engagement in the process.
 - \circ Project team to choose one publicly and one privately owned facility from each health authority to participate (N = 10).

The Project Team to implement the project would include:

- A project management team/coalition led by a contracted consultation group including project manager, clinical lead, and five on-site culture change consultants, one for each community, to supervise and coordinate the contributions of all project partners.
- A data/metrics manager to track and document progress/ changes and inform planning, provided by a Health Authority
- One Health Authority to provide a full time Clinical Nurse Specialist (Ph.D. required) to supervise adoption and implementation of best practice guidelines aimed to optimize care of physical, emotional and spiritual needs.
- A health sciences principal investigator who would lead the research team and engage graduate level research students, provided by a University
- Allocated time from the office of the Seniors Advocate to support residents and families and monitor response.

Appendix D: Statements

- Considering A Moral Compass for Long-term Care (LTC): Dr Patricia Rodney, Dr. MaryLou Harrigan, and Dr. Peter McKnight
- Data Collection and Interpretation in LTC Facilities—Issues with the RAI-MDS 2.0

The Importance of Registered Dieticians in LTC. Shauna Prouten, RD, IFNCP

- Ensuring the psychosocial health and human rights of long-term-care residents and their families: A social work perspective by Dr. Shari Brotman, Dr. Louise Stern, Dr. Ilyan Ferrer and Dr. Wendy Hulko (Authors of Gerontological Social Work in Action: Anti-Oppressive Practice with Older Adults, their Families, and Communities. Routledge.
- Proposal for Change Supporting Residents in Care. Vancouver Island Association of Family Councils (2020).

Considering A Moral Compass for Long-term Care (LTC)

Dr Patricia Rodney, Dr. MaryLou Harrigan and Dr. Peter McKnight

"It's COVID that unearthed these problems and brought them to the forefront, but these had been problems that we knew existed for a long time."¹

LTC Crisis

"The COVID-19 pandemic shone a light on the significant gaps in the long-term care (LTC) system as never before. COVID-19 has precipitated, in the worst circumstances, high levels of physical, mental and emotional suffering for our older adults. Those unnecessarily lost lives had value. Those older adults deserved a good closing phase of their lives and a good death. We failed them. We broke the covenant."²

The document "Improving Quality of Life in LTC – A Way Forward" (2020), led by Action for Reform of Residential Care (a British Columbia citizen's group made up of families, clinicians, seniors and researchers concerned about seniors' care and quality of life in LTC) demonstrates that we have both the ability and the responsibility to fix this crisis in LTC. But any remedy must be grounded in and guided by an ethical framework.

A Moral Compass to Lead System Change

An ethical framing gives us normative direction regarding the 'oughts' of health care delivery. More specifically, an ethical framing helps us to analyze what *is* happening in health care delivery, what *ought* to happen, and *how* to navigate the difference in health care practice and policy. We see the ethically-based framing in the document *"Improving Quality of Life in LTC – A Way Forward"* as promoting a *moral compass* for complex and value-laden practice and policy questions arising for individual patients and family members; population groups (such as older adults); health care providers from diverse caregiving/professional backgrounds; and health care leaders.

A moral compass can assist us to work toward the development of ethically sound policy, including the establishment of clear values and standards by which to judge policies and performance and evaluate proposed reforms for delivery of care. Accountability is central, and related policy ought to be grounded in clear and consistent values, with a visible interplay among the various levels of health care policy-making.³ This in turn can shape particular policies and guidelines at the individual level of care.⁴ Clear ethical standards are needed for LTC, and "the direction of our health care system must be shaped around health needs of individual patients, their families, and communities."⁵

Indeed, "our policy decisions are moral decisions. They are issues of care and responsible citizenship."⁶. Present day societal views ultimately influence public policy. For example, ageism promotes societal stereotypes and myths equated with powerlessness, linked to assumptions about disease, disability or uselessness.⁷ Quality of life judgements may unfairly disadvantage older adults.⁸. To safeguard older adults including those with dementia the "connecting, synthesizing link is the morality of civic equality."⁹ Decision makers need an ethical framework to guide decisions made at provincial health authority levels in relation to policies, resource allocation, and access to services/support for seniors in LTC.

The "principlist" approach to clinical ethics emphasizes the application of specific ethical principles, notably autonomy, beneficence, non-maleficence and justice, to clinical situations. Although this approach had its origins in the aftermath of the Second World War, medical paternalism still sometimes compromises the principles, and in particular infringes the principle of autonomy.

The *patient*-centred approach arose in reaction to medical paternalism. In contrast to the paternalistic model, which places power and control in the hands of the health care provider, the patient-centred model relocates control of the care setting to the patient.¹⁰ Health care services and interactions are designed to meet the needs and values of the patient rather than dictated by the health care provider.

Similar to the patient-centred model, the *person*-centred approach emphasizes the importance of patient dignity and autonomy in the care setting. However, the person-centred approach focuses on the relationship between resident, family and provider, on mutuality in the care setting.¹¹ This relational outlook serves to recognize and respect the needs and values of both resident and provider, thereby producing an ethically sound foundation for practice and policy.

The concepts of relational autonomy, relational social justice and relational solidarity can ... "help to reclaim and centre the common and collective good at risk in pandemic and other emergency situations. require a policymaking process that is truly transparent, fair and inclusive; is sensitive and responsive to the workings of systemic inequalities; and requires public recognition of the fact that we enter any crisis with varying degrees of inequity."¹² Core concepts of person- and family-centred and relational care respect dignity (e.g., values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care), information sharing, participation and collaboration." ^{13 14}

Setting the Compass to Needed System Change: Staffing, Knowledge and Resources

Health care providers have a *duty to care*, and have "the knowledge and the resources to take immediate steps toward restoring the trust [that has been] broken."¹⁵ The desired outcome in British Columbia and beyond is a LTC system that is adequately funded and staffed to implement person centred and relational care by a stable and well-supported staff. Yet health care providers face the challenge of "negotiating between the tension by competing perspectives of 'the good' in general situations and applying these in particular moments of practice with particular person."¹⁶ This tension has greatly increased in the current pandemic, and has generated significant stress for health care providers as well as health care leaders and health care policy makers. At the same time, there is increasing empirical evidence that challenges such as inadequate staffing, inter or intra-professional conflict, and moral distress can adversely affect the quality and safety of health care delivery. Such challenges are exacerbated in the context of COVID-19 and deplete health care delivery as well as the health care workforce overall.

An important consideration for the development and implementation of a moral compass for health care delivery is therefore that the well-being of health care providers is linked to the well-being of those whom they serve--at individual, organizational and larger health care systems levels.¹⁷ While the focus on individual through to population well-being is paramount in health care delivery.¹⁸ This focus depends on inter-professional health care team members who are well prepared, well deployed, and well supported. Robust programs of support for health care providers are therefore essential during (and after) the pandemic. Support programs ought to be planned under the guidance of professional associations/groups. And participatory engagement of all health care provider groups at all levels of health care delivery in the planning and evaluation of such programs is essential.¹⁹

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RAI-MDS 2.0 – Documentation in LTC

RAI-MDS 2.0 (Resident Assessment Instrument-Minimum Data Set) is a tool used for applying standardized assessments within Long-term Care. It is also used for facilitating care management within our complex care communities by assisting the care providers to develop and individualize residents' care plans based on the assessment of the resident's strengths, limitations, and their personal preferences.

When RAI-MDS 2.0 was mandated in the province of British Columbia in 2009, along with it came funding to support RAI Coordinators. Those positions were integral to ensuring that the data collected and submitted to CIHI (Canadian Institute for Health Information) was valid and submitted in a timely manner. This position also ensured that regular auditing of the data submitted was not only consistently assessed and documented, but also accurately inputted by the nurse entering it. The information was then used to identify quality care gaps and education and support could be highlighted in those clinical areas identified. When trends in quality indicators are analyzed at all levels of care governance (organizational level, health authority level , and provincial level) they help to identify and promote organizations/health authorities that have positive outcomes, that if shared; could positively impact and improve the delivery of complex care across the country.

Unfortunately, for many organizations those positions have gone by the wayside as the rate of staff turnover/shortages continues to be staggering. And for those organizations that still have RAI coordinators, those nurses are often pulled from this important work to support the understaffed/care requirements on the floor.

Another compounding factor is that RAI-MDS is not adequately embedded into the curriculum in all health programs (RN, LPN, HCA). As a result, we are relying on nurses that are currently doing the work from the corner of their desks, (and often coding incorrectly) to train the new. By not building a strong foundation for these students in their training we have lost the 'bigger gains' of consolidating the whole clinical picture. It is here where the true 'buy-in' could take place.

Unfortunately for many staff, the meaning and purpose of the RAI has been lost in translation. Without a true understanding of its benefits, coupled with the lack of trust in the accuracy of the data submitted (staff have shared that during the 7 day observation period that colleagues either untrained/uncertain often copy information from the shift previous thus impacting its validity), many go through the motions of manually submitting data into the software 'as a means to an end'. Thought as 'just another task that must be accomplished' rather than an opportunity to forecast changes in care requirements and significantly impact the outcome of resident care in the most positive way.

Organizations would benefit from hiring RAI consultants that are not their employees. The cost (financially) of the monthly maintenance of such a contract would be far less in the long-term when factoring in providing benefits (vacation/sick time) and ongoing training; especially when dealing with the constant turn over of staff. As well there is no risk of pulling employee to work in a short-staffed environment, therefore the continuity of service is ensured. Having an external body auditing for trends and validating coding practices also ensures that organizations cannot 'massage the data' for their own purpose.

There are a few provinces in Canada that have RAI-MDS outcomes attached to their funding. Although suggested that this would be the outcome here one day, this has not yet come to fruition. So we are left to conclude that the reason that it isn't, is because the government doesn't want to be held accountable to the dollars that would be necessary to ensure the quality of care required based on those assessments (case mix index/RUG) be granted. This would likely explain why 'buy-in' for RAI-MDS has not happened for most staff because 'the what's in it for me' adage is not appeased by improved funding to enhance staff to meet increased care levels.

The Importance of Registered Dieticians in LTC

Shauna Prouten RD, IFNCP

In LTC, Registered Dietitians are the allied health professionals with the appropriate education and skills to assess residents' nutritional status, identify nutritional deficiencies and imbalances that may be contributing to a resident's wellbeing, health status and level of functioning. Dietitians in LTC are responsible to perform nutrition assessments utilizing several tools including Nutrition Focused Physical Assessments which provide practitioners with a wealth of information about potential deficiencies and existing gaps in meeting residents nutrition needs. They are present in the dining rooms at meals offering oversight of dining rooms at meal times – to troubleshoot/problem solve any issues residents are having with meals and to provide solutions and modify residents nutrition care plans and diets to ensure residents nutrition needs are being met. Many Dietitians are trained in dysphagia (swallowing) assessment as well as the use of texture-modified diets. Dietitians are knowledgeable about therapeutic diets and should be the professionals involved in creating appropriate diet rotations to meet the needs of residents with specialized needs outside of the General/regular menu. For example, residents with food intolerances, allergies such as gluten intolerance, dairy or wheat allergies or even those who follow vegetarian diets – all should have access to a variety of food with a broad spectrum of nutrients to ensure nutritional adequacy. Without a menu rotation and standardized recipes, this is not likely to be achieved as most cooks do not have the training or the time they rely on basic choices and the diets for these individuals becomes repetitive and monotonous. Dietitians provide training/education to staff – direct care and support services staff to ensure they understand the importance of the various diet interventions that are recommended. Dietitians work closely with residents, families, substitute decision makers and nursing staff, physicians and other allied health professionals to ensure that care plans are resident centered and effective. Dietitians are trained to prescribe enteral (tube feeds) and nutrition supplements and are monitored in the practice of restricted activities – they are often relied on by facilities to assist in accessing appropriate tube feed formulas and equipment. Dietitians are knowledgeable about potential drug nutrient interactions and depletions and work collaboratively to mitigate residents' nutritional risk in the face of polypharmacy use. Nutrition is a major factor in the presence and duration of wounds - as such Dietitians are a valued team member for collaborative wound management care plans. Dietitians are responsible to monitor the facilities where they work using the Audits and More tools that require the completion of audits for food quality/presentation, dining environment, nourishment delivery, hydration audits, as well as the monitoring of nutritional adequacy of menus, menu substitutions etc. and communicating gaps and collaborating with facility staff to resolve problems. Currently there is nothing in the residential care act that identifies facilities must employ Registered Dietitians or how many hours they must be employed/contracted for per resident/month.

Ensuring the psychosocial health and human rights of long-term-care residents and their families: A social work perspective by Dr. Shari Brotman, Dr. Louise Stern, Dr. Ilyan Ferrer and Dr. Wendy Hulko (Authors of Gerontological Social Work in Action: Anti-Oppressive Practice with. Older Adults, their Families, and Communities. Routledge.)

It has become evident over the past few months that there are significant problems in Canada's long-term-care system. Disturbing stories of understaffing and neglect have become commonplace in daily media reports on the COVID-19 pandemic. Attention is now being placed on addressing some of the most pressing problems faced by long-term care residents, their families and the staff working within them. These include safeguarding health and safety to reduce the risk of further outbreaks of COVID-19, improving wages and working conditions, and ensuring that families will never again be barred from visiting loved ones. But as we scrambled to guarantee that residents are taken care of at the most basic level, we have yet to face the ongoing and significant neglect of their psychosocial (mental) health and well-being.

The COVID-19 pandemic has revealed a longstanding problem - we have been neglecting the needs of our older residents for decades – and ageism is the cause. Our long-term-care system through its funding mechanisms, policies and practices has, to date, focused almost exclusively on 'body care'. That is, government funding and regulation has prioritized the bodily care of older residents with an almost total neglect of the need to ensure the availability of specialized support for their psychological, emotional, relational, cultural and social well-being. While doing their best, personal support workers and nurses on the front line of body care, have been burdened by large caseloads of residents with ever increasing acuity and mental and physical care needs. Mental health challenges and issues are often dealt with through the use of medications – rather than complemented by holistic, non-medical supports and care. These strict timelines, large and demanding caseloads leave little room to understand how to better engage in quality conversation, learn about residents' life histories and realize people's values, ideas, wants and interests in the context of body care. While frontline care staff may have been formally educated as to the psycho-social and spiritual needs of older residents, they are not afforded time or direction as to how to integrate it into their work, especially in the context of a pandemic.

The long-term care system has come to rely almost exclusively on family members to fill this significant gap in psycho-social care. So, when families were blocked from entering long-term-care-homes at the start of the pandemic, it was no surprise that, not only did the physical health of residents rapidly decline, disturbingly so did their emotional and psychological health. The central role of families in providing for the psycho-social needs of residents is a necessity borne out of austerity and governmentality which has resulted in the denial of residents to ongoing and daily access to psychosocial supports and mental health professionals, including and most notably social workers. This means that, even in the best of times when there is no pandemic to contend with, social workers if they are present in long-term care, are only able to fill a limited role almost exclusively focused on transition planning and crisis management.

Social workers are well-educated and best-placed to attend to the psycho-social well-being of residents and their families, the diversity of their experiences and identities, and as a complement to the provision of physical and body care by front-line care staff. These include:

- personal, relational, educational and advocacy roles, such as those related to ensuring all staff are aware of the perspectives, needs and values of individuals and their families,
- engaging in family counselling and support,
- organizing and supporting family and resident councils

- assessing the psychosocial needs of residents through the transition to their residency and as their needs evolve, and;
- advocating for institutional and systemic change.

Social workers are trained to recognize and honour individual and collective identity across the life course, give voice to vulnerable and marginalized people, advocate for inclusion and belonging and to advance the human rights and citizenship of residents as daily practice. Given the funding limitations and lack of prioritizing of social work in long-term care and the absence of the voice of social workers at the policy decision-making table, it is no wonder that the mental health of residents and their families took a drastic turn for the worse during the COVID-19 pandemic and that responses to improve the situation have focused almost exclusively on body care.

Currently, there is limited and variable policy, legislative and licensing requirements in Canada, for psycho-social supports in long-term care facilities; and these are often focused on and interpreted as social-recreational needs only. Governments must provide adequate funding to ensure that every long-term-care home has the necessary mental health support staff to safeguard the human rights and dignity of all residents and their families. This can be partly accomplished by setting reasonable caseloads and ensuring full-time work for social workers. Only then will social workers be able to do their job in a way which reflects their professional values and ethical standards and ensure that every resident is acknowledged as an individual with a history, family, community, values, beliefs, desires and needs and that they have access to the support, relationships and activities, beyond those related to their functional capacity, that bring meaning to life. This is a fundamental human right.



January 2015 Updated June 2020

Proposal for Change - Supporting Residents in Care

Vancouver Island Association of Family Councils

The Vancouver Island Association of Family Councils (VIAFC) is a network of individual Family Councils from residential care facilities throughout the Island Health Authority area. Our goal is to "enhance the quality of life of residents and to provide a voice in decisions within the facilities that affect them." (BC Guidelines for the Development of Resident or Family Councils). Please see Addendum 1 for more information about our specific goals.

VIAFC is fortunate to enjoy a very healthy, productive relationship with Island Health, culminating most recently in the joint creation of the "Resident/Family Council, or Family Support Group Guide". We appreciate their efforts to provide a platform for Family Councils to continue to advocate for those in care.

At the 2014 VIAFC Annual General Meeting, we worked to identify concerns that were shared by our general membership. Two significant and consistent concerns were identified as roadblocks to our efforts:

- Marginalization of Family Councils, and
- Staffing instability

This document addresses concerns about Family Council operation and provides specific recommendations for change.

Background

Family Council Operation

Many Family Councils are welcomed by facility management, resulting in partnerships that work hard to enhance the quality of life for residents. In these facilities, residents are benefitting from the willingness of patient-focused managers to listen and provide a voice to their independent Family Councils.

Vancouver Island Association of Family Councils C/O 6872 Harwood Drive, Lantzville BC VOR 2HO Phone: 250-390-2311; Cell: 250-616-3054 Email: kcslater@shaw.ca Unfortunately, some facilities still refuse to support or even recognize independent, selfdetermining Family Councils. Some managers will not speak to representatives of Family Councils who are trying to exercise a collective voice. Some managers refuse to permit organized Family Councils to meet on site. Some managers instruct their staffs not to speak to friends or family members who have been identified as Family Council members. Instead, some managers will have management-led information sessions with only a few family members and call that their "Family Council", while dismantling a much larger, selfdetermining Family Council that has followed Ministry of Health and Island Health Guidelines, and is trying to operate independently and in good faith.

Family Council Membership

Another significant problem faced by Family Councils is sustaining membership. Supportive facilities are now using the intake process to seek permission from families new to a facility to share family contact information with existing Family Councils. In those situations, Family Councils can advertise when they have guest speakers or events that might be of interest to new families, friends or representatives of residents. By being able to connect directly with these contacts, family councils can sustain or expand membership numbers. In those settings, family council meetings and projects are well attended, despite the relentless turnover caused by deaths or relocations of residents.

Unfortunately, other facilities refuse to advertise anything for Family Councils. They will not direct potential new members toward the Family Council and will not help with announcements about events such as council-arranged guest speakers. Those guest speakers typically range from the Alzheimer's Society, to recreation consultants, to experts on best practices within long-term care, to experts on legal documents such as Representation Agreements, and so on. Families new to residential care also lose the advantage of having Family Councils guide them through the enormous learning curve that accompanies entry into residential care. Lack of management support usually results in diminishing numbers within the Family Council, and certainly limits learning opportunities and support for friends and family who are new to the facility – all at a cost to residents in care.

Conclusions

Some facility managers choose to refuse to provide support and a voice to Family Councils by ignoring Ministry of Health Guidelines that suggest that a Family Council "is a group consisting of persons in care and/or their representatives, family members and contact persons." Other managers also choose to ignore Island Health's Guidelines that state that a Family Council is "self-led, self-determined, and democratic." This is possible because guidelines are not binding, and actual regulations or policies coming from the Ministry of Health do not require residential care facilities to acknowledge, support, or work with independent Family Councils.

Recommendations

We request that the Ministry of Health develop and adopt regulations and policies that entrench opportunities for Family Councils in all residential care facilities within British Columbia, and require all public and private facilities to cooperate with and assist Family Councils.

Regulations and policies should achieve the following:

- I. Family Councils be defined in regulations as independent, self-determining, democratic groups of family members, or representatives, or persons of importance to individual residents, who advocate for residents in care and work to advance the quality of their lives.
- II. Family Councils have the ability to:
 - i. provide assistance, education, information to residents and their families, representatives, and/or persons of importance to residents;
 - inform residents, their families, representatives and/or persons of importance to residents about their rights and entitlements under The Seniors Bill of Rights, Residential Care Regulations, the Hospital Act, and the Home and Community Care Policy Manual;
 - iii. inform the facility of any concerns or recommendations that the Family Council might have, and request the facility to respond to those concerns or recommendations within a reasonable time frame; and
 - iv. obtain detailed information with regard to "allowable fees" being charged within a residential care facility.
- III. Residential care facilities be required to:
 - i. provide a mutually agreed upon staff liaison who will attend Family Council meetings when requested;
 - ii. provide a meeting space for the Family Council if requested;
 - iii. permit and support the operation of the Family Council;
 - inform every new resident and their family member, representative, or person of importance to the resident, of Residential Care Regulations or the Hospital Act, and the Home and Community Policy Manual;
 - v. establish an on-site process for responding to complaints;
 - vi. provide every new family member, representative and/or person of importance to the resident with contact and operational information about the Family

Council, and also to seek to share (with permission) their contact information with the Family Council;

- vii. inform resident's family, representative and/or person of importance to the resident of the importance of the establishment of the Family Council; and
- viii. appoint a facilitator to help start and operate a Family Council in the event that family members, representatives or persons of importance to residents are experiencing difficulty in the process. The facilitator must have the intention of stepping out of the leadership role as soon as leadership can be found within the Family Council membership. While the facilitator is acting in a leadership role, family members must be granted the opportunity in every meeting to discuss issues without the attendance of the facilitator.
- IV. Ministry of Health be required to:
 - provide assistance for the establishment of Regional Associations of Family Councils in every Health Authority, including arms-length funding for such things as websites and annual general meetings of Regional Associations;
 - ii. ensure consistency in any/all publications from the Ministry of Health, other related Ministries, and Health Authorities with regard to rights, expectations, guidelines and operating procedures as they relate to Family Councils.



VIAFC Addendum

What is a Family Council?

A Family Council is a self-determining, democratic body composed of friends, family members, or other persons of importance to residents in residential care.

A successful Family Council will:

- Provide a way for all its members to share ideas and experiences with each other...
- Provide its members with educational experiences...
- Establish effective lines of communication between all stake-holders ...
- Have regular meetings that can provide a forum for safe, productive discussion, and help participants to identify strengths that they want to protect in a facility, as well as issues that are a concern to many family members...
- Offer suggestions to management on matters related to delivery of quality care for seniors...
- Provide input to processes such as accreditation...
- Work on projects that will benefit seniors...
- Link with Family Councils in other facilities to identify and address concerns that are systemic between facilities, communities, or Health Authorities.

(excerpt from VIAFC website, 2014)





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The Call for Mandated Social Work Positions in Long-Term Care and Assisted Living

January 2021 Update to the Summary of the Brief presented to Minister of Health, Hon. Adrian Dix in 2019

The Seniors Community of Practice, under the auspices of the British Columbia Association of Social Workers, submitted a Brief to the Minister of Health in 2019 entitled: The Call for Mandated Social Work Positions in Long-Term Care and Assisted Living (BCASW S CoP, 2019). The following Brief outlines the need for more professional social workers to be included in Long Term Care due to their expertise in working with families and advocating for vulnerable seniors. The current Covid-19 crisis has demonstrated just how vulnerable seniors are in long term care. Social workers are educated and trained to work with, and advocate for, older adults and their families. The erosion of not including or minimizing the role of social workers as part of a multidisciplinary team in Long Term Care contributes to the potential for institutional neglect that has been demonstrated, especially in times of pandemics. In addition to holding core values of respecting human rights and focusing on respect and dignity and self-determination of all clients, social workers are committed to the role of advocacy. While we respect the roles of other professionals and workers within these settings, social workers have a unique and essential role working with older adults, especially those who are vulnerable. Internationally, this pandemic has highlighted the essential role of social workers in fostering the resiliency needed within communities to protect the most vulnerable (Truell, Compton, 2020). In addition, social workers are committed to promote social change to enhance, not only the lives of residents and their families (if they have family), but to advocate for systemic change at the organizational level, including change of social policies (BCASW Seniors Community of Practice active members, 2019).

As Health Authorities take a "home is best" approach (British Columbia Ministry of Health, 2013), people are moving to Assisted Living and Long-Term Care with more complex health care needs than in the past. Family caregivers are experiencing higher levels of distress (Office of the Seniors Advocate, 2017a). With the proposed changes to the Community Care and Assisted Living Act in Bill 16 support services offered in Assisted Living will evolve and grow. To meet these changing needs, social workers are ideally positioned to be integral members of interdisciplinary teams at both Assisted Living residences and Long-Term Care homes. Resources to fund mandated social work positions would benefit residents, families, and care teams in Assisted Living and Long-Term Care (formerly known as Residential Care).

Current Situation

Social work is not a mandated service in Assisted Living or Long-term Care. Generally, individuals in Assisted Living have limited ready access to a social worker unless their Health Authority Liaison happens to be one. Some Long-Term Care sites have a social worker; some do not

(British Columbia Law Institute, 2019). When there is a social worker, often the ratio of hours to the number of residents is large. One social worker can be responsible for service to well over 100 residents (Munn & Adorno, 2008; Rockwell, 2012). To better understand the gaps and varying availability of social work services to residents and their families in Assisted Living and Long-Term Care, the BCASW Seniors Community of Practice sought out provincial data on the number of social work positions in BC. To date, we have been unable to secure any provincial data.

The British Columbia Ministry of Health (2019a) notes that, "long-term care services include: (...) clinical support services (e.g. rehabilitation and social work services) as identified in the care plan." Long-term care sites also provide "end-of-life and palliative care services" as outlined by the British Columbia Ministry of Health (2019b) that include "psychological care" and "loss and grief support for family caregivers." Considering these important aspects of long-term care services, it is critical to ensure sufficient and appropriate social work services are available to all individuals in Long-Term Care across our province.

Changing Landscape in Assisted Living and Residential Care

With the introduction of Bill 16 (2016), Assisted Living sites will be encouraged to offer more services to meet increased health, care, financial, and psychosocial needs of residents. People are entering Long-Term Care with complex and life-limiting health conditions, including dementia. Many Health Authorities and Long-Term Care homes are moving towards *a palliative approach to care* (Bacon, 2012; Pallium Canada, 2018; Webley & Edmunds, 2015), which is more holistic for residents and families, emphasizing quality of life and comfort.

A palliative approach to care focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of frailty or chronic illness, not just at the end of life. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It supports and encourages earlier and more frequent conversations about the goals of care when patients and families are faced with a life-threatening illness. (Canadian Hospice Palliative Care Association, 2016)

Social Workers Unique Perspective and Knowledge

Social workers have a unique multi-faceted skill-set and bring an important psychosocial lens to an interdisciplinary care team (Jackson, 2014; Sanders, Bern-Klug, Specht, Mobily, & Bossen, 2012). Person-centred care is a primary goal in Assisted Living and Long-Term Care. It is also at the core of social work values. Social workers encourage the care team to go beyond the medical model and basic care needs to see the whole individual including history and current psychosocial needs (Sanders et al., 2012). Social workers advocate when a resident may not be able to advocate for themselves. Social workers work to eliminate systemic and cultural barriers that individuals may face when they identify, for example, as Indigenous, LGBTQ, minority culture, or as having language barriers.

Moving to an Assisted Living residence or Long-Term Care home can be traumatic for both resident and family. Social workers ease this transition with information and education as well as practical and emotional support. Building trust with the care team is key to positive outcomes for a resident and their family. Having a social worker as the first point of contact facilitates this relationship from the beginning. All Long-Term Care and Assisted Living sites would benefit from

having social workers to provide additional support to residents and families during initial stages (Fields et al., 2012; Jackson, 2014; Malench, 2004; Sussman & Dupuis, 2014).

Family support improves quality of life (Leedahl, Sellon, & Chapin, 2018; Malench, 2004). Social workers versed in family dynamics and family systems strengthen ties between the care team and a resident and their family. Social workers provide support to address challenges, including those related to living in Long-Term Care, caregiving, grief and loss. Social workers offer practical support and information on accessing government benefits and community resources. In regard to healthcare decision making, "social workers play a positive role in supporting families to understand their rights and responsibilities" (British Columbia Law Institute, 2019, p. 226). Often, social workers are the liaison for Family Councils in Long-Term Care (Community Care and Assisted Living Act: Residential Care Regulation, 2009). Family Councils can enhance a family member's experience and connection with a Long-Term Care site, through education, peer support, and community-building opportunities (Baumbusch, Reid, & Koehn, 2017; D'Souza, 2017).

Social workers take a lead role in advocating for, and protecting, the rights of vulnerable residents. Financial abuse is more common than one would like to believe (Seniors First BC, 2019). With understanding of adult guardianship legislation, social workers try to intervene earlier to help prevent financial abuse. Social workers offer support and information about personal planning, adult guardianship, pension management programs, and make timely referrals to local agencies. Social workers are a vital support to residents who do not have family or friends to assist them. They are a key liaison for enhancing quality of life when a resident's financial and/or personal affairs are managed by a third party.

Social workers bring strong communication skills to complex and challenging situations. They are well poised to take a lead with the "palliative approach to care," initiating conversations with residents and their families about personal planning, quality of life and end-of-life wishes. Social workers often assist care teams to work through ethical issues prevalent in Assisted Living and Long-Term Care sites such as intimacy, living at risk, and treatment options. According to a recent report by the British Columbia Law Institute (2019), "social workers across the region are supporting health care staff and physicians to better understand and apply health care consent law" (p. 222).

With their unique skill-set, social workers take a leadership role within an interdisciplinary care team, mentoring and modelling skills in communication, conflict-resolution, and personcentred care. Many social workers facilitate workshops for colleagues on topics such as ethical issues in practice, personal planning, and mental and emotional wellness. Social workers are ideally skilled to address the Office of the Seniors Advocate's (2017b) recommendation, following the Residential Care Survey for "ongoing education for all care staff on the importance of resident emotional well-being" (p. 46). Social workers have a comprehensive vision and critical lens with a focus on social justice and the individual. Knowledge of legal and practicebased issues allows them to contribute to the development of policy and procedures in Assisted Living and Long-Term Care sites.

What is Needed?

Social workers and their unique contribution to care are vital to the quality of life of residents in Assisted Living and Long-Term Care. The social work role needs to be more widely recognized and valued by management and the interdisciplinary team. Social workers need to figure prominently as integral clinical support team members and sufficient resources need to be allocated specifically for this role. A Canadian Association of Social Workers report (2002) states, "in order to provide adequate core services a (Long-Term Care) facility requires one full-time equivalent (FTE) clinically assigned social worker for every 60-70 residents." This ratio would allow social workers to do effective and meaningful work. We believe that all Assisted Living sites should have a social worker available on a minimum regular part-time basis. Residents in Assisted Living and Long-Term Care have a right to holistic care from skilled professionals who offer psychosocial support, advocacy, and referrals to community agencies. Mandating sites to have a social worker to provide clinical support services will enhance holistic care and quality of life for adults in both Assisted Living and Long-Term Care.

References and complete brief found on BCASW website, Seniors Community of Practice.

www.bcasw.org