

# **AN ILLUSION OF CARE**

Promise vs Reality of Long-Term Care Facilities

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# An Illusion of Care Promise vs Reality of Long-Term Care Facilities

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# Preamble

Vulnerability due to the increasing care needs of people who are ageing and/or who experience disabilities often triggers a search for ways and means of ensuring that those care needs can be provided for. That search often brings people to a startling reality in Ontario. There is a precious little support available other than placement in a long-term care facility. Ageing at home with support to do so is woefully unavailable for most people, despite this being a clear preference of many.

# Who Cares What Seniors Want?

The Ontario Ministry of Health and Long-Term Care (MOHLTC) has for decades opted to invest in an institutional model of care for vulnerable elderly and for numbers of younger people who have disabilities. There has been a corresponding paucity of investment in the development and expansion of alternatives that would support people in their own homes or in small home-like settings in their own communities. The fact that the majority of people express repeatedly they do not want to be "put in a home", as it is so often euphemistically phrased, is beyond the point. In a research study done for the Canadian Institute for Research and Public Policy, researchers Williams et al summarized, "As insightful observers in Ontario and elsewhere have commented, older persons overwhelmingly wish to age at home" and they went on to identify that the "goal is to maintain older persons and their caregivers as independently as possible for as long as possible in their own homes and communities" (Williams et al). This observation has been acknowledged by many others, and is the singular most often stated preference by all (Abdi et al, 2019; Sinha, 2012; Spindel 2020; Till, 2020; Drummond et al, 2020; Lord, 2020; Donner, 2015; HomeCare Ontario, 2020; Neville et al, 2016;).

In a comprehensive report on the needs of **older adults**, the National Institute on Aging clearly stated "older Canadians overwhelmingly want to age with dignity and autonomy in their homes and communities with appropriate care and support" (National Institute on Aging, 2019).

Taxpayers have been, and continue to be ignored on this point. Institutional care is the primary model of care provision for this group within this province, and alternatives are simply not being developed in any meaningful way.

# **Misguided Beliefs**

Contributing to the underpinnings of this practice is the oft-held belief that there will always be some people who require institutional care. This author has extensive experience with people who have very complex and challenging care requirements, and can state unequivocally that such beliefs are simply and blatantly false. "Extensive evidence exists that people with even the most challenging support needs can be appropriately and safely cared for in their own homes, or in small home-like settings in the community. In so doing, they can be enabled to live more comfortable, healthy, normalized, valued and meaningful lives than those who have been relegated to large impersonal congregate settings" (Till, Envisioning a New Future, Nov 2020; SSAO, 2021).

People First of Canada have a long history of advocacy, and institutionalization has been a major concern on their part since their inception. As they identify, "from the earliest to most recent times, arguments have been advanced to justify institutionalizing people. Typically these arguments included notions that institutions could provide better care or ensure better health, that people would be happier "with their own kind" or that people with severe disabilities, complex health or behavioural issues could not be supported in community" (People First and Canadian Association of Community Living, 2010). The success of a wide number of initiatives to ensure inclusion in typical societal settings for people with many types of vulnerabilities has clearly laid bare the inaccuracies of these assumptions.

#### What Comprises Ontario's Long-Term Care System?

Two main residential options exist within the system of elder care in Ontario. One is affordable only by those with the personal financial means to purchase it and is primarily comprised of apartments or condo-style residential facilities, offering supplemental care as needed. These are typically referred to as Retirement Homes. They are not funded nor subsidized by the government. It should be noted that many of these settings require residents to leave and move into the second of the two options should their personal or medical needs increase past an established threshold. While preferred, supports to enable a person to remain in their own home are woefully inadequate, and therefore seldom a viable option.

The second of the two main options is a partially government funded institutional model of care, most often referred to as a Long-Term Care (LTC) facility, previously known as a Nursing Home or "Home" as many people still refer to them. Individuals must pay a portion of their care in these settings when they have the funds to do so, and may be subsidized with regard to that obligation if they do not. These two styles of care settings differ at times to some extensive degrees. The private-pay Retirement Homes are able to provide a greater degree of choice in what they provide, and some may arguably provide small living settings that still enable individuals the opportunity to maintain some control over their lives. However, neither model can fully escape the pitfalls of institutional settings anywhere, with the LTC facilities repeatedly demonstrating the worst of these impacts.

Families, desperate for care for their loved one, must accept what they can find, often after having been on a waitlist for an extended period of time. For those without financial means to purchase care in any of the private settings, there are seldom any options other than to accept care in one of the LTC facilities. Usually, individuals are offered little time from the notice that a "bed" has been found until the time the individual must move in or lose that opportunity and face an extended further wait. This creates a de facto situation in which there is effectively no choice but to make arrangements for the placement of the individual in that setting. LTC procedures require consent for the admission of the individual into the facility, signed by either the individual themselves if deemed capable, or by a person legally authorized to sign on their behalf. In light of the clear preference so widely held for not being "placed in a home", along with the unavailability of alternatives where care needs can be responded to, the consent signing creates a false narrative – it is not agreement in principle, but

reluctant acceptance of an unwanted option in the face of no real choice in the matter (Crawford, 2007; Till, 2020).

# Assumptions of Care

As families search for LTC facilities, they are met with highly reassuring and compassionate-sounding promises of individualized professional care for their loved one from the facilities' promotional material, as well as in conversations with placement or admissions coordinators.

Extendicare, one of the larger corporations providing care in LTC facilities in Canada, promotes their facilities as follows: "Our services include licensed professional nursing, personal care on a 24 hour basis, access to a physician and other health professionals, medication administration, restorative care and specialized therapies as well as social, recreational and exercise programs designed to meet the individual needs of residents and patients. We also provide hospitality services including pleasurable dining and special diets, and specialized programs to address the needs of persons with responsive behaviours and advanced Dementia, complex chronic diseases or at end of life". Additional assurances are made indicating that all residents "Will be treated with courtesy, respect and dignity, free from mental and physical abuse, and provided with a safe, clean and healthy environment. Each will have access to programs that meet physical, spiritual, social, emotional and intellectual needs, and that provide opportunities to develop interests, abilities and potential; each will receive nutritious meals and snacks appropriate to diet needs and which meat Canada's food guide; and each has privacy when receiving counseling, treatment or personal care."<sup>1</sup>

Sienna Senior Living is another of the large corporations operating LTC facilities and its promotional material echoes such promises: "Special attention has gone into developing opportunities for residents to celebrate their culture, such as menu options, activities, social events, and spiritual programs. Warm and friendly nursing and recreation teams deliver great programs and resident-focussed recreational activities, including art, gardening, pet, and music therapy programs". <sup>2</sup> Other LTC corporations offer similar care commitments with similar expressions of concern from families about actual conditions in those facilities, including Chartwell, Revera and Rykka, three of the other largest corporations operating Long-Term Care facilities.

These promises of care create a pervasive societal assumption that is compelling and they lead to a belief that the care will, in fact, be provided as outlined. For many, the reality is starkly different. Documentation over many years has demonstrated a wide variety of failures: failure to provide adequate nutrition and hydration, to ensure adequate personal care, to ensure adequate staffing levels, to ensure individualized care plans are developed and followed, to ensure fall prevention strategies are implemented, to ensure appropriate medications, to ensure adequate infection control strategies are followed, to protect people from a multitude of abuses, to ensure the environment is

<sup>&</sup>lt;sup>1</sup> These excerpts were obtained from the website of Extendicare's Canada's Head Office, in a document entitled Extendicare Canada. Extendicare...... Helping People Live Better. These commitments are also detailed on the Website of Extendicare Guildwood, where families allege starvation **contributed to** the death of their loved ones. (McBride, 2020). <sup>2</sup> This information was obtained from the Sienna Senior Living: Woodbridge Vista Care Community website.

Yet this is the home were a resident died of starvation and dehydration (inanition) during the first wave of the Covid-19 pandemic. He was perhaps the only resident for whom a Coroner was called to determine a cause of death, and where examination of the body explored circumstances beyond simply identifying a COVID infection (Glover, C. (June 9, 2020). Family reeling as senior dies of malnutrition, not COVID-19 inside long

term care home. https://www.cbc.ca/news/canada/toronto/ontario-long-term-care-death-1.5604030 )

clean and hygienic, to ensure residents are provided stimulation and programming supports (Spindel 2020 & 2021; McBride, 2020; McKeen & Nuttal, 2021; Gardner et al, 2020; Warnica, 2021; Welsh & McLean, 2011; Welsh, 2020; Dubinski, 2018; Sourtzis & Bandera, 2015; O'Keefe, 2018; Ouellette & Brown, 2018; Anderson et al, 2018; Pederson et al, 2020; Wallace, 2021; Toronto Star, Feb 7, 2021).

Jane Meadus, lawyer with the Advocacy Centre for the Elderly, reports "We hear stories of people being illegally detained, of being left in bed for days, filthy conditions, cockroaches, assault" (Spindel, 2020). Dr Patricia Spindel is a long time advocate and policy analyst who has documented concerns and critical flaws in LTC facilities for over 40 years. In an examination of MOHLTC inspection reports, Spindel has reported "What few inspection reports have been completed in 2019 and in the years before tell a tragic story of abuse, neglect, falls and injuries, medication errors, homes in poor repair, not enough linen, RNs not on duty for days at a time, staffing shortages, and a host of other problems. Many of these homes were a disaster waiting to happen" (Spindel, 2020). Star reporter Rosie DiManno quoted one PSW who spoke about appalling conditions that exist within the LTC facility she works in "Cockroaches, ants, leaks, mold, holes in the walls, rooms not being cleaned. There are a couple of rooms that have not been cleaned in six months. How do I know? I put dimes on the floor and they're still there" (DiManno, 2021).

The COVID-19 pandemic has brought concerns about LTC facilities into substantial public exposure but it must be understood that significant issues of concern have been documented and reported on for decades, with no effective resolution throughout that time. (Toronto Star, Feb 7 2021). In a recent Toronto Life exposé, McBride noted "last June, a report on the future of long-term care by the Royal Society of Canada detailed the distressing, often scandalous conditions in many Canadian homes. Residents assaulted by staff or dying from infected bedsores. Severe staffing shortages. Dementia patients being overrun by mice. These appalling accounts span a decade of research, but reforms have been extremely slow to come" (McBride, 2020). What **is now** of critical importance is to recognize that no amount of shoring up **of** an institutional model of care can make any institution a good place for a person to live. People justifiably don't want to live in them. (Spindel, 2020; Till, 2020; Lord, 2020; Drummond, 2020; Neufeldt, 2020).

#### Harms of Institutionalization

The well-documented evidence is extensive and is abundantly clear. Institutions, by their very nature, harm people. They simply cannot provide the kind of environment in which people thrive and can be cared for, appropriately meeting all measures of their needs as a human being. That this is the case has been established for many years, and has been the basis for the progressive dismantling of institutional care for many marginalized groups who were once placed in such settings. Amongst these are children in orphanages, Indigenous children in Residential Schools, and people with Developmental Disabilities in provincially run institutions.

The National Council on Disability issued a report in which they highlight the harms of institutionalization, noting that in such settings, people have "no choice over how they spend their time, interact with others outside the home, and make decisions that affect their daily lives and schedules". They further explained that "confinement in an institution severely diminishes the everyday life activities of individuals including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (National Council on Disability, 2012).

A joint task force established with People First of Canada and the Canadian Association for Community Living (now Inclusion Canada) stated that the institutionalization of persons with disabilities "is a denial of their basic right of citizenship and participation in community". They noted that criticisms and court judgements have condemned North American institutions as "inhumane, harmful and a violation of human rights" and further acknowledge that "today it is recognized almost universally, that institutions are unnecessary and harmful and that life in the community is a fundamental Human Right" (People First and Canadian Association for Community Living, 2010). This Right is now protected by Article 55, in the UN Convention on the Rights of Persons with Disabilities (UN Convention on the Rights of Persons with Disabilities).

In fact, harm has been acknowledged **to the extent** that court decisions have directed financial compensation to people who were harmed by the very fact of having been placed in these settings. In referring to a \$36 million settlement in a class action lawsuit against the Ontario provincial government on behalf of people with developmental disabilities who had been placed in residential facilities between the 1960s and 1999, Attorney General Madeleine Meilleur expressed acknowledgement that the residents "were harmed in a place that was intended to provide them with care" (Leslie, 2016).

In a comprehensive report about institutions in Ontario, Brown and Redford provide historical context about the history of institutionalization and the progressive movement towards a re-conceptualized response to meeting the needs of people. They have identified that the closing of the institutions for people with disabilities "has created an opportunity to establish a set of values that support the overall goals of social inclusion and enhanced quality of life: respect for the place of a full range of abilities and skills within our broader culture; value and dignity of each person's life; the right participate fully in the community life of our choosing; opportunities from which to choose and the freedom to make choices; and the celebration of one's individuality in concert with social and cultural participation" (Brown & Redford, 2015).

During testimony for the Ontario LTC Commission, Geriatrician Dr Nathan Stall of Sinai Health stated emphatically about the people who lived in LTC facilities during the Covid-19 pandemic "Had all these residents not been in congregate care settings which are outdated, crowded, with staff who are underpaid, living often in the Covid hotspots of our city and unknowingly importing virus and facing difficult decision of themselves about whether to work or not because of an absence of sick pay, I'm confident we could have avoided hundreds if not thousands of deaths." He further explained that deaths among **older adults** in the Long-Term Care facility population shows a 90 fold increased risk of death over the rate of death amongst the community dwelling population (Stall, 2020).

Subsequent to the closing of the last large institutions for people with developmental disabilities, policy developments have been established in all provincial and territorial governments in Canada in support of community living (People First, 2010). Notably, however, there has been no recognition that the harms so clearly identified on behalf of this group of people could and should also be acknowledged as equally applicable to **elders**.

Chris Beesley, Executive Director of Community Living Ontario lamented that people are "not heeding the lessons of our institutional past". As he explained, "in 2013, Ontario's premier apologized for our long institutional history. She acknowledged them as dangerous, segregating, congregating, and

isolating places that lacked oversight and accountability. They lacked proper health and safety standards. They lacked personal support and stimulation. We need only look at the military's recent report of conditions in LTC, to see the tragic similarities, not to mention over 3000 COVID related deaths" (Beesley, 2021). Yet these very types of institutional settings continue to be the primary care response for most vulnerable elderly and some disabled people in this province.

# Quality of Life (QOL)

Architects of social system change have argued that Long-Term Care could be re-conceptualized and re-developed into a broad spectrum of individualized supports in people's own homes and in small home-like settings within their own familiar communities. In doing so, people would be enabled to age in place in settings most familiar to them, with resulting substantial benefits to their Quality of Life (QOL). (Williams et al; Drummond et al, 2020; Brown & Redford, 2015; Donner, 2015; Till, 2020; Abdi et al, 2019). Dr Samir Sinha, geriatrician at Sinai Health, oversaw a comprehensive provincial consultation process in Ontario in 2012 and detailed his findings in the report Living Longer, Living Well. As he stated "we heard a clear call .... to afford more older Ontarians the opportunity to age in place of their choice" (Sinha, 2012). Nevertheless, change remains elusive.

Aldred Neufeldt, professor emeritus from the University of Calgary has explained "To change the status quo requires a reimagined vision transforming "long-term care" into "networks of caring" that support seniors in living meaningful lives through to death"(Neufeldt, 2020). Such re-conceptualizing and redevelopment would, however, require both a comprehensive grasp of the compelling reasons to do so, as well as a broad determination to embrace the meaningful systems change that would enable it.

Those compelling reasons to do so start with a recognition of the litany of problems associated with the current institutional model coupled with a recognition that these problems are inherent in the model itself. The model must cease. Quality of Life is an elusive concept to both describe and measure, although many have attempted to do so. Inevitably, most efforts settle on identifying a number of factors that describe life experiences that most people would value in their own circumstances, and therefore lead others to believe that these factors have some universality to them. Common descriptors of QOL indicators include such things as adequate nutrition, hydration, hygiene and shelter; a sense of safety, security, and order; physical comfort; a sense of belonging; enjoyment; meaningful activity; personal relationships of ones choosing; functional competence; respect; dignity; privacy; individuality; autonomy/choice; cultural and spiritual well-being (Forsund et al, 2018; Goya et al, 2016; Kane, 2001; Sourtzis & Bandera, 2015; Ouelette & Brown, 2018; Sinha, 2012).

A comprehensive study completed by Slaughter et al documented many concerns about the impact on the lives of people after admission to a LTC facility. Among these they identified that such settings utilize numerous strategies that significantly cause, among other issues, a "rapid decline in mobility after admission to a long-term care facility" and they establish a clear connection of mobility to quality of life (Slaughter et al, 2011).

As noted already in this document and as will be addressed in further detail in the following sections, there is a plethora of documentation that shows QOL indicators are universally NOT the experience of people living in institutions. Starvation and dehydration, inadequate personal care, dirty

environments, over-medication, inappropriate use of restraints, lack of meaningful choice in their living circumstances, incidences of abuse and assault, loss of dignity......These do not comprise quality of life for anyone.

"The tragic truth is that the way we treat older adults and younger people with disabilities – warehousing, isolating, and putting them away in facilities – is not the way anyone should be treated, especially those with complex care needs who are in the final stages of their lives" (Spindel, 2020). And as Lord has explained "Research is clear – people's conditions get worse after they enter an institution. Frail elders often suffer with chronic pain, Dementia, or other illnesses. In a long-term care facility, suffering unnecessarily increases, brought about by a rigid, institutional system that focuses on disease rather than wellness" (Lord, 2020).

#### When Profit Is Added To The Equation

A further problematic aspect of LTC facilities is that many are operated on a for-profit basis. Extensive research (Warnica, 2021; Brown, 2021; Lightman, 2020; Spindel, 2020; McGregor, 2005; Sourtzis & Bandera, 2015; Ritts' 2020; Baines, 2007; Pederson et al, 2018 & 2020) from countries worldwide, has demonstrated unequivocally that the risks to people in these settings when operated for profit, are immense. Simply put "there's an irreconcilable tension between providing care for the most vulnerable and maximizing profit" (McBride, 2020). As Dr. Ernie Lightman, professor emeritus of social policy at the University of Toronto, puts it "my PhD in economics tells me that maximization of profit is the goal of the corporation (or most other businesses), and that profit is the difference between what comes in (revenue or income) and what is paid out (costs or expenses). Maximizing profit means increasing the former and/or decreasing the latter"(Lightman, 2020).

Numerous other reports and investigations yield the same conclusion. MacLean's magazine, in reporting on the Canadian Military's 4th Canadian Division Joint Task Force report about conditions in LTC facilities in May 2020, found that "The for-profit homes had 2 to 3 pages of neglect and abuse documented where the not-for-profit had a mere half page"<sup>3</sup>. McGregor et al reported that "public money used to provide care to frail elderly people purchases significantly fewer direct care and support staff hours per resident-day in for-profit long-term care facilities than in not-for-profit facilities" (McGregor, 2005). Dr Nathan Stall has noted "there is this broad - like decades and decades - line of inquiry into for-profit homes compared to non-profit homes across a number of outcomes. And it consistently shows that for-profit homes tend to deliver inferior care" (Warnica, 2021). Pat Armstrong, Professor of Sociology at York University in Toronto, who is leading a large global study on nursing home standards, has acknowledged that some of the money received by long-term care homes is going to for-profits, and "in order to get the profits, they have to cut back in some

<sup>&</sup>lt;sup>3</sup> The Canadian Military was called in to assist in several LTC facilities during the spring of 2020, when the Covid-19 pandemic was overwhelming the capacity of these facilities to provide adequate care to their residents. The subsequent report of their findings sent shockwaves through the general public, and prompted the Ontario Premier, Doug Ford, to express a commitment to provide an 'Iron Ring' around the facilities as a means of protecting them. Subsequent government actions have led many to believe that the only protections introduced were for the protection of the LTC corporations and the government itself, in the form of legislation to prevent legal actions arising as a result of Covid-19 deaths in these settings (Bill 218), as well as an apparent decision to not call upon the Military for further assistance when other facilities experienced Covid-19 outbreaks that they were unable to manage, and where excessive resident casualties resulted. See military report - <a href="https://www.macleans.ca/wp-content/uploads/2020/05/JTFC-Observations-in-LTCF-in-ON.pdf">https://www.macleans.ca/wp-content/uploads/2020/05/JTFC-Observations-in-LTCF-in-ON.pdf</a>

areas"(Warnica, 2021). Seniors for Social Action Ontario has explained that frail, old people and individuals with disabilities unlucky enough to be funnelled into these medicalized institutions have become a means of production and wealth creation for large multinational corporations (SSAO, 2021).

Researcher Madeleine Ritts details a comprehensive analysis of the financialization of long-term care, in which she identified that the risks of a for-profit system of care for vulnerable people is magnified in situations where the LTC corporation is traded on the stock market, becoming even less focused on resident care provision, and more focused on shareholder dividends. Three such corporations Chartwell, Extendicare and Sienna Senior Living – are publicly traded on the stock market. As Ritts explains, "Investors, many of which are financial institutions managing money on behalf of clients, evaluate these companies according to factors like growth, profit and risk". In Ritts' experience, care provision was not a part of the dialogue at the shareholder meetings.

In fact, profit accumulations accounted for shareholder dividends amounting to over \$170 million during the first wave of the Covid-19 pandemic, even though the pandemic was ravaging those LTC facilities, and there were extensive reports that during that same time there was serious understaffing, inadequate infection control procedures and supplies, and an inability to attend to residents' needs including feeding, hydration, and personal and medical care (Wallace et al, 2020). In detailing her findings, Ritts states "Based on hours of care, pandemic deaths and much research indicating that for-profit long-term care homes have worse outcomes, it has become increasingly evident that the profit incentive compromises quality of care". Her conclusion is stark "Long-term care has devolved into an investment class, subsidized by the government and backed by real estate assets. Our elders deserve to be cared for in a system that is devoted to their best interests, but for this to occur, we need to remove shareholder returns from the equation" (Ritts, 2021).

While the Covid-19 pandemic is by no means the only reason why there have been so many catastrophic outcomes in LTC facilities, the reality is that it has laid bare the critical flaws in that system of care for vulnerable people. An analysis of Ontario LTC facilities established that in facilities outsourced to Extendicare, the largest operator in Ontario, mortality rates were 81 percent higher than the industry average (Roy & Huynh, 2021).

Global news investigative reporters Bell & Russell conducted an extensive review on the issue of forprofit ownership of LTC facilities and the impact on resident mortality rates during the Covid-19 pandemic. Their findings are jaw-dropping, and unequivocal. As they summarized those findings, they quoted from an interview with Natalie Mehra, Executive Director of the Ontario Health Coalition, who put it bluntly "And so the bottom line is, it is now irrefutable that the for-profit homes, the larger chains, in particular, have a strong correlation with the highest death rates of COVID-19 in our province" (Bell & Russell, 2020).

A comprehensive stratified analysis by Star investigative journalists extensively explored the mortality rates in LTC facilities throughout the Covid pandemic to date, examining multiple factors that could be deemed to have contributed to the overall number of deaths in these facilities. The conclusions of their study were supported by numerous research experts, but was roundly disputed by spokespersons for the for-profit sector. The Star report is extremely thorough and it unequivocally

debunks the claims of the for-profit LTC industry that factors other than their for-profit status are the actual causes of the statistically proven higher mortality rates in these facilities. "The result shows that even looking only at homes by the factors the for-profit sector has consistently said create the highest risk for worse outcomes, for-profits nonetheless performed much worse on average" (Tubb et al, 2021).

These views from some of our foremost leaders who care for vulnerable people, and from those who have delved deep into research to document the critical nature of the problems, speak volumes. These leaders repeatedly see evidence of the unacceptable risks of a profit-driven system, and it is essential that their collective knowledge guide corrective measures to ensure redevelopment of our care system into a non-profit structure.

While the need for change is clearly demonstrated, achieving such change has proven massively challenging. Spindel, in a scathing report on the impact of both profit and power dynamics impacting lives of people in LTC facilities, reports that families, devastated by the horrible conditions their loved ones experienced in LTC facilities "are suing these corporations, they are speaking out in the press, and they are attempting to take individual action, but when confronted with the power and money of large multi-national companies that have sometimes been known to engage in bullying tactics to silence them, it is not an easy task" (Spindel, 2020). Advocates, physicians and other care providers, and academics amongst others, have also been voicing these concerns, and seeking every possible remedy to address them.

Nevertheless, although bringing about change to the deeply entrenched system of Long-Term Care is something many people have pursued for years, as Spindel further explains "the public remains blissfully unaware of what is going on right in front of it because of the institutional nature of these facilities where residents are shut away out of sight, out of mind. Sadly the first time members of the public often encounter this system is when it is too late – when someone in their family, or they themselves are forced into one of these facilities" (Spindel, 2020).

#### Health Care and Related Medical Interventions

Advancing age may bring with it an increase in health conditions requiring medical treatment or intervention. Some people with disabilities are also known to develop ever-increasing health challenges. When this kind of situation develops, families may be advised that placement in an LTC facility within which the required care can be provided is the best option. Some of the types of care requirements that may trigger consideration of placement into an LTC facility, and which are believed to be provided there include: certain medications including injections, narcotics and end-of-life meds; tube feeding and medication administration via tube; skin/wound care; specialized nutritional needs; oxygen; respiratory treatments, such as chest physio (percussions/compressions/vibrations) and nebulizer treatments; catheterization; suctioning, including deep suctioning; PICC Line management; tracheostomy care; ventilator support and behavioural issues related to Dementia and other conditions.

None of the medical interventions described above require LTC placement. In fact many of these procedures are not delivered in LTC facilities, or if delivered, may not be done optimally. LTC facilities have, historically, failed to deliver these kinds of medical interventions correctly or reliably because

they rely heavily on Personal Support Workers (PSWs) who lack the skills to perform them, and training is often not provided to enable such skill development. For many of these procedures, PSWs are expressly for bidden to perform the skill (Oxford College, 2020). Registered Practical Nurses (RPNs) and Registered Nurses (RNs) are at a premium in LTC facilities and many shifts which should be filled by someone with these qualifications are not filled. Many LTC facilities refuse admission to people who require this level of care (West Park). Behavioural supports are few and far between, and the institutions themselves do not lend themselves to effective behavioural intervention since by their nature they may exacerbate "responsive behaviors".

It is important to note that each and everyone of these procedures and interventions can be managed outside of hospital or any other institutional setting, and indeed is being done in community for many individuals. Thus, leading families to believe that institutional care is essential is mis-leading. What is also mis-leading is the suggestion that these care needs will be provided in LTC settings. Simply put "Long-Term Care Resources are not at the levels necessary to enable the quality of health and social care required in general, and essential in times of crisis" (Government of Canada Task Force, 2020). The reality is that adequate in-home resources have not been developed to high enough levels to ensure the provision of these supports, but they indeed can and should be available outside of institutional settings.

#### **Mortality Rates**

Mortality rates in for-profit facilities have been particularly egregious both pre-and during the COVID-19 pandemic, both in Ontario, as well as widely documented in other jurisdictions. (Bell & Russell, 2020; Steele, 2020; Tanuseputro et al, 2015; Marian, 2020; Gotzsche, 2015; Tupperware, 2020; Anderson et al, 2018; Welsh, 2020; Stall, 2020; Du et al, 2019; Murray-Thomas et al, 2013).

Contributing factors are wide and varied. It is often assumed that the high mortality rates in LTC are primarily related to the advanced age of the people living in those facilities. But detailed examination of the evidence paints a different and alarming picture. As Ontario Deputy Minister of Long-Term Care Richard Steele testified to the Ontario COVID-29 Long-Term Care Commission, approximately 22,000 residents die in LTC facilities every year, unrelated to Covid-19. During the Covid-19 pandemic, over 80% of Canadian COVID-19 fatalities occurred in LTC facilities (Tupper et al, 2020). The total number of LTC deaths related to COVID infections escalates daily, and is well over 4,000 at the time of this writing. These deaths would be expected to result in an overall substantially greater annual LTC mortality rate once they are added to the average figures for previous years.

Examining those figures in greater depth, Taneseputro et al conducted a recent study of 640 publicly funded Long-Term Care facilities in Ontario, and found that publicly funded for-profit facilities have significantly higher rates of both mortality and hospital admissions. They calculated mortality rates to be as follows: "the crude mortality rate in for-profit facilities was 208 per 1000 PY versus 185 per 1000 PY in not-for-profit facilities." (Taneseputro et al, 2015).

That is a significant difference, and raises once again the serious risks the for-profit model of care presents. Given that the population of the for-profit LTC facilities and the not-for profit facilities is essentially identical, the fact that the not-for-profit facilities have a substantially lower mortality rate is highly illuminating, and cannot be explained away by virtue of arguments of greater acuity or more advanced age of residents in the for-profit facilities.

Anshesel et al (2000) have conducted years of research on factors influencing life expectancy and mortality rates related to older adults. Their research has documented that the mortality rates for the populations of people of similar age and need living in their own homes is dramatically lower than the mortality rates that develop after admission to a LTC facility. Their findings indicate that the act of placement in the LTC facility in and of itself has a direct negative impact on survival. As they explain, there are a multitude of conditions associated with placement and life in an institution that influence whether and how long one continues to live. These include the deleterious health consequences of eventful life change as well as the ongoing stressful experience associated with placement in the LTC facility. "Admission to a nursing home epitomizes the worst features of potentially health-threatening life events. Relocation completely disrupts the ordinary patterns of daily life, requiring readjustment of virtually all behavioral patterns, some of them life-long routines; nursing home admission is viewed almost universally as undesirable; the patient is likely to have little or no control over placement decisions, especially when health conditions impair cognitive functioning; moreover, the move may weaken or sever social connections to family and friends that might otherwise mitigate the full force of this trauma" (Anshesel et al, 2000).

Other factors that contribute to higher mortality rates in LTC facilities include, but are not limited to, the adequacy and suitability of nutrition and hydration; the effects of medications that might not otherwise be administered; minimally trained staff; staffing inconsistency; inadequate staff-resident ratios; escalated infection risk related to congregate living environments; abuse and assault; poorly maintained physical environments; and social impact factors such as loneliness, isolation and depression. (Murray-Thomas et al, 2013; Du et al, 2019; McBride, 2020; McKeen & Nuttal, 2021; Spindel, 2020 & 2021; Sourtzis & Bandera, 2015; Pederson et al, 2018 & 2020; Brophy et al, 2019; Dubinski, 2018; Welsh & McLean, 2011; Wagner & Rust, 2008; Taneseputro et al, 2015; Gardner, et al, 2020; Slaughter et al, 2011).

#### Inspections

Residents, families and the general public look to a comprehensive inspection process by the government to ensure compliance with provincial regulations established to govern the operation of LTC facilities, and to ensure quality of care. However the system of inspection of LTC facilities is permeated with inadequacies that render that process incapable of holding LTC operators accountable in this regard. The inspection process has been weakened even further over the past few years by virtue of government reductions in the nature and frequency of required inspections. As Spindel reports "For a very long time, many in Ontario have known what has been going on in the long-term care industry. Provincial auditors have raised it. Advocates have for years, bemoaned the absence of inspections and effective sanctions being brought against these facilities" (Spindel, 2020). Dr Samir Sinha, a well-known geriatrician with Sinai Health, has testified twice at Ontario's COVID-19 Long-Term Care Commission, and in that testimony he has said "currently our inspections process is broken" (Stone, 2020).

CBC Marketplace aired a deeply troubling report in the fall of 2020 that pointed to serious care violations such as residents who were unfed, unattended, in physical pain, suffering infections, malnutrition, neglect, and abuse. Their report stated "when there is little to no oversight, especially in facilities operated by large multinational corporations, caring for extremely vulnerable people, it is a recipe for disaster - exactly the kind of disaster that occurred during the 2020 pandemic" (Pederson et al, 2020). Marketplace isolated 21 violation codes for some of the most serious or dangerous

offences, including abuse, inadequate infection control, unsafe medication storage, inadequate hydration, and poor skin and wound care among others. The Ontario Ministry of Health releases inspection reports on Long-Term Care facilities, and an inspection history including indications of violations can be found for every long-term care facility in the province. The litany of violations is extensive and disturbing, but significantly little in the way of consequences are ever levied. Even for the most egregious violations, the responses have been pitiful. As Jane Meadus has stated in an interview during that Marketplace report, "a home has never even been charged criminally for what I think is criminal behaviour" (Pederson et al, 2020).

Spindel has provided a detailed exposé of tragic circumstances in LTC facilities with regards to inspections, and her conclusions reflect the gross inadequacies of the LTC inspection system. As she reports ""the inspection branch is so weak that the law is literally unenforceable. These operators are let off the hook even after repeated compliance orders and director's orders. They just go about their business as usual and don't have to take the inspection service seriously at all (Wallace, 2020).

Most notably, when there are no alternative settings to which people could be moved, many operators can and do repeatedly ignore Ministry inspection directives to comply with the governing legislation. A Toronto Star interview with Jane Meadus of the Advocacy Centre for the Elderly describes the dilemma of inspection inadequacies explicitly, "if you found out your child had been left in a dirty diaper for eight hours at a daycare, and you reported that, that would be a very serious offence. And likely, if (the daycare) had a history of that, they would be shut down. That is an everyday occurrence in long-term care in many places. The reality is that operators know the government is unlikely to shut homes down. The principles of economics don't work here because supply and demand would normally get rid of the bad apples, except we don't have enough supply," she said. "The government is over a barrel because if you get rid of a home, then what do you do? Where do those people go? We don't have anywhere for them to go" (Wallace, 2020).

Clearly, reliance on the inspection process to ensure adherence to Ministry Regulations governing the care and safety of people residing in LTC facilities is not likely to produce any degree of reasonable compliance or assurances of appropriate care.

#### **Adverse Effects**

Dr. Patricia Spindel has persistently called for meaningful change that would see vulnerable people treated with the dignity they deserve, but repeated calls for action remain unanswered. "For decades, there have been press exposés showing that residents are not safe in Long-Term Care facilities; that adequate care is not provided; and that residents are subject to abuse, neglect, falls, injuries, medication errors, and other serious breaches in care standards" she states (Spindel, 2020). In a recent policy statement, Seniors for Social Action Ontario, an advocacy organization Spindel co-founded, is explicit as to the reasons why this has been the case. "The fact that the Ford government has been willing to stand by as elders die in the thousands in these institutions..... the fact that police have refused to investigate what are clearly criminal acts documented in the military reports..... the fact that people still believe institutions are the only answer as people age and develop care needs..... all reveal the underlying ageist attitudes in society itself" (SSAO, 2021). Ageism and its partner ableism, are discriminatory attitudes that justify treatment towards people who are elderly or disabled that would not otherwise be tolerated for a typical person. This devaluing of the individual is the underpinning of the systemic flaws in current responses to the needs of this population.

#### Women and People with Disabilities Are At Most Risk

Multiple adverse effects abound in the current system of LTC's for vulnerable people. These disproportionately affect women and people with disabilities for several reasons. Women comprise the majority of residents in LTC facilities - a factor largely influenced by the demographics of longer life spans of women and the additional fact that women experience lower income status to a greater degree than men. They thus become institutionalized in LTC facilities at a greater rate than those who can afford non-government subsidized alternatives. Women are also generally on the lower end of the economic scale, and survive to older ages in greater proportions than men, so they comprise greater numbers of people requiring support due to aging. With their overall lower economic means, women tend to have less disposable income and many are only able to access multi-bed rooms where the copayment requirement is the lowest. When financial assistance to subsidize that copayment is required, only basic accommodation is covered which also equates to the four-bed rooms. These congregate rooms have a greater probability of enabling infection transmission, lowered privacy options, a requirement of shared facilities, less independence, and less individualization.

People with disabilities are especially vulnerable because of their dependencies, as well as related to societal attitudes about disability itself. Disabilities may be those that have been experienced lifelong by an individual or may be acquired by conditions which include but are not limited to: age-related cognitive and functional challenges such as Dementia, neurological disorders such as Parkinson's, Multiple Sclerosis or ALS, physical disabilities, and acquired brain injuries such as stoke, traumatic injuries or birth injuries like cerebral palsy. Seen in this context, the incidence of disability within the LTC facility population is almost total.

Communication challenges are substantial in this population, as are limitations in social skills, perceptivity of risk situations, and cognitive functioning. These all pose additional factors that increase the vulnerability they experience in these institutional environments.

Human rights organizations have acknowledged that violence and discrimination are, as Mandl et al (2014) identified "omnipresent". Researcher Rannveig Traustadottir has studied women's issues for years, and notes that physical violence, neglect, coercion and sexual abuse is commonly reported in institutional settings, particularly for women and people with disabilities. She states the imbalance of power between staff members and residents is a factor which weakens the position of women with disabilities, particularly in regard to self-determination and autonomy, and further notes that this finding is consistent across all of the countries in which she conducted research. (Traustadottir, 2014).

Mandl et al (2014) explored these concerns in depth, noting that the disempowerment experienced by women with disabilities was a major factor in enabling an environment and the people within it to utilize violence, and to do so with impunity. As they noted, when violence occurred within an institution "the affected women were often not believed, especially if the perpetrators were also workmates of those that the woman tried to talk to". The alleged abuses were seen more often as structural or systemic violence, not recognized as criminal behaviour by the abuser, nor by the facility administrators. "The situation was exacerbated even further if the woman saw the perpetrator every day in her institution. In cases where the woman had been violated by a male resident, staff were often helpless in regard to knowing how to react" (Mandl et al, 2014).

# Infections

Independent of the Covid-19 pandemic, which has ravaged the population in LTC facilities, infection risks abound in LTC facilities for a multitude of reasons. Much of the challenge is related to infection control knowledge and practices of the LTC staff, and include respiratory illnesses and infections related to skin integrity breakdowns such as pressure sores. Infection control supplies cost money and are often absent or severely rationed. Added to the congregate nature of the multi-bed shared sleeping and bathroom spaces provided to most residents, there are building factors such as congregate eating and recreation areas, in adequate or nonexistent air filtration systems, and multi-user elevators and long hallways to get from one area of the building to another. During times of potential infection outbreaks, such congregate spaces create significant opportunities for transmission of infectious agents. (Arya, 2020; Center for Disease Control, 2020; Huyer et al, 2020; Traustadottir, 2013 & 2014; Concerned Friends, 2020; Ombudsman, 2016; Spindel, 2021; Mandl et al, 2014; Williams et al, 2016; Baines, B, 2007; Welsh & McLean, 2011).

# Assault and Abuse

Power imbalances between staff and residents have long been recognized as a factor influencing assault and abuse. Powerlessness of the victim has been identified as stemming from a number of factors, including: the perception that women could not fight back, extreme vulnerability due to degree of physical or cognitive impairment, disbelief of the woman's allegations, communication disabilities, isolation within the facility and away from protective agencies, the degree of control exercised over women, and fear of repercussions (Mandle et al, 2014; Welsh & McLean, 2011; Ouellet & Brown, 2018; Spindel, 2020; Sourtzis & Bandera, 2015).

In 2018, CBC Marketplace did an exposé of 40 nursing homes with the highest rates of abuse in the province. Its documentary Crying Out For Care showed that violence was escalating in these facilities, more than doubling between 2011 and 2016. Staff to resident abuse was up 148% from 2011 to 2016. "In 2016, there were 2,198 reported incidents of staff-on-resident abuse. This means, on average, that six seniors at long-term care homes in Ontario are abused every day" (Ouellet & Brown, 2018).

In society at large, more women than men are particularly vulnerable to sexual assault and the same holds true in institutional settings, exacerbated by the above noted factors. Staff-to-resident assault and resident-to-resident assault are not infrequent occurrences within these facilities, yet the institutional model continues to predominate as the default care response for vulnerable people without any substantial consequences for the violence perpetrated against them, nor any meaningful shift to safer alternative settings. (Anderson et al, 2018; Bannerjee, A., 2007; Ombudsman, 2016; Gardner & Holmes, 2020; Toronto Star, 2021; Spindel, 2020; Wallace, K, 2021; McKeen & Nuttal, 2021; Pederson et al, 2018; McBride, 2020; Romano, 2009)

The most horrific assault - murder - is also not unknown in these settings, as clearly documented during the inquiry into the murder of elderly residents in the Caressant Care LTC facility in Woodstock. Elizabeth Wettlaufer, a nurse at this and at other facilities, eventually confessed to the

intentional overdose deaths of residents, but only after having been caught. She was convicted of eight counts of first-degree murder, four counts of attempted murder, and two counts of aggravated assault (Gillese, 2019).

Cases of resident-to-resident murder have also been reported (Welsh & McLean, 2011; Ouellet & Brown, 2018; Sourtzis & Bandera, 2015; Toronto Star, 2021). While these crimes may be few in total number, they remain serious risks and cannot be ignored. Certainly, even the issue of failing to ensure adequate nutrition and hydration in and of itself, as has already been discussed, can be seen as a potential criminal act perpetrated against a vulnerable resident, or at the very least, can be seen as gross negligence. In either case, a resident ends up dead at the hands of others, while in a setting obligated to provide a safe environment and to provide appropriate and adequate care.

#### Can Harm Be Mitigated?

Disability support organizations and families have attempted to mitigate the risk of harms posed by these settings for the people they care about, but the results have been uniformly poor. To this end, they make arrangements to ensure a family member is present on a frequent basis, often daily, in order to feed, hydrate and keep their loved ones clean and socially engaged. Where families cannot provide that level of added care, they often resort to hiring outside agency help, despite the fact that the care being purchased is care that was promised in the glowing descriptions of the LTC facility at the time of admission.

Once again it needs to be understood that the harms inherent in the institutional model are not fixable. One of the outcomes as a result of family-provided care or privately purchased supplemental staffing provided to residents in these settings is that even less LTC staff care is provided. Many times the LTC staff assume they themselves need not provide the required care to the resident, since it is believed that it is already being done. The resident is perceived as not the responsibility of the facility staff. Problems arise when family or private staff cannot be present for any reason, as these assumptions of non-responsibility persist.

This was made abundantly clear during the COVID-19 pandemic, when government directives prohibited family from being present in LTC facilities, based on an assumption that spread of the virus would be escalated if they were allowed in. Although this assumption has since been quite robustly de-bunked, the visiting prohibition triggered massive and calamitous hardships for residents, and for families alike. Multiple reports document serious depression; isolation; loneliness; experiences of residents not being fed nor given hydration; not being given appropriate medication; residents being drugged into sedation in order to control their distress; and subsequent lonely deaths by thousands of residents, without family being able to be with them through their illnesses and at the time of their deaths (Warnica, 2021; 4<sup>th</sup> Canadian Joint Task Force, 2020; Spindel, 2020; Ritts, 2020; Armstrong, 2021; Gardner et al, 2020; Tupper, 2020; Wallace, K., 2020)

# Dementia

Dementia is the leading diagnosis of those in LTC facilities, and presents a very specific set of challenges. According to statistical records, over 70% of residents in LTC have been diagnosed with dementia (Huyer et al, 2020). Dementia is a neuro-degenerative condition and as such, residents with this diagnosis may present ever-changing needs. Years of cumulative research have led to a deep

knowledge base and a wide range of strategies that have been acknowledged as useful in providing support to this population. Chief amongst these strategies, is the understanding that people supporting those with dementia must be fully equipped with that in-depth understanding and be well-versed in the particular supportive interventions that are of most value. This requires dementia-specific training, something not generally available to the majority of PSWs who are the primary staff in LTC facilities.

Forsund et al (2018) completed a meta-synthesis examination of much of the existing research specific to the needs of the population of people with Dementia. Their efforts revealed four main categories of need, as follows: "1. Belonging; 2. Meaningfulness; 3. Safety and Security; and 4. Autonomy." They identified these as essential elements for the living space for people with dementia and explained they greatly influence their well-being. They cited the World Health Organization's "age-friendly" policy movement and dementia awareness campaign which expressly suggests that people with dementia would be provided the most optimal support when enabled and assisted to remain autonomous and active citizens of society.

Numerous clinicians and researchers have established that facing new environments threatens the person with dementia's sense of existence, such as the ability to uphold a sense of control over one's own life, protecting privacy, and making choices of importance. They acknowledge that anxiety symptoms among persons with dementia could be a reaction to loss and worry, especially the experience of dealing with a new situation such as relocation. Anxiety among these persons, as Goyal has stated "must therefore be understood as existential in nature" (Goyal et al, 2016). Anxiety symptoms are common among persons with dementia and might lead to negative impacts such as decreased function in activities of daily living, increased dependencies, behavioural challenges and emotional distress(Forsund et al, 2018; Goyal, et al, 2016; World Health Organization, 2012; Canadian Institute for Healthcare Information, 2017).

Forsund et al, (2018) in speaking about the negative impacts of relocation for people with dementia made it clear, "the replacement of the lived space might threaten all of the essential dimensions of belonging, meaningfulness, safety and security, and autonomy." Given this finding, practices that attempt to enhance the institutional environment in order to make it more dementia-friendly obviously miss the mark entirely. Clearly, older people have had it right all along, when they state unequivocally that they want to age-in-place in their own homes, and be supported to do so. It's not just their desire to do so - the research establishes the critical importance of doing just that.

An oft-cited concern related to people with Dementia is their risk of wandering, and the risk of what are euphemistically termed "responsive behaviours". Coupled with the confusion and memory challenges of this population, many caregivers resort to restraints or locked facilities in order to contain the individual, or to prevent behaviours that may hurt staff or others. There are detailed directives established by the Ministry of Health and Long-Term Care relating to the use of such practices, yet as has been discussed already, the Ministry's own inspection reports demonstrate that there remain outstanding difficulties in ensuring compliance with any of their directives. What is seldom discussed is the need to examine the very environment and life experiences of people living in institutional care in an effort to isolate intrinsic factors within those settings that may be contributing to, and exacerbating the challenges facing this population. In a recent government Task Force report to the Chief Science Advisor of Canada, the contributing specialists brought this point out, explaining that "All wandering and impulsive behaviour has meaning. Look for and address underlying causes for

the behaviour". They elaborated on this point by identifying that the environment alone "often challenges the ability to protect the well-being of older adults, especially those living with Dementia" (Government of Canada Task Force, 2020).

Fall risks, social and emotional concerns, the use of restraints, both physical and chemical, and elevated mortality rates may all be issues that exist in a high percentage in this population precisely because of the disruption in their lives brought about by the move away from their familiar home and into an institutional LTC, and the subsequent way in which their care is, or is not provided in those settings.

The specific needs of residents with dementia are significant, and when appropriate techniques and approaches are utilized, care for this population can be highly effective and successful. However, for a multitude of reasons, large institutional LTC facilities are poorly equipped to meet these needs, despite claims to the contrary. Most care in these facilities is provided by PSW's who have a very low level of training overall and relatively little specific to dementia. Much of what they practice has been learned on site, influenced by the practices of their equally poorly trained peers. Registered Practical Nurses (RPNs) and Registered Nurses (RNs), while promised, are in critically short supply for many reasons in LTC settings, and this is especially so in for-profit facilities. The fact that it costs more for RPNs and RNs influences the proportion of people with this level of certification who are hired. As Roy and Huynh (2021) report, an overall shortage of RNs throughout the province has presented a serious challenge, and they note that families allege that cost-cutting measures in at least one of the large for-profit corporations (Extendicare) have exacerbated the existing shortage. Extendicare vigorously denies this.

Additionally, many nurses are loathe to work in these settings, preferring alternative employment when they can obtain it (Pederson, 2015; Spindel, 2020; Warnica, 2020; Roy & Huynh, 2020). As Lord has explained, "most staff are good and caring, but 'the 'medical model' they're trained in offers little to ensure meaningful existence for people with diminishing physical or cognitive abilities" (Lord, 2020).

Canadian researchers Brophy et al (2019) explored staffing issues in relation to institutional violence in Ontario LTC facilities, and found that violence was symptomatic of institutions that undervalue both their staff and residents. In examining the issue Global News reporter Davis identified that nearly 90% of Ontario long-term care staff experience violence, often triggered by resident fear, confusion, and agitation, along with such underlying causes as insufficient training, task-driven organization of work, understaffing, inappropriate resident placement, and inadequate time for relational care. As he reports "long-term care staff are bloodied and broken both physically and psychologically", and as he further explains "these facilities are largely staffed by women whose work is based on compassion and care, and yet they themselves are expected to tolerate an environment in which physical, verbal, racial and sexual aggression are rampant" (Davis, 2019). Little wonder that violence may be perpetrated against residents when the environments themselves are so permeated with violent and dehumanizing experiences for all.

Understaffing is a perpetual problem in LTC facilities, and has become an issue of massive proportion during the Covid-19 pandemic. Even before the pandemic, the Ontario Health Coalition explored staffing adequacies in LTC facilities and found that "in every town, and in virtually every long-term care home, on virtually every shift, long-term care homes are working short-staffed (short 1-2 PSW's

on almost every shift, a shortage of 5 to 10 PSW's in every 24 hour period). Some homes were reported to be short 20 to 50 PSW's in 24 hours. This means that many residents are not getting even basic care in these homes". (Ontario Health Coalition, 2020). Subsequent to the onset of the COVID-19 pandemic Ritts found that mismanagement and neglect within Ontario's Long-Term Care facilities are disturbingly widespread. "Reports of LTC misconduct revealed an alarming number of those who died from COVID-19 were already suffering in environments marked by grossing dignity and, in some cases, abuse" (Ritts, 2020).

The Canadian military noted a "culture of fear" as they referred to it, among exhausted and poorly paid workers. They observed that staff are afraid to speak out or question employer practices, and they pointed out that the conditions of employment in these settings had led to high staff turnover, disruptive care, dangerous communication issues during shift changes, poor continuity of care (especially important for seniors with dementia), and little opportunity for staff to build meaningful therapeutic relationships with residents. "The current LTC system treats residents and care workers alike as highly disposable" (Roy & Huynh, 2021).

#### Inappropriate of Psychotropic Drugs

Because residents with dementia comprise the majority of the people living in LTC facilities, factors associated with this condition drive a significant number of practices within these settings. The known challenges of supporting this group of people are magnified when they are congregated in large numbers, and supported by poor staffing ratios and inadequately knowledgeable staff. Wandering behaviours trigger facility responses of locked floors, and physical restraints in the form of straps or of chairs or beds that the resident cannot get out of. Agitation, distress, and aggressive behaviours also trigger a facility response of the use of restraints, and these are not always physical but may also be chemical in nature. Such chemical restraints typically come in the form of drugs that may be intended for a different purpose or population, but are used in this population because they have side-effects such as sedation. Psychotropic (frequently referred to as anti-psychotic) drugs, intended for individuals with psychosis, are one class of drugs often used in these settings.

The Canadian Foundation for Healthcare Improvement (CFHI) found that in 2017-2018 there were 1 in 5 residents in LTCs who did not have a psychosis diagnosis, but who were nevertheless prescribed anti-psychotic medications (Canadian Foundation for Healthcare Improvement, 2018).

The Canadian Institute for Healthcare Information (CIHI) examined the use of such medications in Long-Term Care facilities and found that seniors with dementia are at an increased risk of being physically restrained and at double the risk of being given potentially inappropriate antipsychotic drugs than other seniors, and they further went on to state that "the use of physical restraints (such as wheelchair lap belts or bed rails) and potentially inappropriate antipsychotics often reflects the challenge of caring for residents with combined physical and mental illnesses and challenging behaviour" (Canadian Institute for Healthcare Information, 2017). The recognition that this practice is primarily beneficial for the management of a group environment from the facility's perspective and is potentially harmful to the elderly is widely established (Enderlin et al, 2015; Marla, 2020; Bruser et al, 2014; Tepper, 2015; Tepper & Auger, 2018; Schepis et al, 2018; Gotzsche, 2015; Wagner & Rust, 2008; Kane, R., 2001). While compliance and sedation may be the desired side-effect for meeting the facility's needs, these drugs are not in the best interests of the individual to whom they are prescribed and administered.

As many researchers have indicated, there is a lack of evidence to support the use of these drugs for this population and for the purposes generally intended. These drugs act directly on the central nervous system, and there is a widespread acknowledgement that they can cause severe side effects, including confusion, dizziness, stroke or even death. Other side effects might include increased confusion, memory issues and cognitive functioning; urinary retention; constipation; organ dysfunction including kidney, liver, heart and brain; reduced mobility leading to pressure sores and muscle atrophy; blurred vision and orthostatic hypotension (sudden drop in blood pressure which can lead to fainting and/or falls). Some of these medications cause drug-induced Parkinsonism and extrapyramidal symptoms which negatively impact balance and coordination. Elevated fall risk is therefore a high frequency outcome of the use of these drugs. When residents have other existing conditions, some of which they may also be receiving medications for, the additive effects of the side-effects can create even more substantial complications. (Enderlin et al, 2015; Glab et al, 2014; Bauer et al, 2012; Wilson et al, 2011; vanStrien, 2013; Witchel et al, 2003).

Death attributed to inappropriate anti-psychotic drug use is another high risk potential outcome, particularly in the elderly population. While some of the previously mentioned undesirable side-effects might clearly contribute to circumstances which could lead to death, there is a well-known significant impact on cardiac function, most particularly as a result of arrhythmias leading to sudden cardiac death (Du et al, 2019; Enderlin et al, 2015; Gotzsche, 2015; Murray-Thomas et al, 2013; Alvarez & Pahissa, 2010).

Drugging an individual who may be experiencing needs that should, and could be responded to differently is certainly not in the best interests of the individual, and additional side-effects that can result may be significantly harmful. The intended goal is control of the individual, and when many people are equally medicated, the result is control of a large population. However, these medications in fact are specifically identified by the manufacturers and by physicians and researchers who specialize in developing a broad knowledge base about these medications, as drugs that should not be prescribed to people who do not have psychosis, and most particularly, not for elderly people (Marlan, 2020).

When the Covid-19 pandemic broadsided LTC facilities, the prescription of these drugs became even more widespread. Geriatrician Dr Nathan Stall, speaking to the Ontario Long-Term Care Commission, testified that residents in LTC facilities were being heavily drugged with antipsychotics, benzodiazepines, and anti-depressants to allow them to tolerate the conditions of the COVID-19 lockdown because the homes were in crisis, there was no one to provide care for them and they were responding with chemical restraints to control these residents (Stall, 2020).

The risks of the use of these drugs is so well-established, that Health Canada has reported that "antipsychotics have explicit warnings that they are not approved to treat behavioural disorders in elderly patients with Dementia, and that to do so increases risk of mortality" (Marlan, 2020), yet as Dr Joseph Tepper has acknowledged on a Health Quality Ontario blog, "as many as 67% of LTC residents are prescribed these medications" (Tepper, 2015).

Health Quality Ontario notes that the prescription of antipsychotic medication without a diagnosis of psychosis has fallen from 35% in 2010/11 to 20.4% in 2016/17. They have established guidance for physicians with a goal to see a reduction of antipsychotic prescriptions without a diagnosis of psychosis down to a provincial benchmark of 19% (Health Quality Ontario, 2015).

The MOHLTC sets benchmark goals for psychotropic prescription reduction in Long-Term Care facilities, but this very fact raises a serious conundrum. Why is there a goal for any prescription of such drugs in the absence of a condition (psychosis) for which they were intended? In fact, why is there any tolerance at all of this practice? Why does there exist a conviction that these drugs are essential? What behaviours are occurring that are believed to require chemical restraint to control, and why might they be occurring? What factors in the LTC itself might contribute or cause the very behaviours deemed to be in need of suppressing through such powerful chemical restraints?

Given the abundance of evidence of the harm of this practice, and the clear indication that the practice is for the benefit of the facility and staff rather than the individual, this aimed-for benchmark is completely incomprehensible, appears highly unethical and clearly begs for investigation as a potential act of malpractice or criminality.

# Falls

As people age the risk of falling increases. This risk is often a trigger for placement in a LTC facility, under the assumption that the individual will be monitored around the clock and kept safe from falling. Once again the reality differs dramatically from the assumptions. Facilities resort to the use of restraints, either physical, chemical or environmental (such as locked wards or rooms) "in order to manage a group environment" (Wagner & Rust, 2008).

A common practice in congregate settings where staff to resident ratios preclude an adequate level of close monitoring in regards to fall prevention strategies, is to restrict the movement of the individual in such a way as to prevent falls, along with preventing wandering, restricting resident-to-resident interaction etc. Physical restraints can take the form of straps, ties or other methods of keeping someone in a designated place, such as trays on wheelchairs or geriatric chairs from behind which the resident cannot get out, as well as bed rails that are intended to keep a resident in bed. As Wagner and Rust (2008) explained, the use of such restraint is undertaken "in order to manage a group environment".

Nevertheless, physical restraints can have the opposite effect, exacerbating fall risk through such circumstances as the determined efforts of people to escape their restraints. Additionally, the enforced reduction in mobility can lead to reduced overall strength, coordination, balance and stamina, all of which can lead to increased risk of falls when the individual does try to walk (Anderson et al, 2018; Enderlin et al, 2015; Glab et al, 2014; Tepper & Auger, 2018; Bauer et al, 2012; Wilson et al, 2011; vanStrien et al, 2013; Woolcott et al, 2009).

As has already been mentioned, psychotropic drugs are major contributors to increased fall risks for this population. As Gotszche reports, "falls are an important cause of death in people taking psychotropic drugs" (Gotzsche, 2015).

Physicians Tepper and Auger (2018) explored the incidence of falls in facilities and found that although the provincial benchmark is 9% of the actual percentage of long term care residents who suffered falls in 2016/17 was 15.8% - almost double the anticipated rate (Tepper & Auger, 2018).

Health Quality Ontario developed a comprehensive guide intended to help facilities develop strategies to reduce falls amongst their population, and in it they acknowledged that injuries from falls among people 65 years and older living in LTC facilities are more frequent than those living in the community. For every 100 LTC facility residents there are about nine falls each year, which are serious enough to require an emergency room visit (Health Quality Ontario). Yet, in its report on inspection issues within LTCs, Concerned Friends of Citizens in Care Facilities noted that the top 3 areas for which homes were cited as being non-compliant with Ministry of Health regulations were "falls prevention, care planning and adherence to internal policies" (Concerned Friends, 2020).

Certainly the multitude of factors endemic in LTC facilities that have been identified in this report paint a clear picture that the assumption that people will be better protected from falls by arranging placement into a LTC facility does not transpire.

# Social/Psychological Implications

Significant change in one's life experiences can be stressful for anyone. As people age, they are often already experiencing major life changes, such as the losses of a spouse, friends and cultural norms, the onset of major health challenges, and the progressive loss of function that frequently accompanies aging to name just a few. The additional stressors of having to leave one's familiar surroundings, and enter into a wholly unfamiliar setting with rules, rhythms, and interactions that are completely foreign to any previously known experiences can be devastating. The psychological implications are substantial and traumatic. Depression, boredom, isolation, grief over the loss of preexisting relationships, dissatisfaction over the inadequacy of pseudo-relationships, a sense of helplessness, functional decline and "responsive behaviours" (ie: resistance, non-compliance, and aggression, etc) are frequently seen in the institutionalized population. As previously discussed, the generally accepted experiences that contribute to quality of life are sadly lacking in these settings. Any one of these negative experiences can trigger significant harm. As Cacioppo et al (2016) explain loneliness alone "is a risk factor for broad-based morbidity and mortality". The cumulative effects of the psychological traumas is devastating. (Slaughter et al, 2011; Gardner et al, 2020; Tupper et al, 2020; Abdi et al, 2019; Wen et al, 2014; Anderson et al, 2018; Bruggencate et al, 2018; Cacioppo, 2016; Neville et al, 2016; Canadian Institute for Health Information, 2016; Bannerjee, 2007; Buckley & McCarthy, 2009).

Learned helplessness is a recognized phenomenon, observed in both humans and other animals when they have been conditioned to expect pain, suffering, or discomfort without a way to escape it. Eventually after enough conditioning, the individual will stop trying to avoid the pain at all (Ackerman, 2020). As Kane (2007) explains in her research on the psychological impacts of institutional settings, learned helplessness informs us of "the destructive effects such regimens have on the human spirit, creating listlessness, depression and abandonment of efforts to exert control".

Incidence of diagnosed depression in LTC residence is reported to be between 18 and 31%, and 50% of residents with dementia showed signs of aggressive or responsive behaviours (Canadian Institute for Health Care Information, 2016; Abdi et al, 2019; Bannerjee, 2007).

A multi-review of 37 studies found that "suicidal thoughts (active and passive) are common among LTC residents with a prevalence of between 5 to 33%, although completed suicide is rare. Correlates of suicidal thoughts among LTC residents include depression, social isolation, loneliness, and functional decline" (Wen et al, 2014). Dr Briony Jain has also explored this issue, and indicates that "suicidal ideation and behavior among nursing home and long-term care (LTC) residents is of growing concern internationally" (Jain, 2020).

Given the multitude of overwhelming and often negative experiences people encounter in institutional settings, the questions really need to be asked - to what extent are the behavioural presentations of the institutionalized population of people in LTC facilities a normative and understandable response to those lived experiences, or intrinsic to the conditions of aging and/or dementia? And correspondingly, what can be done differently to minimize people such traumatic experiences and enable people to live in dignified ways, with choice, autonomy, and valued experiences? As Bruggencate et al (2019) have established through their systematic literature review examining the needs of older people "the themes that emerged are diversity, proximity, meaning of the relationship and reciprocity. These themes offered several intervention implications. Participation in hobbies and in volunteer work and being connected were among the main findings. Interventions should focus especially on the connectedness, participation and independence of the older adult", none of which are replicable in a meaningful way in institutional settings where unfamiliar others are congregated, and with whom the individual has little to no history, shared interests, or established connections. Neville et al expanded upon this, stating "it is important that health professionals and social service providers recognize the importance of social connectedness, and provide a range of options to support continuing social connectedness and community engagement for older people. Being socially connected is linked to positively influencing older people's ability to remain living in their own homes and has been shown to support independence and enhance well-being" (Neville et al, 2016).

#### Do Not Resuscitate (DNR); Do Not Hospitalize (DNH)

People with disabilities and elderly people experience a high frequency of approaches from health professionals, inquiring as to what is referred to in colloquial terms as "their wishes". In more specific terms, those inquiries are asking about what are more formally referred to as advance directives, which relate to the individual's preferences in the event that they experience a sudden health crisis that necessitates extensive intervention in an attempt to treat. An underlying assumption is that many people would not choose to live a life dependent on life support and might choose to avert that possibility through such advance directives. In the event that a competent person establishes that they do not wish such interventions, a do not resuscitate (DNR) order is developed. Within LTC facilities, amongst other settings, this inquiry is explored upon admission of the individual, or where the person is not able to give informed consent due to cognitive challenges, the discussion and decision is entered into with a substitute decision maker, typically a family member who has been given Power of Attorney. Correspondingly, in LTC facilities, it is not uncommon for a further discussion to take place, inquiring as to whether the individual is to be transported to hospital for treatment. When a decision is made against such a transfer, the signed form is referred to as a DNH order.

According to the Canadian Institute for HealthCare Improvement, research in 2016 indicated that 75% of residents in LTC's have a DNR order in place while 20% have a DNH order in place. They further acknowledged that there were anecdotal observations and reports that identified LTC coercion/expectation of such orders although they did not have concrete data to support those reports. They further identified that 34% more male residents than female residents were hospitalized even when DNH orders were in place. Factors deemed to justify overriding the DNH order included fractures and treatable infections (Canadian Institute for HealthCare Improvement, 2016). The reports of possible coercion in signing such documents are disturbing. Such a practice would clearly be unethical, and illegal.

According to a report in the Toronto Star, long before COVID-19, "Ministry of Health collected data on potentially avoidable emergency department visits from LTC residents. Among the medical conditions which were considered justified to avoid an emergency visit were congestive heart failure, seizures, injuries from a fall, septicaemia and pneumonia (Welsh, 2021). It would be quite reasonable to suggest that residents would not necessarily concur with decisions that would preclude them from receiving hospital treatment for such conditions.

In an interview with the Toronto Star, Jane Meadus of the Advocacy Centre for the Elderly explained that DNH orders could result in an individual never seeing an emergency department again, even if experiencing a treatable infection. "Someone signs a form three years ago and the home takes it as 'that's what they want now'" she said. She further proposed that perhaps a better question could be "If you get a very infectious disease which could infect the entire home and kill everybody would you want to stay there? Or would you want to stay there even though the home is not going to provide you with proper palliative care, nutrition and hydration?" (Wallace, 2021).

The often rigid interpretation of advanced directives is one of the many reasons why residents with COVID-19 were not sent to Ontario hospitals for treatment or for a less agonizing death with palliative care support. Additionally, directives from either government, LTC administrations, or public health authorities resulted in decisions to not transfer LTC residents to hospital when they became very ill during the COVID-19 pandemic (The Economist, 2021). Given that the CIHI data show that only approximately 20% of LTC residents might have had a DNH order in place, then as Wallace (2021) reports "a large number of people were left without hospital care that they would have wanted and could have benefitted from.... only 15% were actually transported to hospital."

Dr Nathan Stall has been conducting an analysis of COVID-19 deaths in Ontario and his figures show that from March to December 2020, nearly 80% of those aged 80 to 89 who were still living in the community were sent to hospital when they incurred a COVID infection. By comparison just over 24% of LTC residents were sent to hospital before they died. He states "as we saw from the spring and we are seeing now, just because you have an order to 'do not resuscitate' somebody or 'do not transfer' to hospital doesn't mean there is also not an order to treat them. Or care for them. 'Do not resuscitate' does not mean 'do not treat'. No one signed up to go into a nursing home and die an uncomfortable death of suffering" (Welsh, 2021).

Dr Stall, in his testimony before the LTC Commission, stated clearly that people were intentionally not transferred to hospital during the first wave and he made it clear that those decisions may have contributed to the high death rates for this population during the pandemic. He further indicated that people were not even transferred for just basic care when the LTC facility facilities were in crisis, nor

were they transferred for palliative care to be able to die with dignity. As he says, they were "officially triaged out" (Stall, 2020).

#### **Family Experiences**

For decades, families have struggled with the decision to place a loved one in an LTC facility. For decades they have agonized over what they observed their loved ones experiencing in those settings. For decades they have called for change. And for decades very little has changed.

Families had every reason to expect relief from the intensity of supporting a vulnerable family member whose needs have escalated. They had every reason to believe they would be satisfied regarding the provision of care their loved one would experience. For many those expectations and beliefs have been dashed. As Burghardt (2014) explained the realities for family are often "regret, guilt, sadness, depression, betrayal, fear, anxiety, exhaustion, and anguish." And as Gaugler & Holmes (2003) report "caregivers who relocated their loved ones.....to residential Long-Term Care suffered higher rates of depression and experienced declines in perceived health."

In some circumstances families report appreciation of the nature of the empathetic responses of the direct care staff interacting with their family member. Not everyone has had that experience however, and for some the staff interactions have been horrific, given the reports of abuse and assault that repeatedly come forward.

Families have had to recognize that despite the assurances they received upon their loved one's admission to an LTC facility, the care provided is often so inadequate that there exists a necessity of family involvement in the direct care of their loved one or the necessity of hiring supplemental care from outside agencies. Sometimes these agencies are owned by the same corporation that operates the LTC facility, effectively increasing their profit margins.

Such supplemental support is essential in order to ensure the resident gets fed, receives adequate hydration, their personal care is completed, laundry is done, stimulation is provided, etc. This support is not available to those without family or other caregiver support and those residents must rely on the LTC staff for what is often sub-optimal care. Government pays almost \$183 per day for this, and residents' obligatory co-pay contributions range from approximately \$63-\$90 per day. Yet families must provide this supplemental care without compensation, all the while paying the facility for that very care. Not surprisingly, the National Institute on Aging has identified that Canadian unpaid caregivers are at an increased risk of burning out (National Institute on Aging, 2019).

Evidence for the necessity of family or privately paid caregivers providing regular assistance to their family member in LTC facilities was never more clear than during the COVID-19 pandemic, when as previously mentioned government directives, ostensibly for infection control purposes, prohibited family caregivers or visitors from entering the facilities. The results were catastrophic. Despite the fact that no evidence has been established that family caregivers or visitors were importing the virus into the facilities, as testified by Dr. Nathan Stall to the LTC commission (Stall, 3020), residents were denied the varied supports their family members had been providing. Many ended up dying of starvation or dehydration, their personal care not completed, nor their environments kept clean. Medical care was exceptionally inadequate, and reports of staff not being present in the facility and of physicians refusing to attend to their patients in the facilities were pervasive in media reports and

in the report of the military after they were called in to intervene at one point (Warnica, 2021; Welsh, 2020; Wallace, 2020 & 2021; McKeen & Nuttal, 2021; Pederson et al, 2020; Stone, 2020; Bell & Russell, 2020; Marlan, 2020; 4th Canadian Division Joint Task Force). "Radically shielding the older adults from contagion may offer increased security and order; but it is not enough. It does not foster dignity, spiritual and social care, and can have unintended undesirable consequences, such as social isolation and loneliness, resulting in negative physical and mental health impact" (Government of Canadian Task Force, 2020).

#### Breach of Duty of Care; Breach of Contract; Malpractice

When an individual enters into an agreement to place a family member into an LTC facility they are doing so with clear expectations as to the care that family member will receive in that setting, and those expectations have been shown to have been based on commitments made by the facility itself. It can be argued therefore, that there exists a contract between the facility and the resident. Contract law spells out obligations for the parties that are participants in a contract, and further details consequences when there is a failure to meet those obligations. These consequences may be pursued when either party alleges that there has been a breach of the contract. When provision of care is a component of the obligations in a contract, failure to provide the care specified is referred to as a breach of negligence or a breach of duty of care, and is based upon the expected standard of care that is owed by a person who has a duty of care. A breach of negligence would be considered when care is or is not done in a way that a reasonable person would or would not do, considering the circumstances and the knowledge of parties involved. A breach of the duty of care is considered when a person or organization has avoided acts or committed omissions that would likely cause harm to others towards whom they have a direct responsibility or legal obligation (Canadian Public Health Association, 2019; Silverman).

The Long-Term Care Homes Act (LTCHA) in Ontario sets out numerous obligations of Long-Term Care operators in the Ministry of Health and Long-Term Care's guide to the LTCHA, and a specific directive within that document states that LTC facilities must be in compliance with all applicable requirements of the Act. The Guide further states that "the fundamental principle to be applied in the interpretation of the LTCHA and the Regulation is that a LTC facility is primarily the home of its residents and it is to be operated so that it is a place where its residents may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met" (Health Quality Ontario, n.d.).

The MOHLTC also makes specific direct reference to the Resident's Bill of Rights, which includes identification of the rights to "Dignity and Respect; Prevention of Abuse and Neglect; specific references to various care and service obligations, including being properly fed, clothed, groomed, etc; establishes that the Goal of Care is to Maximize Independence; establishes the right to ensure minimized Restraint and then only under specific circumstances; along with many other specified rights (Government of Ontario, n.d.).

There are obviously many provisions that clearly establish direct obligations for the care and safety of people residing in LTC facilities. Additionally, there is extensive evidence that those obligations are not being reliably and consistently met. It becomes clear that residents and families must have recourse to a variety of remedies, amongst which are those of legal actions.

#### Legal Actions

As mentioned previously, Government funding of LTC facilities amounts to almost \$183 per resident day or \$66,800 per year. Resident copayments range from \$63-\$90 per day, or \$23,000 to \$32,850 per year, for a total payment of between \$89,800-\$99,650 per year. With that level of funding, it is quite incomprehensible that the promised care is not forthcoming.

The failure of so many LTC facilities to provide the care required by the residents they admit and to whom they have made assurances of care provision has lent credence to arguments that these facilities are legally in breach of their duty of care. If the signed contracts for admission into these settings and the related payment obligations for the care that families and residents were led to believe would be provided are deemed contracts under the law, then there may be legal breaches of contract (Law Commission of Ontario, 2010). This holds true even in the face of a pandemic such as COVID-19. As Dr Sinha has commented, in reference to the deaths of so many LTC residents, "they might not have died because of COVID, but they die because of starvation and dehydration" (Warnica, 2021). That's clearly not acceptable in any way. Malpractice is another legal allegation that might be pursued in these circumstances (SSAO, 2020).

Of equal importance, when and where facilities failed to provide the necessaries of life as obligated under the Canadian Criminal Code, criminal charges may be justified.

Section 215 of the Criminal Code of Canada establishes that it is a criminal offence if an individual fails to provide necessaries of life to a person under his or her charge if that person is "unable, by reason of detention, age, illness, mental disorder or other cause, to withdraw himself from that charge, and is unable to provide himself with the necessaries of life" (Criminal Code of Canada, 1985).

Legal analysis from the Advocacy Centre for the Elderly identifies that "the necessaries of life refer to those things necessary to preserve life, such as food, shelter, medical attention and protection from harm." (Romano, 2009). Clearly, many people did not receive the necessaries of life in these LTC facilities.

Potential criminal charges may be also be related to abuse and assault including battery, the overuse or inappropriate use of physical or chemical restraints, rape and murder. These would all justify as criminal charges, yet few criminal investigations have been pursued, let alone have criminal charges been laid with any frequency even in the face of abundant evidence.

The COVID-19 pandemic has brought these horrific infractions into the greatest public scrutiny that has occurred for years. The pandemic continues to devastate the population of residents in Long-Term Care facilities and has been doing so at greater proportions than for similar populations in any other settings.

Allegations of various concerns have prompted multiple class action lawsuits against numerous LTC corporations, amongst which are Extendicare, Sienna Senior Living, Revera and Rykka (McBride, 2020; Bildy, 2020; Levy, 2020; Roy & Huynh, 2021; Guly, 2020; Perkel, 2021). Included in these legal actions is a Human Rights case being brought forward by the Justice Centre for Constitutional Freedoms, related to the barring of families and other essential caregivers from being with their loved ones during the COVID 19 pandemic. As lawyer Lisa Bildy explains, when the necessary care that residents

required couldn't be provided by families, the heart-breaking deterioration that ensued may have been worse than the havoc the virus itself may have caused (Bildy, 2020).

It must be noted however, that legal actions against LTC operators have alleged inadequate care for many years, well before the pandemic struck (O'Keefe, 2018; Ontario Health Coalition, 2020). The Ontario Health Coalition has documented at least two dozen legal actions as a result of conditions in Long-Term Care. "Even before COVID-19 struck, over 200 families joined a lawsuit in 2018, known as a "mass tort" against Rivera, Extendicare, and Sienna Senior Living alleging that the nursing homes they paid to look after their loved ones failed them miserably" (Ontario Health Coalition, 2020). In fact, Extendicare, which is one of the largest of the LTC corporations in this province, has had allegations leading to legal actions, settlements and findings of claim in multiple jurisdictions, including Washington, Minnesota, Kentucky, Toronto, Tecumseh Ontario, Ohio, Alberta, and Ottawa (SSAO, 2020).

In light of these potential legal accountabilities, particularly in the face of the Covid-19 pandemic, operators and government have been quite concerned. In 2020, Ontario Premier Doug Ford introduced Bill 218, in an apparent attempt to minimize legal fallout for operators of LTC facilities. This Bill bars legal action related to deaths from C OVID 19 unless gross negligence can be proven, and essentially shields LTC facilities, making it very hard for individuals or families to sue. As Marvin Zuker, former Judge with the Ontario Court of Justice states, "negligent care, with respect, may not equate with being grossly negligent. What this bill appears to do….is limit liability for substandard care" (Zuker, 2020). Substandard care cannot be allowed to be an acceptable experience for anyone.

Noted Canadian Pierre Berton once said, in reference to the horrors being experienced by people with disabilities in an Ontario government institution located in Orillia, "Remember this: After Hitler fell, and the horrors of the slave camps were exposed, many Germans excused themselves because they said they did not know what went on behind those walls: no one had told them. Well, you have been told about Orillia." (Berton, 1960).

Let it be known: **This province and this country have been told about Long-Term Care institutions.** No amount of ostrich-like head burying can excuse inaction. Substantive and comprehensive reconceptualizing of our response to the needs of vulnerable people must occur.

Vulnerable people deserve much better than what they have been getting. There are no arguments that can justify the litany of tragic experiences that they have been enduring, both prior to and throughout Covid-19 pandemic. There is indeed an Illusion of Care within the Long-Term Care system in Ontario, and it is essential that a new Vision of Care, reliably committed to respectful, dignified alternatives be developed wherein peoples' clearly expressed desires to age in their own homes and communities with adequate supports underpins all initiatives.

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