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)

http://arrcbc.ca/

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Suggested Citation: MacCourt P, Amdam L, Clarke L, Prouten S (2020) Improving Quality of Life in Long-Term Care-A Way Forward. Prepared for Action for Reform of Residential Care. http://arrcbc.ca/

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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 and meaning but almost half of all residents in 2018/19 had a low sense of social engagement. Recreation

[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

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 bidder[3], 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.

We recommend that the Minister of Health strike a diverse inclusive multi-sectoral and multi- stakeholder Task Force to develop a post-COVID provincial action plan, building

[3] Key informant interview: operator of 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 health authority director

on the following ARRC recommendations, that would support (1) a paradigm shift from the current institutional model of long-term care to a more humane person-centred relational model that supports residents' quality of life and human rights, (2) a quality work environment, (3) a mandated voice for families (4) increased transparency and accountability for resident care and for public funds.

We recommend that the planning process followed by the multi stakeholder Task Force be collaborative, be tailored to the challenges of senior care, and be inclusive of the interests of all stakeholders in the senior care system.

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 standard 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 minimum standard .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
    - Speech-Language Pathologists (SLPs) hours for the assessment and management of communication and swallowing disorders (dysphagia).
    - 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 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 consider 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.

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

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]

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

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

- support the best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care[8] 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.

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

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

9 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

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

- 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.

Conclusion

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.[11]

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 adequately 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.

[11] 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.

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) facilities[12].

- 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.[13]

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. Our[14] 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

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

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

14 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.

processes 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 Considerations[15]

"Our policy decisions are moral decisions. They are issues of care and responsible citizenship".[16]

"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".[17]

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".[18]

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

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15 For full discussion see Appendix D *Considering A Moral Compass for LTC*

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

17 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.

18 Levitt, D. (2020), Pandemic exposes need to revamp seniors care. *Vancouver Sun.* Published September 8, 2020, p. A9. Retrieved September 9, 2020 from https://vancouversun.com/opinion/op-ed/dan-levitt-it-is-time-to-transform-agedcare/wcm/0197d0cc-7819-40f7-bd0e-28d9e7b2b67a/.

- Quality of care is linked to quality working conditions for care providers
- 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".[19] 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 socio-cultural 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

19 https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/premier-cabinet-mlas/minister-letter/dix-mandate.pdf

systemic/structural factors that continue to keep us from moving forward to support residents, their families and care providers. 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.[20]

> *I am a nurse in Long-term Care and will fight like hell to keep my parents out of this situation*[21]

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*.[22]

The systemic cracks that contributed to the pandemic's course in LTC facilities were there before COVID-19 and will remain.[23] 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

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20 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

21 Personal communication – family member

22 Personal communication – BC senior citizen

23 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.

seniors' organizations, by professional organizations/associations, by relevant work force unions, by the BC 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.[24]
- 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".[25]
- 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.[26]

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).[27] 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)[28]

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

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

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

26 Times Colonist, February 25, 2019. *Recommendations on Seniors Care not implemented 7 years after report: ombudsperson*

27 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.

28 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 year[29]. 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 incidents[30], 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.[31]

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.[32]

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".[33] 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.*[34]

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:

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

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

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

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

33 Medical Health Officer Report to the Board of the Vancouver Island Health Authority
https://www.islandhealth.ca/sites/default/files/nanaimo-seniors-village-mho-report-to-board.pdf p5

34 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).[35]

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.*[36]

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.

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35 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

36 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.[37] 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.[38] 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.[39] 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.[40] 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.[41]

The Seniors Advocate identified the following care needs for 2018/19 across BC[42]:

- Thirty-one per cent of residents are totally dependent on staff for their Activities of Daily Living (ADLs)[43], 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.

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

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

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

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

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

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

43 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

- The average Case Load Mix (CMI) is 0.580[44]
- 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, sexual orientation[45] and race, necessitating the practice of culturally safe care[46]. 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.[47] 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.[48] Depression, the most common mental health

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44 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

45 For discussion about needs of LGBTQ2S+ population see *Appendix D: LGBTQ2S+ Inclusion- The Time Has Come*.

46 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.

47 For discussion about issues and needs of younger adults with MS in LTC see: https://cjds.uwaterloo.ca/index.php/cjds/article/view/648/904 and https://1drv.ms/b/s!AoQDZMupyrsbgsEJovPw8t9vIBbHzg

48 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: www.mentalhealthcommission.ca

problem, is associated with a significant burden of illness that affects seniors and their families.[49] COVID-19 has increased staff and resident stress and many residents suffer from a lack of family contact that they may not understand. (For a full discussion of the impact of COVID-19 on the mental health of residents, families and staff, and recommendations to mitigate these, see the Canadian Academy of Geriatric Psychiatry and Canadian Coalition for Seniors Mental Health position paper). [50]

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.[51] Further, the availability of mental health supports is very uneven 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 best practices to guide the management of behavioural and psychological symptoms of dementia and 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.[52] The Behavioural Supports Ontario Initiative[53], designed to leverage existing resources in the health care system with a focus on three provincial pillars: (1) System Coordination & Management; (2) Integrated Service Delivery: Inter-sectoral & Interdisciplinary; and (3) Knowledgeable Care Teams & Capacity Building, is also instructive.

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.[54]

49 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.

50 Canadian Academy of Geriatric Psychiatry and Canadian Coalition for Seniors Mental Health (2021). *Mental Health Care in Long-Term Care During COVID-19* position paper. Accessed at: https://ccsmh.ca/wp-content/uploads/2021/01/COVID-19-Mental-Health-in-LTC-Web.pdf

51 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.

52 Improvements in regional geriatric care outlined, February 2019
www.kelownadailycourier.ca/news/article_5a7a5adc-30e7-11e9-a0aa-6f5fa51d81af.html

53 See Appendix D: *Behavioural Supports Ontario Initiative* for description and discussion.

54 Personal communication - family member

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)[55] 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.[56]

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:

> 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.[57]

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.*[58]

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

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

57 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

58 Personal communication - care aide

❖ 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.[59]

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.[60]

> *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.*[61]
>
> *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.*[62]

❖ 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 immigrants[63]. 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.

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

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

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

62 Personal communication- family member

63 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.

- Care aides receive the lowest wages in the healthcare sector and rates vary considerably between facilities.[64]
- 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.[65]
- 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 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.[66]

❖ 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.[67] 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.[68] (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 day[69].

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

65 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).

66 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

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

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

69 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

> *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.*[70]

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.[71] 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)[72] for BC facilities was 05.80.[73]

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.*[74]

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.[75] 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

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70 Personal communication - family member

71 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 https://journals.sagepub.com/doi/full/10.1177/1178632920934785

See table of staff ratios https://journals.sagepub.com/na101/home/literatum/publisher/sage/journals/content/hisa/2020/hisa_13/1178632920934785/20200629/images/large/10.1177_1178632920934785-table4.jpeg

72 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

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

74 Personal communication - family member

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

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.[76] Given the aging work force, workplace injuries are likely to increase with concurrent negative effects on staff retention, recruitment, and job satisfaction.[77]

> *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.*[78]

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. 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 measures of health status and patient responsive behaviours, these services are not routinely available in LTC facilities.[79]

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?[80] 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

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76 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

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

78 Personal communication – care aide

79 www.anfiide-gic-repasi.com/wp-content/uploads/2014/07/Donald_et_al-2013-Journal_of_Advanced_Nursing.pdf

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

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![81]*
> *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.[82]*

Medical, Specialized Mental Health and Allied Health Care Providers

Holistic and comprehensive care that supports quality of care, quality of life and mental health and well-being requires attention to the full range of residents' biopsychosocial needs which in turn requires the skills of diverse professionals. Multidisciplinary models have been shown to be particularly efficacious in treating older individuals with complex medical and/or psychiatric co-morbidities characteristic of LTC residents. Physicians, physical therapists, occupational therapists, speech/ language therapists, recreation therapists, dieticians, pharmacists, pastoral care, psychologists, and social workers are needed to support residents' medical psychosocial, emotional, functional and nutritional needs.

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)."[83] This is true in BC.

Medical Care

Residents in LTC are medically complex with multiple factors affecting their quality of life (QoL) and health outcomes. They require a specialized assessment to ensure that their care plans understand and address their medical complexity along with the social and psychological aspects of their disease and environment. Geriatric Medicine is not a mandatory component of physician training in BC and greater Care of the Elderly training for Primary Care would improve the efficiency, health outcomes and quality of life of elderly residents in LTC.

Geriatricians[84] have a foundation in medicine but also training in psychiatry, rehabilitation, and social determinants of health. They carry out Comprehensive Geriatric Assessments (CGA) to create comprehensive care plan which have been shown to lead to improved QoL, decreased hospitalizations, and to greater health coordination and integration. This allows specialists involved (e.g., Geriatrician, Geriatric Psychiatry, and others), primary care physician (traditionally General Practitioners), RNs, Care Aides, Social Workers, Physiotherapists, Occupational Therapists and other allied health team members to work collaboratively based upon this comprehensive care plan.

Specialized Mental Health Care

81 Personal communication – family member

82 Personal communication – family member

83 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.

84 For a full discussion of the role of geriatricians see Appendix D

The majority (76%) of residents in Canadian LTC facilities are diagnosed with mental disorders (40%) or Alzheimer Disease and Related Dementia (36%), highlighting the need for specialized mental health services.[85]

Non-pharmalogical approaches are widely accepted as the first line of treatment for mental disorders, but the use of antipsychotic drugs, often without a diagnosis of mental illness, remains a common intervention in LTC facilities[86]. This practice might be reduced through specialized mental health service via consultation, consultation-liaison, nurse-centred, facility-based staffing, externally based multidisciplinary teams or telepsychiatry delivery models[87]. The efficacy of consultation and consultation-liaison in LTC can be increased by utilizing the complementary skills and knowledge of allied health care providers and by training front -line staff to identify and report indicators of mental health issues so they can be addressed early.

Allied Health Care Providers

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.[88] 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 Dietitians[89]

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

[85] Kehyayan, V.et. al. (2021) Profile of Residents with Mental Disorders in Canadian Long-Term Care Facilities: A Cross-Sectional Study. Journal of Long-Term Care pp 154–166

[86] Foebel, A.D.; Onder, G.; Finne-Soveri, H.; Lukas, A.; Denkinger, M.D.; Carfi, A.; Vetrano, D.L.; Brandi, V.; Bernabei, R.; Liperoti, R.(2016) Physical restraint and antipsychotic medication use among nursing home residents with dementia Journal of the American Medical Directors Association 184.e9–184.e14

[87] MacCourt, Penny; Wilson, K.; Tourigny-Rivard, M.F. (2011). Guidelines for Comprehensive Mental Health Services for Older Adults in Canada. Mental Health Commission of Canada, Ottawa

88 Office of the Seniors Advocate British Columbia (2019) Long-term Care Facility Quick Facts Directory Summary, p 15.

89 For discussion see Appendix D The Importance of Registered Dieticians in LTC

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.

Speech-Language Pathologists[90]

Communication and swallowing disorders (dysphagia) affect a broad range of diagnoses common in LTC (e.g.: stroke, Parkinson's disease, dementia, COPD) and can have a devastating effect on quality of life. Communication problems can impact the ability to effectively communicate needs, participate in directing care, and to establish and maintain meaningful connections with others. Speech Language Pathologists (SLP) can facilitate a means of communication between seniors experiencing decline in speech and language function, and family through the use of adaptive equipment or strategies, particularly near the end of life. Dysphagia places seniors at risk of medical deterioration due to aspiration and/or malnutrition and affects enjoyment of food. SLP are best positioned to assess and manage communication disorders and dysphagia, but British Columbia has the third lowest number of SLPs per capita in Canada, (27.5 per 100,000 population vs the national average of 28.7 per 100,000 population) leaving most Long Term Care (LTC) settings with little or no access to onsite SLP service. (See Canadian Institute for Health Information (CIHI): https://www.cihi.ca/en/canadas-health-care-providers).

Occupational Therapy and Physical Therapy[91]

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.[92],[93] 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, incontinence reduction, cognitive activities, post-hospital rehabilitation, and splinting.[94],[95] 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

[90] For fuller discussion about the need for Speech Language Pathologist see Appendix D

[91] See Appendix D for a discussion of the role of occupational and physical therapy

92 McArthur, C., Hirdes, J., Berg, K., and Giangregorio, L. (2015). Who Receives Rehabilitation in Canadian Long-Term Care Facilities? A Cross-Sectional Study. *Physiotherapy Canada, 67(2), pg. 113-121.*

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

94 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/presentations%20to%20council/the%20role%20of%20physiotherapy%20in%20long%20term%20care%20march%2012%202015.pptx

95 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

Regulatory College practice standards/guidelines.[96],[97] 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.*[98]

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 one care aid to be responsible for providing mealtime 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, including my mother who without assistance could not eat fast enough before the end of the allotted mealtime.*[99]

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.

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.

96 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

97 College of Occupational Therapists of British Columbia. (2011). *Practice Guideline: Supervising Support Personnel.* Retrieved from: https://cotbc.org/wp-content/uploads/COTBC_Practice-Guideline_Supervision2011_2.pdf

98 Personal communication - family member

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

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. [100]

Social Work[101]

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. 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 [102]

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 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,

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

101 For full discussion about the role of social work see Appendix D

102 For full discussion about role of recreation therapy see Appendix D

challenging and age-appropriate 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.[103] 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[104] [105] [106]

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.[107]

> *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.*[108]

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

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

104 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

105 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.

106 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

107 For discussion see Harris, S. (2021). Families Slam 'S**t On A Plate' Food In Long-Term Care Homes. Accessed at: https://www.huffingtonpost.ca/entry/ontario-long-term-care-food_ca_6009ccb4c5b62c0057c4a1d3

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

> *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.*[109]

> *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.*[110]

The Seniors Advocate reported that for 2018/19 the actual cost of raw food per day per bed[111] in LTC facilities is $8.11 (range $5.21- $19.88).[112] In some facilities food costs are reduced by contracting out, often to the lowest bidder, and quality may suffer[113]. 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.* [114]

Life in LTC facilities today is largely institutionalised, representing loss of social relationships, privacy, self-determination, and connectedness, all dramatically increased by restricted visiting policies.[115] 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

109 Personal communication - family member

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

111 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.

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

113 Key informant interview – facility operator

114 Personal communication - family member

115 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.[116]

> *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.*[117]

> *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*.[118]

> *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.*[119]

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.[120] 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"

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

117 Personal communication - family member

118 Personal communication - family member

119 Personal communication - family member

120 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.[121]

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.

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.[122]

> *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.*[123]

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 nine 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."[124]

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

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

123 Personal communication - family member

124 https://www.jccf.ca/legal-warnings-issued-to-long-term-care-homes-who-continue-to-isolate-seniors/?fbclid=IwAR1q46TGuDqu81JoxblnSET_p7yP-uIk_KHi1U9gef9RyZfNsb1aItUS2LY

The Council of Senior Citizens Organizations of BC (COSCO)[125] 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.[126] 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.*[127]

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)"[128]

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:[129]

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125 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.

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

127 Personal communication - family member

128 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.

129 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.

- Autonomy/Choice – refers to the perception that one is making decisions and choices and directing one's own life.
- Dignity – 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.
- Food/Enjoyment – 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.
- Functional Competence – 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.
- Individuality – 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.
- Meaningful Activities – 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.
- Physical Comfort – 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.
- Privacy – 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.
- Relationships – 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.
- Safety/Security/Order – 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.
- Spiritual Well-Being – 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."[130]

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.[131]

Standards for Ensuring Quality of Life

130 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.

131 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.

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.[132] 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.[133] BC has a Residents' Bill of Rights[134] 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.[135] This model, once fully implemented and evaluated, could be considered for adaptation to British Columbia.

Policy, Regulations and Monitoring

Public policy impacts the lives of seniors, determining funding allocated for services, the services available, and regulations related to eligibility, accessibility and delivery. In BC, although there are public policies related to seniors' services (e.g., home care, mental health and residential care), an overarching provincial strategy to connect them is lacking. A provincial strategy, informed by stakeholders (e.g.; seniors, their caregivers, care providers) and framed by a moral compass with quality of life at the centre, would bring coherence to this policy landscape. The Long-Term Care system would then be integrated into a principle-based continuum of seniors' care with attention to transitions.

Recent research has examined how QOL is represented in current BC policies pertinent to LTC. In a Canadian study, researchers analyzed regulatory documents in four provinces to identify how policy supports or did not address residents' quality of life in LTC. Using Kane's QOL domains (discussed earlier) as a lens, they found that among BC policies associated with LTC over the past decade half (12 of the 25)

132 Key Informant – Health Authority official

133 Key informant – Health Authority official

134 https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/policy-and-standards

135 https://www.agedcarequality.gov.au/sites/default/files/media/Guidance_%26_Resource_V9.pdf

support quality of life.[136,137] This suggests opportunities exist to move quality of life interpretation from safety, security and order to domains that include residents' autonomy, dignity and privacy.

Using Kane's QOL indicators, we reviewed the Community Care and Assisted Living Act Residential Care Regulation (Regulations). 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) [138]

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

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136 Hande MJ, Keefe J, Taylor D (2021) Long-Term Residential Care Policy Guidance for Staff to Support Resident Quality of Life. *Gerontologist,* 2021, Vol. XX, No. XX, 1–12 doi:10.1093/geront/gnaa176 . Advance Access publication January 8, 2021

137 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.

138 https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/child-day-care/a_guide_to_community_care_facility_licensing_in_british_columbia_update_spring_2018.pdf p4

indicators.[139] 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.

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.* [140]

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%.[141]

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

139 See Appendix A for discussion of methodology

140 Personal communication - family member

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

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.[142]

> *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?*[143]

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.[144] 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 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".*

142 Reported by several family members

143 Personal communication – family member

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

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 supports human rights and 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 recommendations below support the paradigm shift and 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.

We recommend that the Minister of Health strike a diverse inclusive multi-sectoral and multi-stakeholder Task Force to develop a post-COVID provincial action plan, building on the ARRC recommendations, that would support (1) a paradigm shift from the current institutional model of long-term care to a more humane person-centred relational model that supports residents' quality of life and human rights, (2) a quality work environment, (3) a mandated voice for families (4) increased transparency and accountability for resident care and for public funds.

Multi Stakeholder Task Force

The challenges of senior care, in a sector replete with pressing needs, contested views, and fragmentation, requires an effective community based approach, led by government, in order to achieve the needed changes. See Appendix D for a description of the recommended Task Force process and structure, and http://www.arrcbc.ca/action.html for more detail and instances where the process has been successfully applied.

We recommend that:

- **the planning process followed by the Multi Stakeholder Task Force be collaborative, be tailored to the challenges of senior care, be inclusive of the interests of all stakeholders in the senior care system, and guided by the model described in Appendix D.**

1. 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."[145]

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."[146]

145 "Guidelines for care: Person-centred care of people with dementia living in care homes." Alzheimer Society of Canada. January 2011.

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

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 upon[147] as well as a planned dementia village[148] 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.[149]

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.[150]

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-

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

148 Planned Dementia Village – Comox Valley http://thedailyscan.providencehealthcare.org/2020/06/dementia-village-philosophy/

149 Registered Nurses Association of Canada (2015). Best Practice Guideline for Person-and Family-Centred Care. https://rnao.ca/bpg/guidelines/person-and-family-centred-care

150 Alzheimer Society of Canada (2011) *Guidelines for Care: Person-centered care of people with dementia.* Available: https://alzheimer.ca/en/help-support/im-healthcare-provider/providing-person-centred-care , p3

size-fits-all" approach to care. For example, a resident who prefers to sleep in later can do so. Those who 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 approach[151]—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. The household model, with its small cohorts, minimal pedestrian traffic, consistent care teams, flexible and familiar routines, family-style dining, and resident-controlled care plans, has proven to effectively limit COVID-19 and other viruses. Care facilities purpose built as "homes", based on these models, utilize best practice design with outdoor and garden spaces.[152] At the same time, there is evidence that the house model is cost effective, residents receive more hours of care and staff feel empowered.[153] Vancouver Coastal Health is developing new Long Term Care Design Guidelines that reflect the household concept. Some leading design practices could be implemented in older buildings through renovation but many facilities in BC may lack the capital to do so.

2. Staffing Levels and Mix

151 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.

152 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/

153 For a full discussion of the household model and evidence supporting it, see Appendix D Physical Design & Review of the Household Model

We recommend that

- **the MOH set a standard 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.**
- **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.[154]**
- **the MOH set a minimum standard .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'.[155] 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).[156]

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

154 See Nursing Home Basic Care Guarantee RNAO Submission to the Long-Term Care Staffing Study Advisory Group June 9, 2020 which also has developed staffing formulae for nursing.

155 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.

156 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.

provincial standard of 3.1 hours per day per resident.[157] 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.
- 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.[158]

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.[159] The RNAO contends that these nursing allocations would provide each resident with safe care and quality of life.[160]

Allied Professionals[161]

Residents' quality of life is enhanced when long-term care facilities have adequate recreation/therapeutic programs and activities.[162] 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.[163]

157 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

158 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

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

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

161 See appendix D for discussion of allied professional roles

162 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

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

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.

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 consider 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)[164] 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.[165] She also reported that the average number of funded direct care hours for these facilities was only 3.25,[166] 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.[167]

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 average 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.

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164 British Columbia Ministry of Health 2017, *Residential Care Staffing Review*, British Columbia Ministry of Health, Canada

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

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

167 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

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."[168]

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 ensure seniors receive dignified and quality care"?[169] We think not.

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."[170]

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-19), and implement benefits, including sick leave, for the large and critical unregulated workforce of care aides. Pay and benefits**

168 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.

169 https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/premier-cabinet-mlas/minister-letter/dix-mandate.pdf

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

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." [171]**

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.

The Royal Society contends that a "high-quality, resilient and supported workforce is, without doubt, the major component of quality care."[172] 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.[173] 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

171 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

172 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

173 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

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.[174] 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" 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.[175]

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.[176]

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, 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.**

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

175 Health Career Access Program (HCAP) Key informant interview – for-profit private facility

176 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

We recommend that the provincial government

- **support the best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care[177] 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***.[178]
- **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.**

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 Care*[179] 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.

6. Strengthen Standards to Support QOL and Monitoring

We recommend that the provincial government

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

178 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

179 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

- **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.

Staffing

- 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 Supports[180]

- 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.

We recommend that the provincial government

- **create a mechanism/process/role, or expand the role of Licencing Officers, to monitor the QOL standards.**[181]
- **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 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.

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180 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.

181 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

We recommend that the provincial government

- **mandate independent Family Councils in all LTC facilities and in the CCALA Regulations, require all facilities to 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, 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.[182]

Not every facility has a Family Council given the constant turnover of family as residents die. Although Health Authorities are required by the Ministry of Health to support the development of resident/family councils,[183] 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. Family Councils should have a voice in facility policies, including visitation during COVID and other infectious illnesses.

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.

7. Policy Context for LTC

We recommend that the provincial government

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

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

- **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 Canada[184]) 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 necessary[185]."

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.

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 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.[186]

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.)

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184 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.

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

186 See Appendix C for an outline for proposed research

- 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.[187]

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 adequately funding a system (1) where care is prioritized over profit (2) supports seniors' health holistically while enabling them to live their lives to the fullest, and (3) supports a quality workforce. 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.*[188]

187 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

188 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:
  - 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

<u>Specialized Mental Health Supports</u>

- **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.*[189]

- **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.**

189 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.

Indicators:

- 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.

<u>Specialized Palliative Care</u>

- **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.
    - 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 – Additional Information on Specific Issues

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

[1] Grant, K. (2020). Lessons learned will prove crucial in controlling a second wave of COVID-19. *The Globe and Mai Canada:* Published August 3, 2020 .Updated August 4, 2020. Retrieved August 7, 2020 from https://www.theglobeandmail.com/canada/article-lessons-learned-will-prove-crucial-in-preventing-a-second-wave-of/.

[2] 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 18, 2020 from https://rsc-src.ca/en/restoring-trust-covid-19-and-future-long-term-care.

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

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[3] Kenny, N. P., Downie, J., Ells, C. & MacDonald, C. (2000). Organizational ethics Canadian style. *HEC Forum, 12(2),* 141-148.

[4] Harrigan, M. L. (2005, pp. 141-142). Leadership challenges in Canadian health care: Exploring exemplary professionalism under the malaise of modernity. (Doctoral Thesis).

[5] Canada. (2002). *Building on values: The future of health care in Canada* (R. J. Romanow, Commissioner). Ottawa, ON: Commission on the Future of Health Care in Canada.

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

[7] Butler, R. N. (1989). Dispelling ageism: The cross-cutting intervention. *The ANNALS of the American Academy of Political and Social Science, 503(1):* 138-147.

[8] Gillett, G. (2020). Living through the pandemic in New Zealand. *Hastings Center*, September 11. Retrieved September 17,k 2020 from https://www.thehastingscenter.org/living-through-the-pandemic-in-new-zealand/.

[9].Harrigan, M. L. & Gillett, G. (2009). Hunting good will in the wilderness. In D. O'Connor & B. Purves (Eds.). *Decision-making, Personhood and Dementia: Exploring the Interface.* (pp. 47-57). London: Jessica Kingsley Publishers

[10] B rody, H. (2009). *The Future of Ethics.* New York: Oxford University Press.

[11] Nairn, T. A. (2012). Ethics - Who is the person in person-centred care*? Journal of the Catholic Health Association of the United States:* March-April.

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

[12] Kenny, N. P., Sherwin, S. B. & Baylis, F. E. (2010, p. 11). Re-visioning public health Ethics: A relational perspective. *Canadian Journal of Public Health, 10(1):* 9-11. Retrieved August 6, 2020 from https://link.springer.com/content/pdf/10.1007/BF03405552.pdf.

[13] McCance, T., McCormack, B. & Dewing, J. (2011). An exploration of person-centredness in practice. *The Online Journal of Issues in Nursing, 16(2).* Retrieved August 16, 2020 from http://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-16-2011/No2-May-2011/Person-Centredness-in-Practice.html.

[14] Institute for Patient- and Family-Centered Care. *Frequently Asked Questions.* Retrieved December 9, 2018 from http://www.ipfcc.org/about/pfcc.html.

[15] Estabrooks, C. A., Straus, S., Flood, C. M., Keefe, J.,. Armstrong, P., Donner, G., et al. (2020, p. 8). 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 August 6, 2020 from https://rsc-src.ca/sites/default/files/LTC%20PB%20%2B%20ES_EN.pdf.

[16]Rodney, P., Buckley, B., Street,, A., Serrano,, E, & Martin,, L. A. (2013). The moral climate of nursing practice: Inquiry and action. In J.L. Storch, P. Rodney & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed.; pp. 188-214). Toronto, ON: Pearson Education.

[17] Rodney, P., Harrigan, M. L., Jiwani, B., Burgess, M. & Phillips, C. (2013, p. 361). A further landscape: Ethics in health care organizations and health/health care policy. In J. Storch, R. Starzomski & P. Rodney (Eds.). (pp.

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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358-383). *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice. (2nd Ed.).* Don Mills, ON: Pearson Canada Inc.

[18] Rodney, P., Buckley, B., Street, A., Serrano,, E, & Martin,, L. A. (2013). The moral climate of nursing practice: Inquiry and action. In J.L. Storch, P. Rodney & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed.; pp. 188-214). Toronto, ON: Pearson Education.

[19] Yeo, M., Rodney, P., Moorhouse, A. & Khan, P. (2020). Addendum: Reflections on the Coronavirus disease 2019 (COVID-19) pandemic: June 3, 2020. In M. Yeo, A. Moorhouse, P. Khan, & P. Rodney (Eds.), *Concepts and Cases in Nursing Ethics* (4th ed.; pp. 429-469). Peterborough, ON: *Broadview Press*

Giving Voice to LGBTQ2S+ Seniors in LTC – The Time Has Come

Dignity Seniors Society

The Time Has Come – Giving Voice to LGBTQ2S+ Seniors in Long Term Care

Dignity Seniors Society (DSS) is a BC based organization that strives to provide unique, tailored information and programing that meet the needs of LGBTQ2S+ Seniors. DSS, along with many other organizations,[1] has been advocating for years for improvements to long term care facilities to better serve LGBTQ2S+ Seniors. DSS believes that post COVID, and with the collaboration of multiple sectors of society, the time has come for, as the ARRC Report states: "a paradigm shift that details a model of care, staffing requirements, work force stabilization and standards/monitoring processes that address residents' and families' need for quality of life". We ask that, during assessing and implementing the paradigm shift, the voices of LGBTQ2S+ Seniors be heard and included. In advocating for the needs of LGBTQ2S+ Seniors, DSS advocates for all minority groups and indeed each individual in care, which is the very essence of the intentional, person-centred care model recommended by the ARRC report.

DSS wholeheartedly endorses all recommendations put forward by the Action for Reform of Residential Care in - *Improving Quality of Life in Long Term Care – A way forward* (2020). We ask that the recommendations be extended to all senior's LTC settings, including but not limited to, retirement homes, nursing homes, hospices and in-home care. Importantly the report states; "Quality of life 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." Often LGBTQ2S+ residents are made to feel unable to be themselves or be fully 'out', which can lead to withdrawal from social contact and self-isolation. There are many anecdotal reports of residents feeling the need to hide their identity and revert 'back into the closet' for self protection.[1] It is similarly important that service providers are aware that many LGBTQ2S+ seniors are even more likely to suffer from loneliness, depression, social isolation, and a lack of supportive relationships, which the current LTC system exacerbates.

When assessing systemic changes to LTC put forward by the ARRC report recommendations, DSS requests that policy makers include the following:

Recommendation 1. Person Centred Care Model

"Training be made available to all facilities' Directors of Care to prepare them to lead the implementation of person-centred care." ***DSS asks that this training includes frequent and continuing LGBTQ2S+ cultural safety, awareness, and agility training for Directors, staff and residents.***

"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." ***This makes it equally as important to ensure the workplace is welcoming of LGBTQ2S+ employees as it is to ensure all employees have ongoing cultural trainings. LTC facilities must develop and implement staff and resident policies for safeguarding LGBTQ2S+ people against anti-LGBTQ2S+ hostility and discrimination in residential care.***

"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." ***Develop and implement clear staff and resident policies for equity and inclusion of LGBTQ2S+ people (and all minority groups), and particularly older adults, as residents/staff/volunteers.***

Develop policy and procedure to connect LGBTQ2S+ residents with culturally appropriate services and supports where appropriate, and when requested.

Recommendation 4. Work Force Issues

"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. ***Invite regular, paid consultation from LGBTQ2S+ advocates, practitioners, researchers, and other community leaders to review organizational policies, procedures, and training materials for enhanced LGBTQ2S+ equity and inclusion.***

Recommendation 5. Staff Training/Education

"Including social workers in LTC facilities to support front line staff in developing active listening, communication and relationship building skills." ***Most social work education includes LGBTQ2S+ cultural safety, awareness, and agility training, which should be encouraged as part of continuing professional development activities and passed to Directors, staff and residents.***

Recommendation 6. Standards to Support QOL and Monitoring

"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." ***When implementing the role of families as partners in care, and of Family Councils, facility adopt a clear interpretation of "family" and "partner(s)" that is fully and explicitly inclusive of LGBTQ2S+ chosen families and partner(s).***

No need to reinvent the wheel:

DSS offers its services to any LTC facility or policy maker that requires the input of LGBTQ2S+ Seniors and can recommend a host of resources to draw from. Of particular note, SAGE, an American LGBT advocacy organization, has launched their Long-Term Care Equality Index, or LEI program, aimed at building a network of American LTC centres informed on how to integrate person-centred care with working with GSRD seniors. In BC Route 65 is an online tool, developed by EngAge, that matches seniors with B.C.'s leading operators of independent living, assisted living, long-term and home health care services. Seniors living and wellness organizations on Route 65 that consider themselves to be LGBTQ2+-inclusive are marked with a pride icon. DSS commends these initiatives and sees there is much more work has yet to be done.

Our Intention

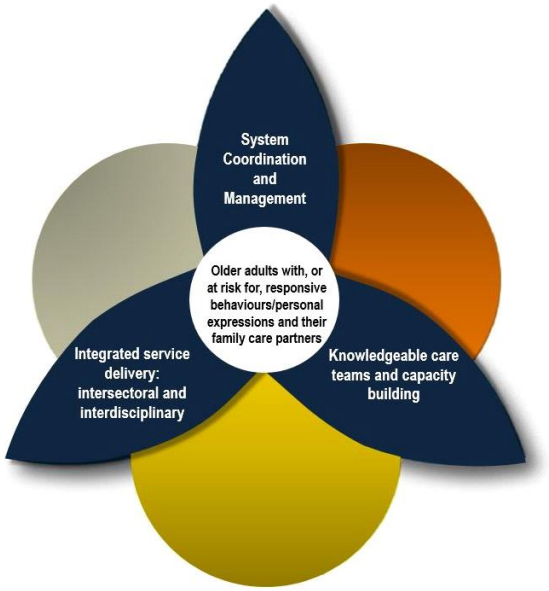
The DSS Board felt it important to give an LGBTQ2S+ voice to the recommendations in the ARRCBC report. In doing so, we give our experiences and knowledge in the hope that it can effect change for all BC residents who need kindness, optimal care and dignity when accessing LTC.

Respectfully submitted on behalf of Dignity Seniors Society Board. March 2021

Supporting Older Ontarians Presenting with Responsive Behaviours/Personal Expressions

SUPPORTING OLDER ONTARIANS PRESENTING WITH RESPONSIVE BEHAVIOURS/PERSONAL EXPRESSIONS: THE BEHAVIOURAL SUPPORTS ONTARIO INITIATIVE

Behavioural Supports Ontario (BSO) provides behavioural health care services for older adults in Ontario with, or at risk of, responsive behaviours/personal expressions associated with dementia, complex mental health, substance use and/or other neurological conditions. In addition to providing direct care services, BSO also supports family care partners and health care providers across all sectors.



BSO was designed to leverage existing resources in the health care system with a focus on three provincial pillars: (1) System Coordination & Management; (2) Integrated Service Delivery: Intersectoral & Interdisciplinary; and (3) Knowledgeable Care Teams & Capacity Building.

PILLAR 1: SYSTEM COORDINATION & MANAGEMENT

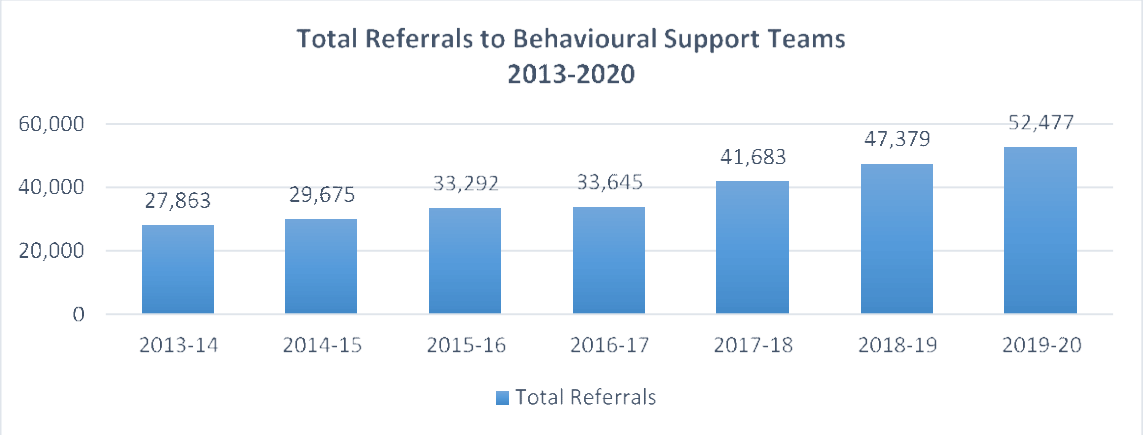
Background:

BSO was launched in 2010 in response to the growing demand to support older adults presenting with responsive behaviours *(or personal expressions)* in the contexts of dementia, geriatric mental health, substance use and/or other neurological conditions. While some BSO teams were immediately available to support older adults across sectors, priority was established within long-term care (LTC).

The Ministry of Health and Long-Term Care's (*now Ministries of Health and Long-Term Care)* original investment totalled $40M which was distributed based on the demographic and population statistics of Ontario's health regions, referred to as Local Health Integration Networks (LHINS) at the time. Unique to this funding was the ability for each LHIN to benefit from the guidance of four early adopter LHINs to design and implement its own model for BSO, taking numerous factors into account such as population, geography and partnerships with existing health and community service providers. Each LHIN had the ability to fund existing health service providers to carry out the BSO mandate, all with the goal of improving system coordination and access to care.

Service Demand:

Over the years, demands for support from BSO teams has continued to grow due the increased complexity of LTC residents and the growing number of people with behavioural health needs in other sectors. Recognizing this growing demand, BSO received additional funds over the time period of 2016-20, resulting in a doubling of the total investment as of 2020. These investments have resulted in the ability to support a greater number of older adults across a wider variety of sectors, as evidenced by the referral data below, however, demands from this population continue to grow.



PILLAR 2: INTEGRATED SERVICE DELIVERY: INTERSECTORAL & INTERDISCIPLINARY

BSO Care Models:

Long-Term Care

Due to the flexibility provided to the LHINs in implementing the original BSO investment, BSO models differed in their designs across the LHINs, however, two primary models emerged for BSO in LTC:

- ***Behavioural Support Embedded Teams:*** Term that describes BSO staff or teams that are located within LTC homes (e.g., Personal Support Workers (PSWs), Registered Practical Nurses (RPNs), Registered Nurses (RNs), Recreational Therapists); funded to support the delivery of care for residents presenting with responsive behaviours/personal expressions. These individual resources or small teams are sometimes referred to as "BSO Champions"; responsible for leading, coaching, coordinating and spreading effective BSO strategies. In some regions, all Long Term Care Homes (LTCHs) have embedded BSO Staff; in others, only a portion of LTCHs have Embedded BSO Staff.

- ***Behavioural Support Long-Term Care Mobile Teams:*** Term that describes behavioural support teams that are led by a lead organization that delivers outreach support to LTCHs throughout a specific region. In some cases, the lead organization is a LTCH delivering care to residents in other LTCHs subject to a formal Memorandum of Understanding. In others, the lead organization is a hospital or other health care organization. BSO LTC Mobile Teams are primarily comprised of RNs, RPNs, PSWs and other allied health care staff (e.g., Social Workers, Recreational Therapists).

While most regions began with either one model or the other, recognition of the benefits of both types of models quickly emerged. In the case of BSO embedded staff and teams, these individuals are well positioned to act as 'go-to' resources within the LTC home. They can provide in-the-moment coaching and build capacity with their colleagues, all while having the benefit of understanding the home's culture and knowing its residents, staff and leadership. On the other hand, the benefits of BSO LTC Mobile teams include their ability to respond using a multidisciplinary approach through deployment of various types of clinicians and direct care team members with varying scopes of practice based on the identified needs in each referral. In addition, BSO LTC Mobile Teams have the ability to replicate approaches and initiatives that are working well in one LTC home to other homes in the region.

The aforementioned additional of the BSO investment has since resulted in most regions adopting a hybrid integrated model, consisting of both embedded and mobile components – which is now seen as a BSO in LTC best practice.

Outside of LTC:

Critical to the structure of the behavioural support system of care is its availability across sectors. While originally funded to primarily support LTC homes, the BSO investments over the years has resulted behavioural support teams being available across sectors, including for individuals living in private dwellings, retirement homes, acute care, etc.

BSO Models outside of LTC differ in their host organizations across the province, however, they primarily fall under three types:

- ***Behavioural Support Community Teams:*** Term that describes community-based behavioural support teams funded to support persons and family care partners residing in the community (including private dwellings, retirement homes, group homes, assisted living, etc.). The development of these teams was often a result of service enhancements and/or realignment of existing resources to ensure collaboration and seamless care transitions. Such teams are often linked with existing Seniors' Mental Health, Geriatric Mental Health Outreach, Home & Community Care or Specialized Geriatric Services team structures.

- ***Behavioural Support Dedicated Acute Care Staff/Teams:*** Term that describes behavioural support staff or teams that support patients presenting with responsive behaviours/personal expressions in the acute care sector. These individuals/teams are also often responsible for building capacity with other acute care staff members. In some regions, teams support multiple acute care sites whereas in others, they are embedded to support one acute care centre.

- ***Behavioural Support Cross-Sector Teams:*** Term that describes behavioural support teams that are funded to support persons and care partners wherever they reside (i.e., LTC, Community, Acute Care, etc.). These teams are sometimes linked within existing Seniors' Mental Health/Geriatric Mental Health Outreach teams and/or Specialized Geriatric Services structures.

Interdisciplinary Teams:

The components of BSO teams differ across the province; however, all regions of Ontario have BSO Clinicians from registered disciplines as well as additional team members from non-registered disciplines across sectors. As such, BSO Roles may be held by Personal Support Workers, Registered Practical Nurses, Registered Nurses, Recreation Therapists, Behavioural Therapists, Social Workers, Occupational Therapists, Social Service Workers, Nurse Practitioners, etc.

The benefits of interdisciplinary teams is well-known in health care and the effective teamwork produced by BSO interdisciplinary teams is a critical element to the success of the initiative:

"Teamwork is the most effective approach in which to accomplish complex tasks. In general, teamwork has been shown to improve production, augment organizational and employee performance, increase

job satisfaction, and enhance decision making. In health care, teamwork is of vital importance in order to maximize patient care delivery. Interdisciplinary teamwork is recommended as a comprehensive approach for health care teams to provide patient-centered care; combining skills, experience, and knowledge to produce a superior outcome."[1]

PILLAR 3: KNOWLEDGEABLE CARE TEAMS & CAPACITY BUILDING

Despite differing models and team structures across the province, BSO is united under common goals and approaches to behavioural health care. This unity comes from the standard set of BSO core competencies (see Appendix 1) and the education and training programs that foster the critical skills for BSO teams.

The PIECES™ Learning & Development Model serves as the foundation for behavioural assessment and support:

"PIECES™ began in 1997, initially in long-term care, in recognition of the need for a system-wide approach to the understanding of and care for the complex and at risk older person. It is a holistic, person and care partner-directed approach, anchored in performance improvement, and designed to enhance capacity. Over the last 18 years the PIECES™ approach has evolved based on best-practice literature and the lessons learned through its implementation and spread across health care sectors within both regional and provincial jurisdictions." [2]

Alongside the sister program for PIECES™, U-First!, and other foundational programs such as Gentle Persuasive Approaches and DementiAbility Methods, all BSO team members across Ontario are trained to provide behavioural support using holistic, person-centred approaches. To build on these foundational skillsets, BSO teams also have access to the Behavioural Education and Training Support Inventory (BETSI), which contains a full listing of recommended education and training programs.

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Behavioural Supports Ontario
Soutien en cas des troubles du comportement en Ontario

Appendix 1

Behavioural Supports Ontario (BSO) Core Competencies

1. PERSON AND FAMILY-CENTRED CARE

Delivers person and family-centred care, supported by evidence-informed clinical best practices, which recognize both the uniqueness of each person (i.e., personhood) and an awareness of one's own contribution to that relationship, including personal attitudes, values and actions. This includes:

a) Contributing to the delivery of the person and family-centred philosophy of care.

b) Acknowledging that the person, the family and care partners all bring expertise and experience to the authentic relationship.

c) Involving the person and family as part of the care team and ensuring that care reflects the person and family's values, preferences and expressed needs and goals.

d) Ensuring that information and care plans are actively updated and shared with individuals and families using appropriate and accessible methods.

e) Preserving and promoting the abilities, self-esteem and dignity of

the person.

f) Considering components of safety, risk and quality of life.

g) Protecting and advocating for the person and family's rights.

h) Demonstrating compassion, empathy, respect for diversity and cross-cultural awareness.

i) Exhibiting effectiveness as an interprofessional team member through collaboration and cooperation in interacting with the person, their families and other partners in care. Ensuring care is continuous and reliable.

j) Utilizing communication strategies that demonstrate compassion, validate emotions, support dignity, and promote understanding.

2. KNOWLEDGE

Within respective scope of practice, demonstrates knowledge of dementia, complex mental health, substance use disorders and neurological conditions and their impact on the person, their family members and other care partners (e.g., health care professionals, front-line staff). This includes a fundamental understanding of:

a) The Importance of perspectives of lived experience from the person and their family members;

b) Types of conditions and causes;

c) Cognitive, neurological and behavioural symptoms;

d) Assessment and diagnostic processes;

e) Stages and progression of conditions;

f)) Current treatment interventions and approaches;

a) Emerging and/or best non-pharmacological strategies and practices to promote optimal quality of life;

b) Environmental factors associated with responsive behaviours/personal expressions; and

c) The Long-Term Care Homes Act and other applicable regulations and/or other legislation that is relevant to the scope of practice.

3. ASSESSMENT, CARE APPROACHES & CAPACITY BUILDING

Within respective scope of practice, conducts and/or contributes to a thorough assessment and recommends, implements and evaluates therapeutic interventions and approaches with respect to the expressed behaviours. This includes:

a) Recognizing that behaviours have meaning and therefore, looking for contributing factors is an essential part of the assessment and care planning process.

b) Assessing the meaning, contributing factors and associated risks of behaviours using an objective, systematic and wholistic process that takes the individual's personhood into account in addition to the physical, intellectual, emotional and functional capabilities of the person; as well as the environmental and social aspects of their surroundings.

c) Identifying non-pharmacological strategies that are abilities focused and person-centred to prevent and respond to expressed behaviours, including recommendations to mitigate associated risks.

d) Collaborating with the person, their family and interprofessional team members to create, share, implement and model an individualized behavioural care plan.

e) Analyzing and evaluating the ongoing effectiveness of the implemented plan including thorough communication of next steps, suggestions for adherence and thorough follow-up.

f)) Providing facilitation, coaching, mentoring and demonstrating team leadership and change management skills.

g) Demonstrating excellent clinical reasoning and critical thinking skills that target prevention of the expressed responsive behaviours by creatively adjusting the social and physical environment; focusing on the person's abilities and knowing the individual, their life story and aspirations.

Documentation in LTC Facilities: Issues with the RAI-MDS 2.0

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.

Geriatric Medicine in Long Term Care Facilities: The Critical Role of Specialized Assessment

Residents of Long Term Care Facilities (LTCF) are medically complex with multiple factors affecting their quality of life (QoL) and health outcomes. The vast majority of the residents of LTCF in British Columbia are seniors. They require a specialized assessment to ensure that their care plans understand and address their medical complexity along with the social and psychological aspects of their disease and environment. This role is carried out by a specialist in Geriatric Medicine, also known as a Geriatrician. Though acknowledged as a special population, the LTCF Resident's care needs have often been ignored due to an "insufficient leadership from above and inertia within the system"[1]. The cause of this is undoubtedly complex, but at the heart of it a bias against the elderly has been documented. Throughout the Western World where socialized programs are designed to support seniors, the elderly, often mistakenly, are seen to benefit greatly from social supports such as pension plans and the like. A bias against them is present because of this misperception and thus "innovation even if cost effective, tends to arbitrarily be ruled out" [1]. Geriatricians' role in modern medicine is not just that of diagnosis and treatment, but also balancing the overwhelming needs of a growing population and advocating for the necessary resources. As we look to rebuild our LTCF approach throughout the province, the role of Geriatricians is crucial.

The specialty of Geriatric Medicine was born in the post-World War Two era when demographics shifted and poor care options for the elderly were highlighted [1]. This evolved through the years to a formal definition of Geriatric Medicine in the late 1970s as a "special body of knowledge focusing on complex medical problems of multiple chronic illnesses and concurrent acute problems that occur with greater frequency in advanced age" [2]. Geriatricians are subspecialists having first completed training and accreditation with the Royal College of Physicians and Surgeons of Canada in Internal Medicine and then a minimum two-year Fellowship in Geriatric Medicine. The skill set of a Geriatrician is broad with a foundation in medicine but also training in psychiatry, rehabilitation, and social determinants of health. The specialized tool of a Geriatrician is the Comprehensive Geriatric Assessment (CGA) which covers medical history, medication review, detailed physical exam with special focus on mobility, cognitive status (MMSE, MoCA), mental status and review of investigations to date. This leads to a thorough assessment and treatment plan that takes a bio-psycho-social approach also known as a comprehensive care plan. The CGA is the precursor to and still considered the superior tool to the Resident Assessment Instrument (RAI). It has been shown that a "CGA leads to improved QoL and decreased hospitalizations. It also leads to greater health coordination and integration" [3]. This allows team members such as the specialists involved (Geriatrician, Geriatric Psychiatry, and others), primary care physician (traditionally General Practitioners), RNs, Care Aides, Social Workers, Physiotherapists, Occupational Therapists and other allied health team members to work collaboratively based upon this comprehensive care plan. The CGA creates an "integrated health information system that has the potential to provide person-centred information transcending healthcare setting" [3].

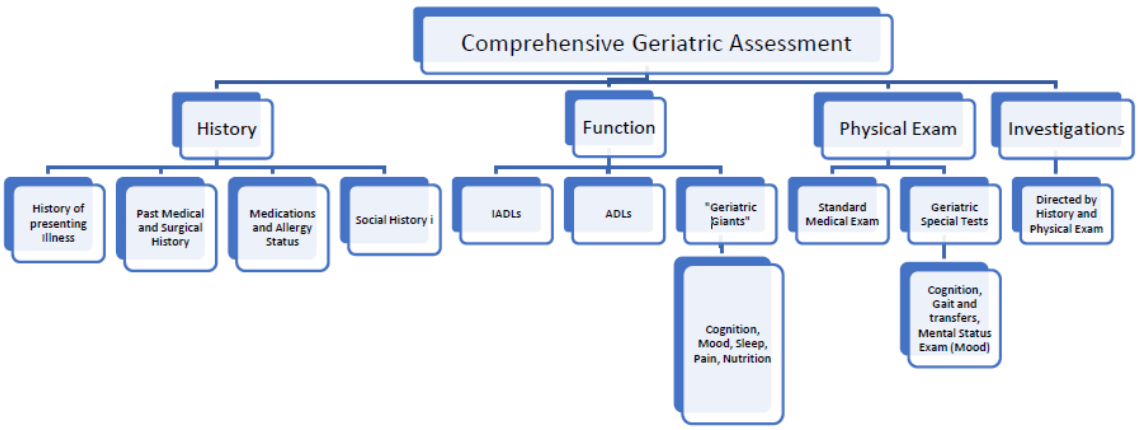

Figure 1: Geriatricians Comprehensive Geriatric Assessment

Geriatric Medicine and its role in LTCF has been proven in-vivo and in-vitro but we are "missing the acknowledgement that better community care, including LTC leads to reduce the non-acute function of hospitals and ultimately better QoL, care and costs" [1] to our health care system. We have the knowledge of how to optimize our care and to improve its' efficiency, but the "inertia" still holds us back. In BC we know how to improve care in LTCF, which would begin with following the American standard practice of CGA for all LTCF residents at regularly intervals, but we are unable to provide this evidenced based care due to lack of staffing. In 2020 Geriatric British Columbians (18.4%) overtook Pediatric British Columbians (15.9%) yet the number of specialist physicians and resources allocated do not reflect this. Currently within BC there are 566 practicing Pediatricians along with multiple subspecialties within pediatrics. There are only 71 Geriatricians and two who have subspecialized into Geriatric Diabetology. The majority of these specialists practice in major centres. As training resources are scant, those who do train tend to fill positions closer to their training location. There are excellent Acute Care resources with Acute Care of Elders wards and consultant services and hospital based Rapid Access Clinics in the Lower Mainland and Victoria. Outside of these major centres that have an acute care focus, British Columbians are left with a single community-based clinic in Vancouver and the remainder of the province has occasional outreach services provided by Geriatricians from the Lower Mainland and Victoria. With the focus being on acute care those in LTCF are left without access to the specialized assessments they need and deserve until they have fallen into a medical or social crisis that brings them to the Acute Care setting. The staff at these LTCF are also left to fill the gap of leadership that is traditionally held by a Geriatricians in Europe and the USA. In LTCF where a Geriatricians is available, they will serve as both a consultant physician completing CGAs on Residents and as Medical Directors leading medical rounds, being involved in family meetings and resource planning for facilities. As specialists take on these roles, the Primary Care Physician for the LTCF is allowed to focus on the immediate needs of the Resident thus improving their care, QoL and minimizing needs for transfer to other centres.

Limitations to CGAs and Geriatricians in LTCF are many with the glaring ones being manpower and facilities. Barriers to Geriatrician recruitment have been researched as "disproportionate reimbursement, poor QoL, lack of role models, inadequate facility resources and funding and the feeling of being unable to make a difference in LTCF because of lack of resources" [2]. "Home-grown" talent is

increasing in BC as UBC graduates more Geriatricians each year, but there is still a great deficit. To use the example of Pediatrics again there are on average 2 Geriatricians graduated per year and 15 Pediatricians. Recruitment of Geriatricians needs to be a priority for the coming decades. There are other educational centres within Canada that have surplus trainees, yet they choose other provinces over BC due to a poor fee structure for Geriatricians. Focus on the Medical Services Plan and a specialized fee code for LTCF treatment is crucial to offset this, attract our current Geriatricians to LTCF and bring in new Geriatricians to the province. Due to the current gap in pay for LTCF many Geriatricians are choosing to work as Internists in the Acute Care setting, if the pay structure was reorganized to value the work at LTCF equally to Acute Care as it should many of our current Geriatricians would choose to work in their own specialty. The population base in BC cannot be managed in the short- or medium-term population projections by Geriatricians alone, so further exposure to Geriatric principles in training of medical students and Family Practice trainees is also needed. This would require a push to include Geriatric Medicine as a crucial and mandatory component of training in BC which it currently is not. Though work is being done towards this, pressure from the Ministry of Health and Ministry of Advanced Education to make this a priority is needed as is funding to accomplish this.

It is also prudent to note that as Geriatricians produce comprehensive care plans and work with the care teams to enact them through time, they also collaborate frequently with other medical subspecialities. Focus on improving access to Geriatric Psychiatry and greater Care of the Elderly training for Primary Care are also a vital part of improving the efficiency, health outcomes and quality of life for Residents of LTCF.

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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.

The Necessity of Speech-Language Pathologists in LTC

Krista McDermott (RSLP) & Janelle Fredrickson (RSLP)

Speech-Language Pathologists (SLPs) are experts in the assessment and management of communication and swallowing disorders (dysphagia). Our care directly aligns with the person-centered approach that supports autonomy and dignity for seniors in our province, many of whom experience devastating impacts on quality of life as a result of these disorders. Despite the clear role and value of SLP care for this vulnerable population, British Columbia has the third lowest number of SLPs per capita of all provinces, leaving most Long Term Care (LTC) settings with little or no access to onsite SLP service.

Dysphagia affects a broad range of diagnoses, including stroke, Parkinson's disease, dementia, COPD, and sarcopenia, conditions that are common in the LTC population. Without comprehensive and timely management, dysphagia places seniors at risk of medical deterioration as a consequence of aspiration and/or malnutrition. Nutrition is critical both in maintaining the physical wellness of seniors, such as through its contribution to mobility and skin integrity, and in improving their quality of life. SLPs have the expertise to collaborate with dietitians in order to balance malnutrition and aspiration risks with the overarching goal of maximizing nutrition-related quality of life while allowing seniors to make informed choices, even if those incur risk. Further, SLPs support interdisciplinary teams through documentation, individualized care plans, and education for team capacity-building in their knowledge and confidence when working with people with dysphagia. For many seniors in LTC, food can be one of the last remaining pleasures, and it can be the tool through which family members show their love and care during special visits. Seniors should be given the autonomy to make an informed choice regarding their nutrition, and SLPs are central to the informed decision-making process, as it relates to dysphagia management.

Communication is the foundation of optimal care and quality of life. It is central to preserving the psychological, emotional, cultural and social well-being of seniors in LTC. Many seniors have suffered the devastating effects that stroke, dementia and acquired brain injury can have on their ability to effectively communicate their needs, participate in directing their care, and to establish and maintain meaningful connections with others. Not only can communication impairments interfere with connection, but communication impairments have also been found to increase risk for an adverse event. SLPs can act as supportive conversation partners (utilizing materials, strategies and clinical training) to help facilitate an individual's participation with health care providers. For example, SLPs can provide strategies for the interdisciplinary team to use to help reveal an individual's communication competency when they have a communication disorder. In this way, SLPs assist seniors in demonstrating their true understanding, competence and cognition. SLPs can also facilitate a means of communication between seniors experiencing decline in speech and language function, and family, through the use of adaptive equipment or strategies, particularly as seniors near the end of life. Additionally, SLPs can have a positive impact on the communication culture in LTC by equipping teams, family/friends, and the seniors themselves by providing education, resources and, when appropriate, personalized supportive communication tools. Communicating in respectful, age-appropriate, and individualized ways will improve psychosocial well-being and quality of life of seniors living in LTC during the provision of consistent and quality care.

In summary, SLPs have the expertise to provide support in two areas critical to the well-being of seniors living in LTC: communication and nutrition. The joy of life is in connection and shared experience. SLPs can help seniors connect through communication, and participate in shared experiences by talking over a satisfying meal with their loved ones. SLPs in BC would be honored to assist our seniors in

experiencing joy, and it is their right to have access to a complete health care team that can address all of the needs that are paramount to their overall health and wellbeing. We recommend increasing the number of practicing SLPs per capita to the national average, at minimum, with specific focus to ensure that seniors with communication and swallowing difficulties have access to critically needed services in Long Term Care.

Occupational and Physical Therapy Services in LTC

Access to consistent occupational therapy and physical therapy services in long-term care facilities have shown to improve residents' function and quality of life (McArthur, C. et al, 2015). These services are provided most efficiently and cost-effectively through the collaboration of occupational therapists, physical therapists, and therapist assistants (OTAs and PTAs).

Areas of therapeutic intervention specific to long term care residents 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, incontinence reduction, cognitive activities, and splinting. (HANS, 2015; OSOT, 2012)

Therapist assistants work under the supervision of occupational therapists and/or physical therapists. The frequency and method of supervision (direct or indirect) will vary based on the specific resident's overall status, the competency of the assistant(s) involved, the environment where the therapy will occur and the therapeutic intervention itself. The therapist's decision to assign treatment intervention to an assistant occurs after the therapist has thoroughly assessed the resident and developed the treatment plan. The process of task assignment to assistants is clearly described in the relevant BC Regulatory College practice standards. (COTBC, 2011; CPTBC, 2018)

The benefits of involving therapist assistants in rehabilitation service delivery is based on their skills and knowledge of both occupational therapy and physical therapy, clear comprehension of their responsibilities to the supervising therapist(s), and their focus on resident treatment. The latter in turn makes more time available for therapists to further assess and plan resident programs, and advocate for residents as required.

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 all residents.

Heather Gillespie, B.O.T, OT (Reg. BC)

Occupational Therapist

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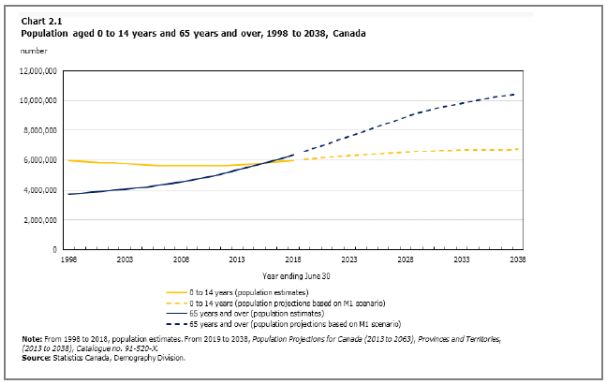
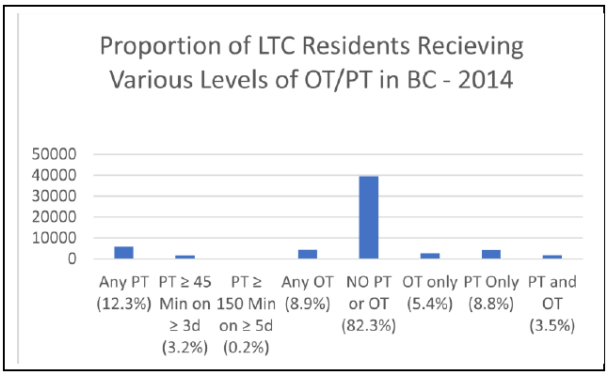
Physiotherapy in LTC

PHYSIOTHERAPY ASSOCIATION OF BRITISH COLUMBIA

Our Seniors

Canada's population is aging**. Over the next 20 years, Canada's senior population is expected to grow by 68%.** The current population is 6.2 million and in 2037, it is projected to be 10.4 million (CIHI, 2017).
A study conducted by the Fraser Institute revealed the impact of Senior Migration in BC. **BC is shown to take the bulk of this migration, with more seniors migrating to BC than anywhere else in Canada.** Between 1980 and 2016, British Columbia experienced the largest net inflow of senior migrants of any province; Quebec and Saskatchewan, among others, experienced a net outflow. **Seniors who migrated to BC between 1980 and 2016 will end up costing the province $7.2 billion, while Quebec will ultimately experience a savings of almost $6.0 billion over the same period.** In population numbers, BC took in over 40, 000 seniors and, by comparison, Quebec lost over 37, 000 seniors. (Clemons et al, 2017).





Physiotherapy in Long Term Care

Who is getting what? An article presented in 2014 did a cross-sectional study on who receives rehab in Canadian Long-Term Care Facilities. It indicated that only 12.3% of the seniors in LTC received Physiotherapy with varying levels of care. (MacArthur et al, 2015). The Office of the Seniors Advocate reported in 2020 that the number had fallen to 10%. Covid-19 has not helped our LTC population (Office of the Seniors Advocate, 2020). **Physiotherapists are medically trained to design and teach evidence-based programs that will improve balance and prevent falls, increase self-confidence and reduce the fear of falling.** Importantly, physiotherapy can reduce hospitalizations and other costly medical treatments, while also assisting seniors in retaining their independence for as long as possible (Office of the Seniors Advocate, 2015).

Physiotherapy is proven to be beneficial for seniors diagnosed with Parkinson's, as Physiotherapists can "design and teach movement strategies to overcome difficulty in generating automatic movement and thought" (The Chartered Society of Physiotherapy, 2016). **Physiotherapy can provide a valuable service in proactively speeding up seniors' recoveries after surgery and other medical treatment.** All evidence supports how crucial time can be in determining the extent to which a frail senior will recover from a period of inactivity or traumatic event such as a stroke or a fall. **The earlier physiotherapy begins, the greater the likelihood of regaining maximum function** (Office of the Seniors Advocate, 2015).

PHYSIOTHERAPY ASSOCIATION OF BRITISH COLUMBIA

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Ensuring Psychosocial Health and Human Rights in LTC

Ensuring The Psychosocial Health And Human Rights Of Long-Term-Care Residents And Their Families: A Social Work Perspective

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 psycho-social 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.

The Call for Mandated Social Work Positions

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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, LGBTQ2S+, 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 person-centred 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 practice-based 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 https://www.bcasw.org/ Seniors Community of Practice.

Quality of Life and Therapeutic Recreation Teams in LTC

BCTRA | British Columbia Therapeutic Recreation Association

Therapeutic Recreation Improving Health Maximizing Well-Being

Quality of Life and Therapeutic Recreation Teams in LTC

Therapeutic recreation is recognized as an essential person-centered healthcare service that employs evidence-informed leisure and recreation opportunities to improve and maximize health, physical function, social and emotional well-being and overall quality of life.

Purpose:

To provide rationale for a standardized approach to support the organization, delivery and evaluation of Therapeutic Recreation (TR) services in long-term care (LTC) homes to address the health and quality of life of residents. This must include specific staff qualifications and ratios for both leaders of recreation therapy and their assistants.

Recreation Therapy and the Therapeutic Recreation Team

There is a difference between an entertainment focused recreation program and a therapeutic recreation program. A well developed, comprehensive TR framework Is needed to ensure that residents' needs and interests are assessed, planned for and met.

Recreation therapists provide an evidence-informed framework whereby staff lead purposeful and meaningful recreation and leisure opportunities within a structured, comprehensive program. Driven by a person-centered approach, the recreation therapist assesses each person's strengths and abilities and creates an individual care plan to achieve specific outcomes. TR programming targeting physical, social, cognitive, emotional and spiritual domains, facilitates the achievement of individualized outcomes that improve quality of life indicators such as increasing social interactions, improving mood and healthy sleep patterns. By enhancing these abilities individuals will experience a decrease in responsive behaviours, falls and subsequent injury, social isolation, apathy, use of medications such as antipsychotics, and the use of physical restraints. The achievement of these and other outcomes, demonstrates recreation therapists' integral part in improving interRAI outcomes. TR is a profession that focuses on individuals' abilities which in turn, maintains their independence and supports active-aging initiatives.

A TR team, comprised of recreation therapists and TR assistants, is uniquely trained and educated to address the health and quality of life needs of residents in LTC. The BC Therapeutic Recreation Association (BCTRA) believes the TR team is essential in LTC to provide meaningful TR opportunities for all residents, regardless of abilities. Recreation therapists not only plan and implement these opportunities but also provide leadership and supervision to TR staff. The lack of TR leadership and planning causes reduced job satisfaction which can lead to increased turnover in staff. However, more importantly, when TR teams are poorly trained and supported it leads to a lack of capacity to create engaging and meaningful TR one-to-one and group programs for residents. Conversely, when planned and organized well, TR teams provide quality of life services that support and engage residents and their families to live a life of meaning and connection.

In addition to the person centred benefits of TR, the culture of the home is strengthened by the positive outcomes from TR programs which impacts quality of life and comfort during end-of-life care and increases staff morale due to the positive effect on residents' engagement and abilities. Further, the skillset of the recreation therapist aligns with the care home's strategic plan to improve upon the lives of individuals in need of long-term care as set forth by provincial governing bodies.

A number of recent documents, the Royal Society of Canada (2020), the BC Care Providers (2020 & 2021), the 2015, 2016, 2017-2018, and 2019 BC Seniors Advocate reports, the 2018 CALTC study and the New Brunswick (2014) study, acknowledge and describe the important role that recreation therapists play in improving the health and quality of life of residents in LTC.

The Government of BC has regulations and acts that require certain services and rights for residents in care. Recreation therapists are able to deliver services that comply with these regulations to promote the health and quality of life of residents including:

- a care plan that is based on resident's "unique abilities, physical, social and emotional needs, and cultural and spiritual preferences". (Residents Bill of Rights 2009)
- "protection and promotion of his or her health, safety and dignity" (Residents Bill of Rights 2009)
- "treated in a manner, and to live in an environment, that promotes his or her health, safety and dignity" (Residents Bill of Rights 2009)
- "lifestyle and choices respected and supported, and to pursue social, cultural, religious, spiritual and other interests" (Residents Bill of Rights 2009)
- a care plan that must include a recreation and leisure plan (Residential Care Regulations)

However, there are barriers to reaching these outcomes for older adults in LTC.

In 2016, representatives from BCTRA met with BC Seniors' Advocate to discuss how recreation therapists could help address the concerns she had raised about the over-prescription of antipsychotic medications to manage responsive behaviours, the premature admission to LTC, and the need for better data. We discussed how intentional involvement in meaningful recreation helped to reduce responsive behaviours and to preserve the physical and cognitive functions of older adults. Over the last number of years, as reported in the Seniors' Advocate's annual reports, while the number of LTC residents receiving

recreation therapy services has improved (29% in 2019), a majority of residents are not recorded as having received TR services. This is clearly not adequate to address older adults' quality of life needs, and in particular, to address the urgent needs identified by the BC Seniors' Advocate. Recreation therapists still remain challenged to meet licensing expectations for TR services due to a lack of time and staffing resources.

The right skill mix, as well as the numbers of TR staffing, are critical for providing services to maintain/ensure quality of care and quality of life.

The Royal Society of Canada (2020) report also stressed the need for educated and qualified staff. Recreation therapists and TR assistants are already working in many LTC communities, but there are many communities with recreation staff who have no formal TR education or training. Multiple titles, qualifications and roles have been used for staff providing recreation services which has created inconsistency within services provided and impacted the ability to meet residents' needs. (Adams, D et al. 2008). Risk of harm and negative health outcomes must be mitigated by using evidence informed practice and creating an ethos of quality improvement. (ATRA 2015. "Standards of Practice."). A consistent standard of education and training for recreation therapists and TR assistants is needed to ensure qualified TR teams are supported and employed in LTC so that care quality and quality of life measures can be achieved.

The Royal Society of Canada (2020) report highlights the lack of data available to fully understand how LTC facilities are performing, to determine and measure care quality, and to ensure standards are met and residents are experiencing quality of life. The report acknowledges the interRAI LTC as the international standard for reporting and evaluating care quality and the achievement of quality of life outcomes. Recreation therapists are qualified to complete interRAI LTC. Good data is essential but unfortunately, data regarding the provision of TR services is limited and needs to be measured more fully. Not all TR teams in the province have a qualified recreation therapist, and so data is lacking and inconsistent. We have been advocating for recreation therapists to consistently complete data entry into the interRAI.

BCTRA notes with concern that without tangible institutional planning for the delivery of TR services, how do care homes improve overall quality of life? By not planning for services specific to quality of life needs as we do for the medical needs of residents, our institutions are not truly addressing issues of quality of life such as isolation, loneliness and depression in BC's LTC homes. Currently many sites are not able to hire trained recreation therapists and TR assistants because they are not available. Continued lack of planning will lead to more shortages of staff trained specifically in providing TR for this population.

Standardized Recreation Therapy services require:

- Mix of staff to include recreation therapists and TR assistants at each site
- Standard training/education of staff – BCTRA standards for recreation therapists, TR assistants

- Staff numbers per site and staff skill mix to meet the standards in the Community Care and Assisted Living Act, Residential Care Regulations, and the interRAI-LTCF system for data collection

BCTRA supports the call for a minimum of 0.5 direct care hours per resident for allied health, which includes recreation therapy.

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Physical Design and Review of the Household Model

Rudy P. Friesen , MAA (ret.), FRAIC, Hon FAIA, LEED AP

In a few short months, COVID-19 has achieved what no individual, organization or advocacy group was able to do for decades: it has exposed the cracks in the way we care for our older adults. Before this pandemic, almost daily media reports described numerous problems in Canada's long-term care facilities, but nothing changed.

Our long-term care and seniors' facilities are now being called "death pits." They account for more than 80 percent of COVID-19 deaths in Canada. We are hearing calls for every potential remedy from government ownership to more public funding to national standards to surprise inspections.
As a retired architect who has more than 40 years of experience designing facilities for older adults, who has served on boards of facilities and who has researched leading-edge initiatives around the world, I focus mostly on the built environment and the delivery of care. Although I see some merit in all the solutions being talked about, I believe they fail to address the fundamental problem: the need for pan-systemic change.

We need a multipronged approach to caring for older adults. We need a system that is more humane, trustworthy, accountable, equitable, economical, integrated and resilient. There are better approaches out there, but their uptake has been slow. Decision-makers seem oblivious to them, perpetuating a broken system.

Unfortunately, governments are now being urged to fund upgrades of existing care facilities and the construction of new facilities based on obsolete standards. It is crucial that we fix the horrific problems that were identified long before the pandemic and that have mushroomed since it began.

A better model

Beginning in the 1940s, long-term care became medicalized and institutionalized, resulting in hospital-like facilities. They featured long corridors, or "horridors," with shiny floors and glare lighting. Nurses' stations were omnipresent, and there was an authoritarian staff hierarchy. Meals were prepared in commercial kitchens. Common areas were large and impersonal. Care delivery was hospital-like, too, with fixed schedules.

Sadly, most long-term care facilities are still like this. Not only that, but residents are isolated and segregated from the community and warehoused in quarters where disease spreads easily.
One viable alternative is the household model. It provides better quality of care for older adults in a more cost-effective way while giving them freedom of choice.

Household-type facilities are designed to operate like a family home. There's usually a grouping of 6 to 10 residents around a living/dining area. Meals are prepared in a residential-type kitchen. A self-managed team stays with each household. They are specifically trained as universal care partners: they provide personal care, meal preparation, laundry, light housekeeping and companionship. Staff here feel more satisfied than those working in institutional-style facilities. Schedules are flexible and determined by the residents. This is especially important for people living with dementia since they need familiarity.
Because of its scale, the household approach can be incorporated into developments of any size. In suburban Rochester, New York, for example, two 10-resident homes are integrated into an existing

residential neighbourhood. Ideally, two or more homes can also be integrated into large village-like communities that may include multiple levels of care, multigenerational housing, and mixed uses such as shops and services.

Studies show that these household-type facilities cost less to operate because less medication is used; in addition, less food is wasted. Costs to the health care system are reduced, too. There are fewer falls, pressure ulcers and hospitalizations because residents remain healthier.
The household approach is becoming the standard for new construction in Manitoba, where these facilities are being built at almost half the cost of medical-institutional facilities, according to architects involved in the projects. The shift is partially due to changes in the way the building code is being interpreted. Officials now see care facilities using the household model as different from hospitals, which would be governed by more restrictive (and more expensive) requirements.

Better approaches to long-term care are being called for by governments, families of people in long-term care, boomers (who are next in line) and the National Institute on Ageing (NIA). The NIA's recent report *Enabling the Future Provision of Long-Term Care in Canada* describes new approaches and models of long-term care that promote person-centred and flexible care. This organization suggests that innovative evidence-informed models of care should be introduced "to shape an enhanced future for the provision of long-term care."

The NIA report examines the Hogeweyk, a renowned facility in the Netherlands that provides care for older adults living with severe and extreme dementia. Opened in 2008, it is owned by the nonprofit Vivium Care Group. The Hogeweyk emphasizes familiar surroundings and quality of life, with residents grouped according to interests, backgrounds and values.

The report also describes examples such as the Green House Project, a nonprofit organization with approximately 300 homes in the US. Its mission is to create "radically non-institutional" environments that result in "real homes, meaningful lives, and empowered staff." The Green House Project, founded by Bill Thomas in 2003, was inspired by the Sherbrooke Community Centre in Saskatoon, which opened its first households in 1999.

Lessons from COVID-19

One of the most important factors in controlling COVID-19 has been the ability to cohort residents: to create smaller groupings of residents to improve infection control. Self-contained living units such as households accomplish this goal while still supporting relationships.

Susan Ryan, senior director of the Green House Project, told me in an email in May, "The Green House homes are doing quite well amid the pandemic. In many ways, this is a model that was made for this moment. The design features, as well as the consistent staffing and philosophy of person-directed care, combine to create truly synergistic transformation that mitigates the spread of infection."

The Hogeweyk is reporting similar results. Eloy van Hal, senior advisor and a founder of the organization, wrote me in early May, "Although the Hogeweyk is not completely Corona-free anymore, it seems to be under control, in large part due to the small households of 6 to 7 residents and most staff working in only one or two households." He added, "The household model like the Hogeweyk (or small suites) has a lower infection risk because it has the advantage of better controlling and preventing the pandemic."

"There will come a time when we will see this pandemic in the rearview mirror. There will not come a time when we will return to the old normal," says Robert Kramer, president and founder of Nexus Insights, an advisory firm that helps clients "rethink aging from every angle." The new normal for long-term care must include at least two key considerations: small households and more personal space. Small households that support relationships, provide infection control and have a stronger connection with community will be critical. Kramer predicts that seniors' housing and care will change. "Whether it's 60 units or 160, you'll see small neighbourhoods that can easily isolate when an infectious disease strikes."

Juniper Communities, a senior living organization with 22 facilities in the US, is reinventing itself based on its experience dealing successfully with COVID-19. Lynne Katzmann, its founder and president, said at the Senior Living Foresight virtual summit in April, "Cohorting is very important to give peace of mind, to assure safety but also to support building real strong relationships among small groups of people." She also notes that Juniper's nonhierarchical approach to staffing will become more so, and that staff will be retrained to become "true universal workers."

It is also clear now that residents will require more personal space to reduce the psychological trauma of living in small rooms during lockdowns. Kramer observed at the April summit, **"**We now see a desire in design for larger personal spaces rather than having huge congregate spaces with tiny personal living spaces."

A rethink of resident rooms in long-term care facilities could result in small suites with a bedroom (private space) and a living area (semiprivate space). This is already the case in a number of European long-term care facilities. In a recently completed project embedded in a small Dutch community, long-term care will be provided to residents in their small suites by the self-managed care teams of the healthcare organization Buurtzorg.

The COVID-19 pandemic has disrupted our lives and given us incentives — personal and societal, and moral and economic — to reshape long-term care. Let's take full advantage of this opportunity. We can begin the process by dismantling and replacing our archaic systems. We need pan systemic change and we need it now — for Canada's older adults, their families and their care partners, for Canadian society and potentially for ourselves.

Supporting Residents in Care through Family Councils

January 2015
Updated June 2020

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.

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Unfortunately, some facilities still refuse to support or even recognize independent, self- determining 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, self-determining 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;
ii. 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;
iv. 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:

i. 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.

Addendum *(excerpt from VIAFC website, 2014)*

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.

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Multi-Stakeholder Task Force Process and Structure

The April 2021 ARRC report, *Improving Quality of Life in Long Term Care – A way forward,* recommends that the Minister of Health strike a diverse inclusive multi-sectoral and multi-stakeholder Task Force to develop a post-COVID provincial action plan, building on the ARRC recommendations.

This appendix describes a recommended approach for how the task force would be assembled and organized, and the process it would follow in its work. The process has an established history of achieving collaboration among parties who otherwise find themselves in fundamental disagreement. An extended description of the process, instances where it has been successfully applied, and an elaboration of the information in this Appendix, *A Multi-stakeholder Task Force for Senior Care System Reform in BC*, can be found at http://arrcbc.ca/action.

The recommended approach is a departure from traditional commissions of enquiry and advisory panels as mechanisms for consultation and engagement with civil society on critical issues of public policy. The Task Force in this instance would be charged not only with generating recommendations for changes, but would also engage the community in the preparation of action plans for implementation both by government and by stakeholders in the community. The approach is founded on the principles that:

- no one party acting unilaterally (usually Government) can make the needed changes,
- the essential collaboration of many parties can be obtained through a process which generates a shared understanding, creates a consensus on possible futures, and features participatory planning

At the heart of the process is the identification of possible futures for the senior care system, followed by widespread community engagement in the formulation of action plans, informed by an exploration of the scenarios. These steps are led by the task force and are carried out in collaboration by government and the other stakeholders.

It will not be possible to say what changes will be forthcoming, or how they will proceed, until the planning takes place. The interventions in the system may be as straightforward as providing more resources or more training for those who work in the system. Or they may involve – more disruptive- new standards, practices, policies, and organizational relationships. Experimental trials and prototypes may be needed to learn what works. At the extreme, the plans may call for a cultural shift involving new paradigms and models for care. Whatever does emerge from the process should reflect a collaborative venture founded on a shared understanding and a relationship of trust among those involved.

To support this collaborative process, the members of the task force should represent the stakeholder community: seniors, government, care provider organizations, care workers, and the public. Appointed by the Minister of Health, the task force would be charged with managing the collaborative process through to the formulation of action plans for agreed changes, and

the design of an enduring mechanism of stakeholder engagement and collaboration for the sustainment of the senior care system.

The work of generating scenarios, engaging with the community, and consolidating action plans would be carried out by a team, drawn from government and stakeholder organizations, of persons who would subsequently take the lead in implementing changes. This planning team would be appointed by and accountable to the task force. Specialist resources, drawn from academia, government, and the civic sector, would be recruited to advise and support the work of the planning team, and to facilitate the collaborative process, but the responsibility for results would remain with the team under the direction of the task force.