LONG-TERM CARE IN CANADA

From National Shame to a New Ecology of Care

Position paper developed at the time of the COVID-19 pandemic. Provides an overview of long-term care, and a call for radical reformation: a new ecology of care in Canada.

Alberta Council on Aging
December 2020

"The COVID-19 pandemic has had a devastating impact on the long-term care sector around the globe. Now is the time to respond to the International Community's urgent call for action, with innovative solutions and practices that respect and protect the rights of older people living in care facilities and their families."

-International Federation on Aging

The COVID-19 pandemic is revealing both significant strengths and weaknesses across every sector of society. Canada has long prided itself for its observance of human rights and its global ranking as being #1 in the world for quality of life. How then is Canada holding the record amongst similarly developed countries for the highest death rate amongst older adults living in long-term care facilities? By late fall 2020 long-term care and retirement homes reported

12% of the Canadian totals of COVID-19 cases and 75% of total deaths

To understand how we have reached this horrific point, it's necessary that we analyze the culture and system of long-term care in Canada since its inception.

Auxiliary hospitals were created in the late 1950's as a lower-cost and placement alternative to acute care hospitals for patients requiring lengthy recovery or continuous care. Although part of the hospital system, patients in auxiliary care were charged a daily accommodation fee based on the rationale that these facilities replaced the resident's primary dwelling. Years later, post auxiliary hospital program, this ideology was extended to care facilities to include all costs one would have absorbed in their family home: special diets, medications, housekeeping, transportation, incontinent supplies, etc. This is known as **unbundling of services,** or *a la carte* billing, which paralleled the arrival of the **supportive/assisted living** program under the broader **continuing care system**, of which **long-term care** is situated. These programs vastly vary across the country.

Nursing homes (now known as long-term care) were brought into the system to provide a lower level of care than auxiliary hospitals and to respond to the philosophy that **home-like versus auxiliary hospital would provide a better quality of life.** Operators of private enterprise facilities, charitable homes, and new publicly owned homes were given access to public dollars, **subject to regulations and standards**.

Additional pressures from early hospital discharge and dismantling of auxiliary care settings, and specialized rehabilitative programs, meant fewer resources were accessible in the long-term care (nursing home) sector for people living with complex care needs. This coupled with the influx of private care conglomerates brought forward competing ideologies- the belief the old who were very sick, and who would receive high quality care at the end of their life, would come second to the expectation of profit margins. Publicly run facilities were also forced to operate under a corporate model and instill fundraising mechanisms. Hence the never-ending search for efficiencies and cost-cutting measures such as outsourcing laundry, food, and pharmacy, temporary, part time and casual staff, working and managing across several sites, and inconsistent support and guidance from public health.

As much as a **private retirement homes targeted for independent seniors** would add to the overall wellbeing of many older people, there is a point where trouble resurfaces. If a resident's care needs go beyond what is allowable in a particular retirement home (such as two-person transfer, behavioral support) the resident will likely end up in hospital and will enter the bottleneck situation of waiting for placement to long-term care. The backlog is enormous and puts pressure on every aspect of continuing care and hospital systems, so that no one area runs well and outcomes in terms of quality of life are less than satisfactory.

Currently long-term care facilities provide living accommodation for people (over 18, mostly over 65) who require on-site delivery of 24/7 supervised care, including professional health services, personal care, and services such as meals,

laundry, and housekeeping. There are approximately 2,040 such sites in Canada with two different providers of long-term care. Just under 50% of long-term care facilities are publicly run, and the remainder is a mix of for-profit and not-for-profit.

Public lodges, established first in Alberta in 1959, were a mode of publicly subsidized supportive housing outside the healthcare sector. Public lodges were created to provide safe housing, nutritious meals, social opportunities and minimal protective oversight by non-medical staff for independent older adults with minor health problems and limited incomes. Without such supports, these individuals were seen to be at risk for health breakdowns and hospitalization.

> "We were constantly fighting to preserve the culture of home-like environment. Sometimes representatives from the provincial health services, home care division, were like an elephant in the room. They wanted residents to line up for their medications, or to take their insulin shot at the table in front of others. At the same time, we ourselves were often inflexible and resistant to change. For instance, residents could not bring their walker in to the dining room, or make special dietary requests. Activities stayed the same year after year without finding out what the residents' preferences were. We were slow to catch on how many people were living with early-stage dementia."
> *Retired RN and lodge manager, age 80*

A public home care program was established in 1978 to provide nursing and homemaking services to older adults in their homes and lodges. Home care is also under provincial funding and eligibility and program nuances vary from province to province, even from urban to rural settings. Once entirely delivered publicly, by the 1990's, personal care workers were being contracted-out from other agencies. The lodge program, retirement homes and the various levels of supportive housing relies heavily on services provided by home care. The early model of home-like, non-clinical housing has been affected by one system imposing on the other. Programming takes place around systems and schedules rather than within the context of person-centered care. Even at this time of pandemic, in some parts of the country, workers are not being assigned to specific homes or lodges, rather they are responding to the demands of scheduling and moving about sites.

> "Everyday I have a different worker coming in to my apartment. I am nervous as this contradicts what I know about infection control."
> *Retired health care administrator and recipient of home care, age 75*

COVID-19 Response

Initial public health messaging to COVID-19 was "we must lock down. We must keep our old safe." Yet an already unsafe situation was brewing. Years of underfunding, understaffing, over-crowding, and under-resourcing long-term care and upstream systems means that personal care is being supplemented and delivered by volunteers, family members and additional privately contracted companions and personal care aides. Decades of adapting to this culture put residents living in long-term care centers dangerously at risk during the pandemic when the silent, unpaid support staff were overlooked. The transfer of knowledge family

and friends have about a resident was lost. Environments of over-crowding also impacted on the severity of COVID-19 spread. Quarantine orders for the entire continuing care stream were instituted (from public lodges and private retirement homes through all levels of supportive living and long-term care), but done without an assessment as to care needs and how dangerous the immediate lock out of volunteers would be. Under these conditions, residents in long-term care facilities could not possibly have their personal care needs met, let alone their social needs. We must be honest about this when we look back on the pandemic and the years of inequities leading up to this crisis. We must keep the profile of our older people at the forefront. Those living in long-term care are typically living with two or more morbidities and possibly dementia- often very dependant on others to have a drink of water, go to the toilet, become orientated to time and place, receive nourishment, to be able to express and receive human kindness, to be regarded as a human being.

Person Centered Care

The term *person centered care,* as coined by humanist Carl Rogers, has been embraced by this sector for decades, yet the locus of control typically lies with the institution, not the person or resident. This contradicts what is known to be a fundamental building block in wellbeing and self esteem- having a locus of control in one's own life. **We cannot talk about caring for the person if there is no mechanism to allow for the voice of the person.**

> "It is the human connection a person most needs. Care providers, including family and friends, do well to recognize the many facets of a person. They can honor the spirit and uniqueness of the person they are caring for. Listen. Learn from the person."
> *Retired nurse, therapeutic touch practitioner and resident in long-term care, age 89*

If the human rights of the person requiring care and support are not upheld, we will endlessly be programming for the system and its goals rather than with and for the person.

> "I am at the age now where I do as I am told." *Spouse and primary care provider of person living with Alzheimer's disease, age 84*

> "I am terrified for what is ahead. If and when I become incapable of taking care of myself, what is ahead for me? Who will care what I need or even care about?"
> *Community volunteer, age 78*

Solutions to A New Ecology of Care

In Canada, residential schools and institutional care for persons with developmental disabilities have been discontinued because they were sites for crimes against individuals and against humanity. Any long-term care institutions where the basics of life are not being met and properly supported should likewise be discontinued.

Upon deconstructing the challenges upstream and within long-term care, it is evident care of the old, and persons living with disabling conditions, is a culture of wide marginalization. The intersectionality of ageism, gender, ableism and racism is prevalent. Systems, rather than having mechanisms to uphold the human rights of the residents, staff, families, and volunteers, are operating:

1) as an industry focused on high investment returns, or

2) within a climate Carole Estabrooks describes as

"benign neglect" to apathy as expressed by this long-term care administrator, when questioned about meeting regulations and standards, "we have no staff and you do not want your taxes raised."

> "You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete."
> *Buckminster Fuller*

Do we continue to try to fix a culture and system that breeds neglect, low quality of life and ultimately untimely death? Or do we commit to collectively create, on the national level, a new ecology of care?

> "Don't fight against. Fight for"
> *Dr. Doris Grinspun*

> "We are looking for conditions in long-term residential care that support active, healthy aging for residents and staff, taking gender, racialization, contexts, and individual capacities into account. They are conditions that allow residents, staff, volunteers, and families to flourish or at least enjoy as much as possible their time in long-term care ...possibilities for health and joy." - *Physical Environments for Long-term Care Ideas Worth Sharing* -

Aging in place is a concept that supports older adults to live in their home and community, even if they live with disabling conditions and dementia. The same conditions for appropriate long-term care need to exist upstream where service is provided in community within a person's home or residence of choice. A promising practice is broad implementation of age-friendly community initiatives that address the eight domains of supporting healthy aging. Eight domains that cities and communities can address to better adapt their structures and services to the needs of older people: the built environment, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, community and health support services.

We call for a new paradigm in care provision. The new ambassadors of front line care working with older adults within long-term care and community must be **Personal Support Aides**: respected employees of public Home Care regulated and managed under a **National Public Health program;** trained, coached, supported and considered as equal professionals within the clinical and community care teams, cross trained in principles of aging to offer physical care as well as meaningful programming as per client's interests, needs and rehabilitation plan. This delivery of comprehensive care and support is more humane, safe, efficient and representative of public health and dementia care best practice.

Within a **new ecology of care**, the conditions necessary to meet fundamental needs and create a relationship based on trust must be upheld. What is a relationship of trust? The person knows confidences are respected, choice and control are maintained and the person will not be abandoned.

References

Alberta Dementia Strategy and Action Plan

Canadian Institute for Health Information

Cross Country Meeting: Mobilizing Collective Action for Long-tern Care Reform-webinar

Deaths in Residential Care in Canada

Global Age Friendly Cities a Guide

Home Care in Canada- An Environmental Scan Supporting Healthy Aging in Place October 2017 Sask Pop Health

International Long-term Care Policy Network ILPN (ilpnetwork.org)- deaths in LTC

Health Canada- definition of long term care

Key issues and Possibilities in Continuing Care in Alberta

Long term Care Homes in Canada The Impact of Covid-19 Library of Parliament

National Institute on Ageing Long term care Covid-19 Tracker

No easy fix for long-term care, but it starts with working conditions: experts | CP24.com Estabrooks quote

Physical Environments for Long-term Care2016.pdf (policyalternatives.ca)

Restoring Trust: COVID-19 and The Future of Long-Term Care | The Royal Society of Canada (rsc-src.ca)

The Changing Landscape of Healthcare and Social Policy

About Alberta Council on Aging

Our mandate is to improve quality of life of older perons through education, advocacy and inclusion. For nearly fifty- four years, Alberta Council on Aging has advised local, provincial, federal governments and the general public about matters relating to the opportunity for full and equal participation of older persons living in Alberta and Canada.

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