Re:Think...
Long-Term Care

MAKING CHANGE

LESSONS LEARNED FROM 25 YEARS OF LONG-TERM CARE REFORM

November 2021

About *Re:Think Policy Change*

Re:Think Policy Change is a non-profit organization whose mission is to support community services to better engage with the individuals, families and communities that they serve, and to use that engagement to create responsive, accessible and just service systems. Our approach is rooted in our values of collaboration, independence, excellence and evidence-based approaches.

We believe that real change comes from engagement with users of services and their communities. Our role is not to lead change, but to facilitate it by supporting the efforts of those with a direct stake in change. Through our extensive network of specialists covering a broad spectrum of disciplines and skillsets, we conduct research, develop demonstration projects, mobilize knowledge and work to change public policy.

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The Re-Imagining Long-Term Care Project

The Lessons Learned research project is a foundational first step in the Re-Imagining Long-Term Care Project. The Re-Imagining Long-Term Care Project will support much needed policy change in long-term care in Ontario by working to bring new voices into the reform conversation, facilitating the development of shared goals, identifying new approaches to system change, and supporting information-sharing and collaboration.

The Re-Imagining Long-Term Care Project is grounded in a vision of the a long-term care system that is

- Connected to and accountable to communities
- Human in scale and approach
- Grounded in principles of dignity, autonomy and respect
- Flexible to meet the needs of diverse communities
- Resilient in the face of inevitable challenges

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Re:Think can be found on the web at: Rethinkpolicychange.ca.

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1 EXECUTIVE SUMMARY

The tragic experiences and outcomes in long-term care homes (LTCH) in Ontario and elsewhere in Canada over the course of the COVID-19 pandemic have led to renewed calls to re-imagine and reform our long-term care system. There is broad agreement – among LTCH administrators, care-givers, clients, families and communities – that reform must be undertaken with urgency and with a view to correcting the failures of the past. However, while essential, ensuring we never again repeat the experience of the pandemic is insufficient. It is now past time to transform long term care to ensure it becomes an elder-centred system that will enable seniors to live lives of security, dignity, meaning and connection.

Re:Think Policy Change undertook the *Lessons Learned project* to support and help catalyze the long-awaited system transformation that must urgently be undertaken. Rather than focusing on the much discussed questions of what a new system should look like, this paper examines how we can move past barriers to change to see real transformation. Drawing on many of the critical reform analyses of the past twenty-five years, as well as interviews with change-makers from a variety of perspectives, it examines lessons learned over the past more than two decades about pathways to reform, and suggests new pathways forward.

Pathways to reform must take into account the following challenges to change:

- *The power dynamics within long-term care:* Reform efforts are often driven by those most directly impacted by system failures, but in the long-term care sector, the particular vulnerabilities of residents, family caregivers and frontline workers create significant barriers to self or system advocacy.
- *Entrenched interests:* While most of those involved in the current system would acknowledge a need for change, the considerable institutional, financial, physical and individual investment in the status quo has made significant change hard to achieve.
- *Societal ageism:* Widespread and accepted societal ageism has helped to enable the ongoing lack of investment in and attention to this sector. Governments have not paid a significant price for neglecting long-term care.
- *Policy complexity:* The current system is both extremely complex – both to operate and to understand – and very fragile, a combination that has made reform both daunting and high risk for the vulnerable people who depend on its functioning. This has deterred ambitious reforms.
- *The challenges of advocacy:* There is a high level of turnover within the long-term care sector, which has tended to discourage commitment to advocacy; as a further challenge, the low return that advocates have tended to see on their investments in change has led to advocate exhaustion and burnout.

Combined, these factors have meant that traditional government relations approaches have had limited impact. Change-makers suggested that reform efforts focus on:

- *Elevating new voices:* The voices of those most directly impacted by the failures of long-term care are crucial both to the impetus towards and the direction of reform. Advocates suggest that including and elevating more diverse voices, including those of racialized, LGBTQ+ and Indigenous older adults and their caregivers will refresh the vision of reform and energize the conversation. There are examples and structures that can be learned from and expanded.
- *Demonstrating positive options:* The focus on negative experiences in long-term care has led to hopelessness and aversion to the conversation. But while major system transformation has not yet been achieved, meaningful new projects that are transforming the lives of the residents experiencing them have been successfully launched in local communities. Highlighting positive developments and options can provide a clear vision of what we can collectively work towards.
- *Connecting care to community:* The challenges to accountability in the provision of long-term care can in part be addressed by re-connecting long-term care to specific communities, whether these are geographic, cultural or other forms of community. This points towards locally driven design and innovation towards change.
- *Changing the culture:* Without culture change at both the institutional and societal levels, no real reform is possible. Taking approaches rooted in human rights and social justice can help to transform the way that aging and long-term care are understood.
- *Focusing on transformation:* Rather than incremental adjustments to the current system, a broader re-visioning of long-term care is needed. As long as our approach to long-term care is institutional as opposed to community-based, efficiency-focused as opposed to person-centred, and disconnected from surrounding communities and systems, long-term care will fail to meet the needs of older adults and their families.

The approach of *Re:Think Policy Change* to reform is rooted in our values of collaboration, independence, excellence and evidence-based approaches. We believe that real change comes from engagement with users of services and their communities. Our role is not to lead change, but to facilitate it by supporting the efforts of those with a direct stake in change. In light of our mission, our skill sets, our resources, and the vision of change set out in this report, Re:Think will, in the coming months, focus our efforts in three areas:

- engaging new voices in the policy discussions around the future of long-term care;
- facilitating connections and collaborations between those working towards change; and
- developing and sharing new tools and approaches that can support engagement and advocacy from within communities, and demonstrate positive options.

2 INTRODUCTION

Despite its broad and deep impact, long-term care is rarely the subject of sustained policy focus or investment. Those calling for reforms to long-term care in the wake of the Covid-19 deaths in long-term care homes (LTCH) have emphasized that the pandemic encountered a system that was already in deep crisis and had been for many years. The calls for reform are not new. The anguish of families, advocates and providers is exacerbated by a sense of many years of calls unheard.

Almost every Ontarian will be affected at some point in their life by our long-term care system. In Ontario, there are close to 80,000 people living in 626 long-term care homes.[1] Yet this number, large as it is, understates the impact of long-term care on the lives of Ontarians. It does not include the family and friends whose loved ones live in LTCHs and whose own wellbeing is deeply shaped by the wellbeing of those loved ones. It does not include the over 33,000 Ontarians who are waitlisted for placement into LTCHs and who are struggling to lead quality lives in the community while they wait.[2] It also does not include the many older Ontarians and their families who are facing decisions about the future, in light of concerns both about the quality of life available in LTCHs, and the often scanty supports available in the community.

In pushing forward towards reform, then, it is important to take account of the many years of efforts to create a long-term care system that is resilient, sustainable, and provides lives of dignity, meaning and security for residents. What has been achieved, and what remains to be done? Why has it been so difficult to achieve meaningful reform in long-term care? What conditions, capacities or strategies will facilitate meaningful reform?

1. Ontario Long-Term Care Homes Association, *This is Long-Term Care* (May 2018) https://www.oltca.com/OLTCA/Documents/OLTCA_LTC101_May2018.pdf; Canadian Institute of Health Information, *Long-Term Care Homes in Canada: How Many and Who Owns Them?* (September 2020) https://www.cihi.ca/en/long-term-care-homes-in-canada-how-many-and-who-owns-them

2. Seong-gee Um, Thrmiga Sathiyamoorthy, and Brenda Roche, *The Costs of Waiting for Long-Term Care* (Wellesley Institute: 2021).

3 THE LESSONS LEARNED PROJECT

This Report summarizes the results of the Lessons Learned Project, the first project of *Re:Think Policy Change* in its broader initiative to support ongoing efforts to re-imagine and reform long-term care in Ontario. The *Lessons Learned Project* took as its starting point the question of why, despite the efforts of many, meaningful change has been so difficult to achieve in the long-term care sector. The focus was less on the much discussed question of what change is required, than on the issue of how change can be achieved. It aimed to take stock of 25 years of efforts at reform, and identify lessons learned and paths forward.

This Report is intended to share what we have learned with other individuals and organizations that are committed to community-based efforts to change long-term care, and to provide a foundation for future collaborations and change efforts. As such, it does not attempt to describe the current long-term care system, or to summarize the many recommendations for reform that have been put forward.

The *Lessons Learned Project*, like the broader *Re-Imagining Long-Term Care* initiative, is grounded in a vision of long-term care that is:

- Connected to and accountable to communities
- Human in scale and approach
- Grounded in principles of dignity, autonomy and respect
- Flexible to meet the needs of diverse communities
- Resilient in the face of inevitable challenges

The Lessons Learned project had three components, each building on the others.

Review of deputations to Ontario's Long-Term Care Covid-19 Commission: In the wake of the deaths and suffering in Ontario's LTCHs during the first wave of the pandemic, the Ontario government appointed a Commission of Inquiry to investigate how and why COVID-19 spread in LTCHs, what was done to prevent the spread, and the impact of key elements of the existing system on the spread. The Commissioners received deputations from dozens of experts and stakeholders, and transcripts are available on the Commission's website.[1] A review of these transcripts provided an understanding of the current system and its challenges, as well as priorities and recommendations for reform.

Review of previous reports and recommendations: Over the past 30 years, there have been a plethora

1. http://www.ltccommission-commissionsld.ca/transcripts/index.html

of reports and recommendations that make the case for the importance of long-term care, identify the importance of and priorities for reform, and propose recommendations for change. For this project, we reviewed a sampling of reports released between 1991 and 2020. These included Coroner's Reports, government reviews and strategy documents, reports of public inquiries, reports and submissions from key stakeholders, policy reviews and reports produced by think tanks and advocates, and others. Our review, while running to many thousands of pages, only scratched the surface of the materials available.[2] It provided, however, an outline of the history of the current system, of its continued challenges, and of the struggles towards reform.

Key informant interviews: We interviewed 21 change-makers in long-term care, from a variety of disciplines, organizations and perspectives. Our interviewees included those who have been struggling towards reform for decades and those who have more recently entered the fray; those who have taken grassroots approaches and others who have developed evidence-based reports and recommendations; those who have worked at the provincial level to transform laws and policies and those who have worked to demonstrate change at a local level.[3] Our aim was to identify lessons learned about effective approaches to reform of long-term care, and how conditions can be created to support re-imagining long-term care.

There are many individuals and organizations that have been making significant contributions towards long-term care reform over the years. The change-makers that we spoke to are certainly not the complete list. *Re:Think* intends to continue to engage and to learn. The engagement process undertaken for this Report, and the Report itself, are intended as a contribution to an ongoing conversation, and not as the final word.

2. In June 2020, the Registered Nurses Association of Ontario produced a list and analysis of 35 reports addressing staffing and funding in long-term care over the past 25 years. This provided a valuable starting point in accessing some of the key literature. Registered Nurses Association of Ontario, Long-Term Care Systemic Failings:

Two Decades of Staffing and Funding Recommendations (June 2020) https://rnao.ca/sites/rnao-ca/files/RNAO_LTC_System_Failings_June_2020_1.pdf

3. A list of individuals interviewed is provided as an Appendix to this Report.

4 THE LONG-TERM CARE CONTEXT

While long-term care is often thought about in the context of health care, it is in fact, something much broader. Long-term care exists to provide supports to the growing number of people, overwhelmingly but not exclusively older adults, who live with complex medical conditions or frailties that leave them in need of support with the activities of daily living or continuing intensive medical care as they live out their lives. The aim of long-term care is not to treat health conditions and return the individual to their previous lives, but to provide supports to enable individuals to live the best lives that they can in the context of their conditions. This difference has implications that shape – or should shape – every aspect of the long-term care system.

Ontario's long-term care system is complex. It has evolved over time, often incrementally and in response to immediate issues. It is not the purpose of this report (or this project) to describe or analyze this system. However, some elements that are key to understanding Ontario's long-term care context are briefly outlined below.

Competing models: The guiding principle of Ontario's *Long-Term Care Homes Act* is that a LTCH is first and foremost the home of its residents.[1] This means that homes should be operated so that residents may "live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met". In practice, there remains a struggle between the model of 'home' (or, in a kindred concept, a 'person-centred model'), and the longstanding medicalized model of care, which can subordinate quality of life to an overly narrow focus on treatment of biological problems. In practice many LTCHs look and feel little like homes. Instead, they are operated as highly regimented, large-scale institutions, with efficiency, regulatory compliance and risk-avoidance as dominant considerations.

Residents may in practice be offered few choices during the day, including little control over the timing or content of their meals, the décor or layout of their surroundings, whom they room with or eat with, or when they rise, bathe, toilet or go to sleep. Residents may in effect be treated more like 'patients' and the model may in effect be medical, rather than person-centred. No one would describe this as a desirable state of affairs, and there are certainly homes which have gone to considerable effort to chart a better path. The reasons for the ongoing resilience of the medical model in LTCHs are historical, financial, regulatory, institutional and structural.

A system, not an institution: The term 'long-term care' most often is understood as referring to the over 600 homes for individuals with chronic and intensive medical needs that receive funding from Ontario's provincial government and are governed by the *Long-Term Care Homes Act*, 2007. However, these homes

1. *Ontario Long-Term Care Homes Act, 2007*, S.O. 2007, c. 8, s. 1

are but one element of a broader, interconnected system of supports for these residents, including:

- Home and community supports, which supplement the often intensive unpaid caregiving work of family and friends: some of these supports are publicly funded or not-for-profit while others are provided through the private market
- Retirement homes, which are lightly regulated under a consumer protection model, and are funded through fees to their residents: these are increasingly providing intensive supports and services parallel to those provided in LTCHs [2]
- Municipal supportive housing for seniors programs, which may offer low-income seniors services to support independence, such as personal care, light housekeeping, medication checks and more
- Acute care, such as hospitals and rehab centres: because of rationed services and supports, many seniors with intensive needs find themselves cycling between acute and community care, or living in hospitals while waiting for placement in a long-term care home.

These elements were not designed as a coordinated model, however. To understand the interactions of the LTC, acute care and home and community care (HCC) systems is a significant task in itself.

Demographics, pragmatic considerations and the desires of older adults themselves point towards a future in which residential care settings are both more closely tied to community and part of a well-integrated spectrum of services that support aging in the community. In considering long-term care, it is important to see residential settings as one element in a broader system of supports and services for older adults who are in need of sustained and intensive supports in order to lives of dignity, security and inclusion. [3]

Thus, when we refer to long-term care, we are referring to this entire continuum of supports, rather than simply long-term care homes. This Report focuses on the challenges in LTCHs themselves, but understands that Ontario's LTCHs cannot be understood in isolation, and that reform requires a vision of a broader, interconnected system of supports for frail and vulnerable older adults.

Complex governance and oversight: Long-term care is by-and-large provincially regulated, as part of the provincial jurisdiction over health and community services. While long-term care is not listed in the Canada Health Act as an insured service, the federal government does have a role, in that long-term care is included as a basis for federal transfers, with some minimal reporting conditions attached; current work towards national standards may presage a more significant role in future. Municipalities and First Nations play an important role in that many operate their own LTCHs, as well as have responsibility for many of the institutions and services (transportation and built environment, for example) that enable aging in the community.

Because the system is fragmented, so is oversight. The Ministry of Long-Term Care is responsible for

2. For a discussion of the implications of this phenomenon for the oversight regime, see Office of the Auditor General of Ontario, *Retirement Homes Regulatory Authority* (December 2020): https://www.auditor.on.ca/en/content/annualreports/arreports/en20/20VFM_12retirement.pdf

3. This approach is aligned with that of the National Institute on Ageing, which defines long-term care as: "a range of preventive and responsive care and supports, primarily for older adults, that may include assistance with the Activities of Daily Living and the Instrumental Activities of Daily Living, provided by either not-for-profit or for-profit providers or unpaid caregivers, in locations that are not location specific and thus include designated buildings, or in home or community care settings." National Institute on *Ageing, Enabling the Future Provision of Long-Term Care in Canada* (2019)

long-term care homes themselves; while the Ministry of Health oversees the home & community care and acute care systems, and the Ministry for Seniors and Accessibility oversees the Retirement Homes Act and other supports for seniors. Other Ministries and agencies also have roles to play: for example, the Ministry of Labour has oversight of working conditions in LTCHs, and public health bodies have responsibilities related to infection prevention and control.

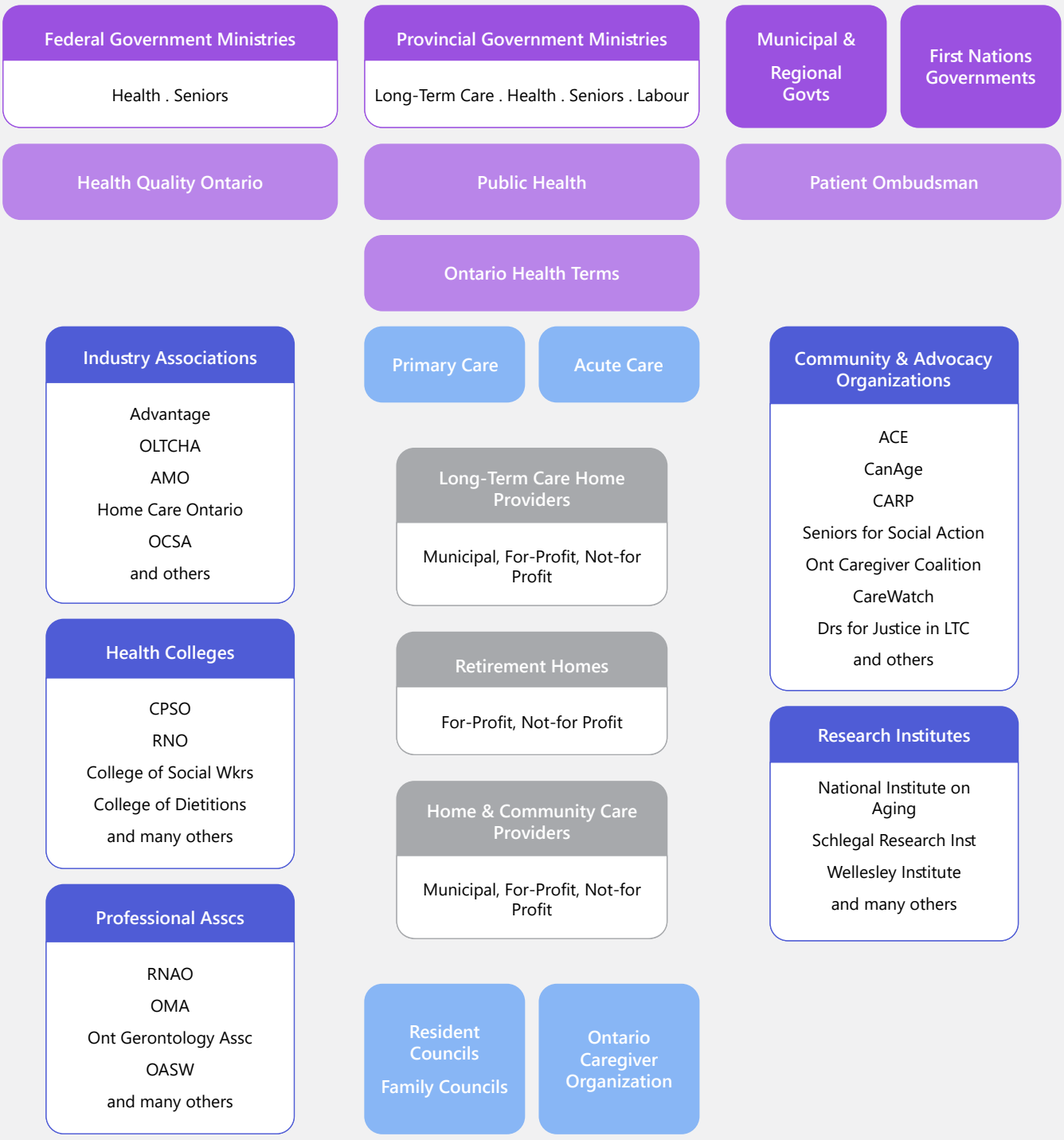
Figure 1 below summarizes some of the key institutions involved in the provision of long-term care in Ontario.

The governing legislation and policy are themselves extensive and challenging to implement. *The Long-Term Care Homes Act* and accompanying Regulations together run to hundreds of pages, not considering other applicable legislation, funding requirements and policy documents. Many deputants to the Long-Term Care Covid-19 Commission spoke of this complexity as itself a barrier to quality care and supports. While intended to ensure that all residents of long-term care have access to consistent, excellent supports, and to enable accountability for providers of long-term care, in practice, these extensive requirements and standards have become ends in themselves, diverting resources and attention from residents themselves towards completing administrative tasks, and encouraging a 'checkbox mentality'.

> *"It is a very regimented system, and when you don't have the lenience, shall I say, or the ability to take your time and, you know, to give proper quality care to these individuals, it literally turns into a factory line."*
>
> Deputation to the Covid-19 Long Term Care Commission
> Ontario Personal Support Workers Association

Thus complexity – regulatory, oversight and systemic - is a defining feature of long-term care in Ontario. There are many institutions and actors to coordinate, many interests to take into account, and many rules to navigate, whether in maintaining and operating the current system, or in seeking reform.

Figure 1: Key Institutional Stakeholders in Ontario's Long-Term Care System



5 LONG-TERM CARE: THE STRUGGLE FOR REFORM

Another defining feature of Ontario's long-term care system is the impulse towards reform. This project looked at 25 years' worth of reports and recommendations on long-term care reform, but even in the mid-90s, this was an ongoing conversation with a lengthy history. While some commentators point to relatively recent developments, such as population aging, privatization and budget restrictions, and changing family norms, as the cause of current challenges, the reality is that there was no halcyon period of long-term care in Ontario.[1] While much has changed over the past 25 years, much has remained unchanged.

25 Years of Long-Term Care: What Has Changed?

The last quarter-century has been a period of rapid change in the context and conditions of long-term care.

Demographics: The aging of Canada's (and Ontario's) population has been so often pointed out as to become a cliché. In 1999, 12.4% of Ontario's population was over age 65.[2] In July 2020, that figure was 17.6%.[3] It will continue to grow in the coming years. This is not the only important demographic change affecting long-term care. Seniors are also living longer with chronic conditions.[4] The diversity among older adults is increasing, particularly in the Greater Toronto Area; however, supports and services that address the needs of ethnically, culturally and racially diverse seniors are not keeping pace.[5] And fewer Ontarians can rely on family for extensive supports, as lifespans expand, more individuals divorce or remain single throughout their lives, individuals have fewer or no children and families become more geographically

1. An excellent and concise review of the history of LTC can be found in Andre Picard, *Neglected No More: The Urgent Need to Improve the Lives of Canada's Elders in the Wake of a Pandemic* (Penguin Random House: 2021)

2. Ontario Human Rights Commission, *Human Rights issues Facing Older Ontarians* (May 2000) http://www.ohrc.on.ca/en/discussion-paper-discrimination-and-age-human-rights-issues-facing-older-persons-ontario/demographics#fn9

3. Statistics Canada, *Population Estimates on July 1, 2020, by age and sex.*

4. Claudia Sanmartin, *Research Highlights on Health and Aging* (Statistics Canada: July 2016).

5. Seong-gee Um and James Iveniuk, *Waiting for Long-Term Care in the GTA: Trends and Persistent Disparities* (Wellesley Institute: September 2020) https://www.wellesleyinstitute.com/wp-content/uploads/2020/09/Waiting-for-Long-Term-Care-in-the-GTA.pdf; Nazeefah Laher, Lauren Bates and Seong-gee Um, *The Changing Face of Home and Community Care: Policy Background and Recommendations* (Wellesley Institute: 2019) https://www.wellesleyinstitute.com/wp-content/uploads/2019/06/Policy-Background-Recommendations-1.pdf; Seong-gee Um and Naomi Lightman, *Seniors Health in the GTA: How Immigration, Language and Racailziation Impact Seniors Health* (Wellesley Institutute: 2016) https://www.wellesleyinstitute.com/wp-content/uploads/2017/05/Seniors-Health-in-the-GTA-Final.pdf

dispersed. Growing numbers of older adults do not have someone to provide supports for independence, navigate systems or advocate on their behalf,[6] and the responsibilities of those who do provide care to family members have become at once more complex and more onerous. In general, the needs of older adults for services and supports are becoming greater, more intense and more complex.

Recognition of the Rights of Older Adults: With population aging and the resultant increase in attention to the experiences of older adults, governments and policy makers have reconsidered approaches to aging and older adults. In particular, there has been a growing emphasis on the value and contributions that older persons bring to society, as well as efforts to combat the stigma associated with aging and remove barriers to inclusion and participation. Work at the international, national and provincial levels have advanced these developments.

Internationally, the *International Principles for Older Persons* (1991), the subsequent *Madrid International Plan of Action on Ageing* (2002), and the World Health Organization's *Active Ageing Policy Framework* provide a foundation for action to enhance the lives of older persons that can be applied across cultures and circumstances.[7]

Nationally, the Canadian government adopted the National Framework on Aging in 1998, and in 2006, the Senate struck a Special Senate Committee on Aging which has released several valuable and far-reaching reports and recommendations.[8]

Provincially, the Ontario Human Rights Commission released a report in 2002 on human rights and older age *(A Time for Action)* and a policy on discrimination against older persons because of age. More recently, the Law Commission of Ontario developed a comprehensive Framework for law, policy and practice as they affect older persons.[9]

Together, these policy frameworks have developed a shared set of understandings about the contributions, value, dignity and worth of older persons, identified the barriers they face to full inclusion and participation in society, and proposed a set of principles that guide law, policy and practice that centre on dignity, autonomy, security, and inclusion. The fundamental values and principles laid out in these frameworks can provide a strong foundation for the design and delivery of long-term care, though difficult challenges of implementation lie still ahead.

Government: Over the past 25 years, Ontario has seen three different governments and five premiers. The long-term care portfolio has seen many cabinet ministers come and go, together with their reviews,

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6. MacDonald, B.J., Wolfson, M., and Hirdes, J. (2019). The Future Co$t of Long-Term Care in Canada. National Institute on Ageing, Ryerson University.

7. United Nations, International Principles for Older Persons, G.A. Resolution 46/91; United Nations, Madrid International Plan of Action on Ageing, Report of the Second World Assembly on Ageing (April 2002) https://www.un.org/development/desa/ageing/madrid-plan-of-action-and-its-implementation.html; World Health Organization, Active Ageing: A Policy Framework (2002) https://www.who.int/ageing/publications/active_ageing/en/

8. Health Canada, Division of Aging and Seniors, *Principles of the National Framework on Aging, A Policy Guide* (March 1998) http://publications.gc.ca/collections/Collection/H88-3-21-1998E.pdf; Special Senate Committee on Aging, *Final Report, Canada's Aging Population: Seizing the Opportunity* (Ottawa, 2009)

9. Ontario Human Rights Commission, *A Time for Action: Advancing Human Rights for Older Ontarians* (Toronto, 2001); Ontario Human Rights Commission, *Policy on Discrimination Against Older People Because of Age* (Toronto, 2007); Law Commission of Ontario, *A Framework for the Law as it Affects Older Adults, Advancing Substantive Equality for Older Persons through Law, Policy and Practice* (Toronto, 2012).

strategies and initiatives for this system. While some strategies and initiatives have been more promising than others, the root problems remain. This is not a partisan issue.

Health System Reform: Ontario's health system has been under almost continual reform over the past couple of decades. In 1996, the Health Services Restructuring Commission was created to expedite hospital restructuring in Ontario, along with exploring means of creating a truly integrated and coordinated health system for the province.[10] This was followed by the creation of the Local Health Integration Networks (LHINs) in 2004, as a means of developing regional health structures and of integrating and reforming the health system.[11] Over the next 15 years, the LHINs would be repeatedly restructured, including through the 2016 *Patients First Act*[12], which aimed to improve coordination and access to health services by creating sub-regions for the LHINs, and to improve accountability through expanded powers for the LHINs.

LHINs no longer exist, as very recently, the health system has been reorganized around the concept of Ontario Health Teams. These OHTs are groups of providers and organizations that are clinically and fiscally accountable for delivering a full and coordinated continuum of care to a defined population. OHTs may include, for example, hospitals, doctors, and home and community care agencies. The first cohort of OHTs was announced in the fall of 2019, just shortly prior to the arrival of the first cases of COVID-19 in Ontario.

Legislative Reform: Over the past fifteen years, the legislative framework for long-term care in Ontario has undergone comprehensive reform. The passage of *the Ontario Long-Term Care Homes Act*[13] in 2007 was the result of a monumental effort that included considerable stakeholder engagement and public consultation. The legislation is grounded in a fundamental principle: that a LTCH is in fact primarily a home, and must be operated so that residents may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met. The OLTCHA consolidated three separate previous regimes to create a consistent framework; included a comprehensive Bill of Rights for residents; strengthened the inspection and enforcement regime; clarified the responsibilities of homes and the standards to be applied to them; included new requirements for training and education; and enhanced protections against abuse and neglect.[14] Its implementation in 2010 was intended to mark a sea change in the lives of residents.

The creation of *the Retirement Homes Act*,[15] which provides a regulatory and oversight regime for retirement homes, followed closely upon the development of the OLTCHA. The approach to regulation of retirement homes was controversial at the time, and remains the subject of debate today. The RHA allows retirement homes to provide a full spectrum of levels of care, equivalent to those in LTCH, but without the same level

10. Canadian Health Workforce Network, *Looking Back, Looking Forward: The Ontario Health Services Restructuring Commission* 1996-2000 (2000)

11. Paul Barker, *Local Health Integration Network: The Arrival of Regional Health Authorities in Ontario* (Paper prepared for presentation at the Annual Meeting of the Canadian Political Science Association, University of Saskatchewan, Saskatoon, Saskatchewan, May 2007) https://www.cpsa-acsp.ca/papers-2007/Barker.pdf

12. *Patients First Act*, 2016, S.O. 2016, c.30.

13. *Ontario Long-Term Care Homes Act, 2007* , S.O. 2007, c. 8.

14. A clear and thorough overview of the legislation was written by the Advocacy Centre for the Elderly upon its implementation: http://www.acelaw.ca/appimages/file/ACE_Newsletter_LTCHA_Insert_October_2010(1).pdf

15. *Retirement Homes Act, 2010, S.O. 2010*, c. 11

of government oversight, and for a fee.[16]

Broader societal transformation: In addition, there have of course been waves of social, economic and technological change over this period. In 1995, the North American Free Trade Agreement had only just come into effect. The caselaw under the *Charter of Rights and Freedoms* was still in the early stages of development – for example, medical assistance in dying, with all of its implications for the last stages of life, was not yet in contemplation, and the battle for same-sex marriage was still pushing uphill. The current laws with respect to health care consent were still in development. It was, in many respects, a different world. And yet, amazingly, despite all of these changes, the conversations around long-term care remain largely unchanged.

Covid-19 Pandemic: Our current moment is of course shaped by the Covid-19 pandemic and the waves of death, loneliness and suffering that have been unleashed as it has swept across Ontario's long-term care system. The pandemic has shone a spotlight on the shortcomings of long-term care, as reflected in the creation of the Long-Term Care Covid-19 Commission. This is a moment both of grief and of opportunity for change.

What Has Not Changed?

A review of reports and recommendations produced over the past 25 years on long-term care reform, when read in conjunction with the deputations to the Long-Term Care Covid-19 Commission, produces startling similarities and parallels. Despite all of the many changes outlined above, and taking into account that in some areas, technical details will have evolved, the fundamental challenges remain. Each of the challenges identified below have been highlighted, both in the deputations to and recommendations of the Long-Term Care Covid-19 Commission, and in multiple reports developed over the past two and a half decades.

It should be emphasized that these are system issues. There are a range of LTCH providers, some of whom provide good or even excellent quality of life, and others where no one would want to see a loved one placed. While good practices can be identified, scaled up and spread, the system problems that have been repeatedly identified enable the continuance of poor quality services and create real barriers for dedicated providers.

Staffing: The OLTCHA requires each LTCH to prepare an annually updated staffing plan that enables the home to meet the comprehensive requirements of the Act and Regulations, and that is consistent with the assessed care and safety needs of residents.[17] Despite this, staffing has historically been the most commonly cited issue in reports, recommendations and deputations. Consistent and grave concerns have been raised that there are not sufficient staff in LTCHs to meet all of the needs of residents safely, let alone to provide the social, emotional and other supports that are important to ensure quality of life.[18] Beyond staffing levels,

16. See, for example, J. Wahl, "Inadequate Protections for Tenants of Retirement Homes: ACE's Concerns about Bill 21, The Retirement Homes Act", *Advocacy Centre for the Elderly Newsletter* (October 2010) http://www.advocacycentreelderly.org/appimages/file/Concerns_about_RHA_-_Oct_2010.pdf

17. O. Reg. 79/10 General, s. 31(3)

18. Justice Gillese cited many of these reports in arriving at her recommendation in her report into the 2019 inquiry into deaths in long-term care: The Honourable Eileen E. Gillese Commissioner, *Public Inquiry into the Safety and Security of Residents in the Long-Term Care Home System*, Volume 3, pp. 115-116 (Queen's Printer for Ontario, 2019) *(Gillese Inquiry)*. She noted that the call for additional funding for staff has been has been "a constant refrain in every review and study of Ontario LTC homes for the past 20 years".s

there are also ongoing concerns about staffing mix, and about skills and training for staff.

These staffing challenges are related, not only to the number of positions funded, but also to difficulties with recruitment and retention. Work in LTCHs can be highly rewarding for the right staff, because it provides the opportunity to develop deep relationships with residents and to make a meaningful difference in their lives. However, difficult working conditions including inadequate pay and benefits, heavy workloads, limited career paths, and leadership shortcomings, lead to very high turnover, and persistently unfilled positions. The OLTCHA describes this as a 'human resources emergency', pointing out that 80 per cent of LTCHs are currently having difficulty in filling shifts.[19]

The Ministry of Long-Term Care recently completed a staffing study, in response to recommendations from the Gillese Inquiry. The staffing study emphasized that the staffing issues in LTC are challenging and systemic in nature, and require urgent attention.[20]

Quality of services and supports: Not surprisingly, much of the focus of reform efforts has been on system issues, and on minimum standards to ensure adequacy of supports and security of users of long-term care. Because the system is under so much strain, there is concern about its ability to deliver at even the most basic levels. However, if the goal is a system that provides a good quality of life for users, then attention must also be paid to issues such as abuse and neglect of residents of LTCH, widespread disregard of legal rights, and poor quality of services and supports. For example, in a 2017 paper, Wellesley Institute pointed out that Ontario LTCHs receive only $8.33 per resident per day for raw food, and that approximately 50 per cent of residents suffer from malnutrition, due to the low quality of food and meal environments.[21] While the pandemic has brought attention to loneliness and toxic boredom in LTCHs, this has been a reality for many older adults receiving LTC supports well before Covid-19.[22] A 2020 analysis by CBC Marketplace of reports of violations of Ontario's LTCHA safety requirements found that six in seven care homes are repeat offenders, and there are virtually no consequences for homes that break the law repeatedly.[23] As well, as Ontario's population continues to become more culturally, linguistically, ethnically and racially diverse, insufficient attention has yet been paid to ensuring that diverse seniors have access to care that is appropriate to their needs[24].

Insufficient access: Ontario has struggled with long waitlists for LTCHs for many years. As noted above, there are currently over 30,000 Ontarians waitlisted for placement in long-term care – this, in a system which currently provides homes for 80,000 people. While the Ontario government has committed funds to

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19. Ontario Long Term Care Home Association, *Challenges and Solutions: Rebuilding Long-Term Care for Ontario Seniors – Ontario Budget Submission* 2020 https://www.oltca.com/OLTCA/Documents/Reports/OLTCA-2020-Budget-Submission---final.pdf

20. Long-Term Care Staffing Study Advisory Group, *Long-Term Care Staffing Study* (Ministry of Long-Term Care: July 30, 2020) https://files.ontario.ca/mltc-long-term-care-staffing-study-en-2020-07-31.pdf

21. Laura Anderson and Seong-gee Um, *Food Quality in Institutional Settings in Ontario: Health Equity Perspectives* (Wellesley Institute: 2017) https://www.wellesleyinstitute.com/wp-content/uploads/2017/07/Food-in-Institutional-Settings-in-ON.pdf

22. S.B. Julian "Confinement and Toxic Boredeom Plagued Long-Term Care Before Covid-19", Policy Options (June 2020) https://policyoptions.irpp.org/magazines/june-2020/confinement-and-toxic-boredom-plagued-long-term-care-before-covid-19/

23. Katie Pedersen, Melissa Mancini, David Common, William Wolfe-Wylie "85% of Ont. nursing homes break the law repeatedly with almost no consequences, data analysis shows", CBC News, October 23, 2020, https://www.cbc.ca/news/marketplace/nursing-homes-abuse-ontario-seniors-laws-1.5770889

24. See for example, Seong-gee Um, Nazeefah Laher and Brenda Roche, The Changing Face of Home and Community Care (Wellesley Institute: 2019)

add 15,000 new beds and upgrade 15,000 more by 2023, very few projects are underway, due to funding and program challenges.[25]

This access issue has roots in and implications for the broader system of health and social supports as a whole. The lack of resources and supports for aging in place in the community, including a lack of supports for family caregivers, drives up the number of individuals for whom long-term care home placement becomes the only viable option. At the same time, the lack of space in the LTCH system means that only the very neediest individuals can find a placement in long-term care, straining the abilities of homes to provide high quality services and supports. It also means that even poor quality homes need not worry about filling spaces, and that the incentives run against suspending operations at poorly run homes.[26] There has also been considerable focus on the strains that the lack of access to long-term care places on the hospital system, as older persons who are not well enough for discharge in community must wait in hospital for placement. This is a totally inappropriate environment in which to live for any significant length of time. It also creates pressure to discharge to unsuitable environments.

Funding: Underlying many of the challenges in long-term care - and particularly challenges in staffing and physical infrastructure - are funding issues. Because of the intensities of needs of users of long-term care, these services are costly to provide. And as needs become more complex and demographic changes increase the numbers of users, those costs continue to grow. As many observers have pointed out, funding has not kept pace.[27] In fact, the sector has grappled with unpredictable funding and with cuts.

As well as inadequate funding levels, the funding model itself is outdated and inadequate. Long-term care homes perceive it to be complex, onerous, inflexible and not responsive to changing needs. It focuses on activities rather than outcomes. It does not incentivize LTCHs to enhance quality and improve health outcomes of residents, and in fact may have the opposite effect.[28] One deputation to the Long-Term Care Covid-19 Commission noted that the Case Mix Funding[29] model actually incentivizes the hiring of part-time staff over full-time staff, because the funding varies so much from year to year that it is difficult to plan ahead.[30] Moreover, because the Case Mix Index measures not the actual acuity of needs, but how homes rank against the average, it has not adjusted to the rising complexity of resident needs within the LTCH sector. [31]

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25. Ontario Long Term Care Home Association, *Challenges and Solutions: Rebuilding Long-Term Care for Ontario Seniors – Ontario Budget Submission 2020* https://www.oltca.com/OLTCA/Documents/Reports/OLTCA-2020-Budget-Submission---final.pdf

26. Deputation of the Advocacy Centre for the Elderly to the Covid-19 Long-Term Care Commission (September 23, 2020)

27. See, for example, Association of Municipalities of Ontario, "Long-Term Care Backgrounder" (August 2020) https://www.amo.on.ca/AMO-Content/Backgrounders/2020/LongTermCareinOntario.aspx; Ontario Long Term Care Home Association, *Challenges and Solutions: Rebuilding Long-Term Care for Ontario Seniors* – Ontario Budget Submission 2020 https://www.oltca.com/OLTCA/Documents/Reports/OLTCA-2020-Budget-Submission---final.pdf

28. Long-Term Care Staffing Study Advisory Group, *Long-Term Care Staffing Study* (Ministry of Long-Term Care: July 30, 2020) https://files.ontario.ca/mltc-long-term-care-staffing-study-en-2020-07-31.pdf

29. The Case Mix Index Case Mix Index (CMI) is the standard measurement of resident care requirements used in all of Ontario's Long-Term Care Homes. It is based on a standardized grouping methodology developed by the Canadian Institution for Health Information, which is used to categorize the clinical and estimated resource utilization similarities of residents

30. Deputation of Revera to the Long-Term Care Covid-19 Commission (October 7, 2020)

31. The deputation to the Long-Term Care Covid-19 Commission by the Ministry of Long-Term Care Policy Branch on Long-Term Care Staffing and Funding (September 24, 2020) provides a very helpful overview of the current model and its many challenges.

Physical infrastructure: Underlying the lengthy waitlists for placement in LTCH are broad challenges in physical infrastructure. Not only is there an insufficient number of LTCHs to meet demand, but many of the existing homes are aging. These older homes often do not meet current standards in terms of privacy, safety standards and living amenities. Some of them are in poor physical condition. Older homes have been hit hard by the pandemic because they tend to lack private spaces for residents and their HVAC systems are outdated. Some can be updated to meet current standards; others need to be replaced. Almost half of all LTCHs require renovation or rebuilding.[32] However repair and replacement are costly, and there has been a decades-long legacy of underinvestment.[33] In densely populated and costly areas of the province, such as Toronto, it is difficult to find appropriate space to create long-term care homes.

Oversight and accountability: While the OLTCHA and Regulations set comprehensive and detailed standards for quality supports and services in LTCH, there is widespread concern that many homes repeatedly fall short of these standards, including grave shortfalls, and that there are no meaningful consequences for failure to meet standards. This means that thousands of residents are persistently receiving care that is not only substandard but that undermines their dignity, places their security at risk, and too frequently may amount to neglect or abuse.

The challenge, like the others identified here, pre-dates the OLTCHA. It was hoped that the inclusion in the Act and Regulations of clear, detailed standards and a reformed compliance and enforcement regime would improve oversight and accountability; however, this is not the case.

LTCHs point out that the current regime, with its extensive standards, is confusing, burdensome, takes time away from resident care, and encourages a "checkbox" approach. The Ministry of Long-Term Care's staffing study points out that the heavy focus on compliance diverts staff effort away from resident care towards paperwork, and is contributing to low morale in the sector.[34] Advocates for residents in their turn point out that homes with poor records continue to operate with apparent impunity,[35] and the Long-Term Care Covid-19 Commission has expressed concern about the apparent lack of enforcement and verification of compliance with Orders issued by the Ministry.[36] Clearly, a new approach is needed.

System integration and connectedness: One of the underlying challenges for long-term care has been its relative disconnection, both from other institutions in the health and social services sector, and at times from their surrounding communities. The Covid-19 pandemic has highlighted the value and importance of closely connecting and coordinating long-term care homes with acute care facilities, public health and other health institutions, and the Long-Term Care Covid-19 Commission has emphasized, in its Interim Recommendations, the importance of strengthening healthcare sector relationships and collaboration.[37]

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32. Ontario Long-Term Care Home Association, *This is Long-Term Care 2019*

33. See for example the deputations to the Long-Term Care Covid-19 Commission of Inquiry of AdvantAge (September 29, 2020), the Ontario Long-Term Care Home Association (September 30, 2020) and from Ministry staff on Long-Term Care Capital Development and Licensing (September 18, 2020)

34. Long-Term Care Staffing Study Advisory Group, *Long-Term Care Staffing Study* (Ministry of Long-Term Care: July 30, 2020) https://files.ontario.ca/mltc-long-term-care-staffing-study-en-2020-07-31.pdf

35. See, for example, the deputation of the Advocacy Centre for the Elderly to the Long-Term Care Covid-19 Commission (September 23, 2020).

36. Long-Term Care Covid-19 Commission, *Second Interim Recommendations* (December 4, 2020) http://www.ltccommission-commissionsld.ca/ir/pdf/20201203_2nd_Interim_Letter-E.pdf

37. Long-Term Care Covid-19 Commission, *First Interim Recommendations* (October 23, 2020) http://www.ltccommission-commissionsld.ca/ir/pdf/20201023_First_Interim_Letter_English.pdf

Summing Up

Trends point towards a future in which long-term care takes on a greater role in our systems of social supports. With changing demographics, gender roles, work patterns and family dynamics, the current approach leads us towards outcomes that appear to be incompatible with our espoused values, our labour force needs, and our aspirations for our own lives.

The current model of long-term care is fragmented, fragile and isolated from broader communities and institutions. It is both expensive and impersonal; both over-regulated and failing to meet minimum standards. LTCHs are seen as an undesirable destination, and yet the system is overwhelmed by demand.

Given these realities, it seems surprising that the system continues to struggle forward in the status quo, stigmatized and under-resourced. Why, when this system affects every Ontarian at some point in time, do we put up with it? Why haven't Ontarians demanded – and got – something better for our loved ones and for ourselves? Why, when voices within and outside of the system have been ringing alarm bells for years, is change so hard?

6 BARRIERS TO REFORM

To understand the barriers that have made reform of the long-term care system so difficult, *Re:Think* researchers interviewed 21 change-makers, in Ontario, across Canada, and abroad. We spoke to individuals with decades-long histories in working towards reform, as well as those who have recently entered the fray, energized by the revelations brought forth by the pandemic. We spoke to individuals from a variety of perspectives – advocates, researchers, innovators, and grassroots organizers, among others. Despite the diversity of experiences and perspectives, certain themes quickly emerged.

Interestingly, despite the common perception that the key barrier to reform is the cost of providing quality care, this was not a significant theme in our conversations. Demographic change will certainly create more pressure on all systems that support the aging population, including the very significant contributions made by unpaid family and friends. This is true regardless of the model of supports chosen. However, the current model is not necessarily the most cost-efficient available model. Nor do all reforms that would improve the quality of life for frail older adults involve a significant additional price tag. As is touched on below, the current structuring of investments in long-term care does create challenges in transitioning to new approaches, but that is a separate – though related – question. [1]

Vulnerability and Power Dynamics

Residents of LTCHs are, almost by definition, vulnerable. They are admitted to LTCHs because they live with medical conditions or impairments so demanding that they are unable to live in the community with the supports available to them there. They live with chronic conditions that may limit their mobility, energy levels, ability to communicate or capacity to understand their circumstances. Ninety percent have some form of cognitive impairment; 86% require assistance with the activities of daily living such as getting out of bed, eating or toileting; over 60% take 10 or more prescription medications; over 20% have experienced a stroke.[2] Because of their medical conditions and impairments, they are highly dependent on the institutions in which they live and the people that staff them. They may need assistance in communicating if they wish to make a complaint, equally they may fear that making a complaint will leave them open to reprisals large or small. This vulnerability is exacerbated by the design of many LTCHs, which are isolated from the

1. Financing and cost projections for long-term care are complex topics, and beyond the scope of this Report. A thorough discussion of cost projects can be found in MacDonald, B.J., Wolfson, M., and Hirdes, J. (2019). The Future Co$t of Long-Term Care in Canada. National Institute on Ageing, Ryerson University.

2. Ontario Long-Term Care Homes Association, *This is Long-Term Care* (May 2018) https://www.oltca.com/OLTCA/Documents/OLTCA_LTC101_May2018.pdf

community, both physically and socially. Residents who live with dementia may live in locked-in wards. Often, there are few visitors. This is not to diminish the potential and importance of their voices – in fact, it makes that voice all the more necessary - but to emphasize that residents of LTCHs will most often require supports to exercise that voice.

The family and friends who love and provide support to residents of LTCHs, or who are providing intensive care in the community, are subject to similar dynamics. They do not have access to a range of options for supports: withdrawal of services by a provider can be catastrophic. They may equally fear that complaints will result in reprisals against their loved ones, or that they themselves will be barred from visiting their loved ones as a result.[3] As well, family caregivers are often experiencing significant psychological, emotional and financial stress in balancing their multiple responsibilities to their aging loved one, their work and their other family members. [4]

Interviewees also pointed out that frontline workers, who have the closest view of the day to day realities of long-term care, also have very little power to make even minor changes or improvement in the homes in which they work. Disproportionately racialized, newcomer women, working in precarious, low-wage jobs, working in a heavily regulated and hierarchical system, the shortcomings of the long-term care system put them at risk of aggression from frustrated residents, and of injury from performing repetitive tasks at a rapid rate. [5]

These significant power imbalances can make it very difficult for those most affected by the shortcomings of long-term care to advocate at the system level. It is difficult enough to navigate and advocate within the system for their own specific needs: few will have the capacity to go beyond that to advocate for broader system change. Thus, the most powerful and urgent voices for change are not often heard.

Entrenched Interests

While most of those involved in the current LTCH system would acknowledge a need for change, it is also true that there is considerable institutional, financial, physical and individual investment in the status quo.

> *"The existing culture of long-term care – which is an institutional, disease-based, medical-health care model, focused primarily on physical health in the narrowest sense, that is, on survival – is arguably the single biggest barrier to change."*
>
> Interview

3. Concerns have been raised on a number of occasions about LTCHs and retirement homes misusing trespass orders to ban visits by family members who have raised complaints or concerns: see for example, E. Payne "Investigate use of trespass law to limit visits in retirement, long-term care homes: Ottawa MPP", Ottawa Sun: November 28, 2019 at https://ottawacitizen.com/news/local-news/ottawa-mpp-wants-investigation-into-use-of-trespass-law-to-limit-visits-in-retirement-long-term-care-homes; K. Pedersen et al., "Seniors homes using trespass orders to ban family members from visiting", CBC News: November 23, 2019 at https://www.cbc.ca/news/business/seniors-trespass-family-banned-1.5365231

4. P. Arriagada, "The Experiences and Needs of Older Caregivers in Canada" (Statistics Canada: November 24, 2020); Ontario Caregiver Organization,"Third Annual Spotlight on Ontario Caregivers" (December 2020); The Change Foundation " A Profile of Family Caregivers in Ontario" (2020).

5. See for example, Katherine Zagrodny and Mike Saks, "Personal Support Workers in Canada: The New Precariat?" Health Care Policy 2017 Nov; 13(2): 31–39.

There is clearly money to be made in the current model of LTCHs, and the aging of society suggests this is a growth sector for investment. For example, Chartwell, an unincorporated open-ended real estate trust which describes itself as the largest operator in the Canadian seniors living sector, indirectly owns over 200 seniors' living communities in four provinces, including retirement homes, assisted living facilities and long-term care homes. According to the Toronto Star, Chartwell paid out $98.3 million to unitholders in just the first three quarters of 2020.

As insufficient to needs as it may be, there is also considerable investment in physical infrastructure in the form of long-term care homes themselves. There are almost 600 LTCHs across the province, almost half of them aging and designed in a now outdated institutional style that involves large numbers of seniors in a single home, ward-style rooms and shared washroom facilities. This type of design makes it very difficult to create a sense of home, or to allow residents the conditions of privacy, security and autonomy necessary for wellbeing. However, it will be challenging enough to build sufficient new capacity to meet need, let alone redevelop the existing outdated infrastructure. [6]

At an individual level, the structures and incentives within long-term care have created in many settings a culture that focuses on compliance, efficiency and routine. Staff who can accommodate to or thrive within this approach are more likely to stay and be promoted, while others, who find this approach a poor fit with their values, are more likely to leave the sector after a period of struggle. That is, staff who are committed to a person-centred approach generally find that they must push against the prevailing culture rather than being supported by it. Many interviewees described this culture as extremely resilient. Without consistent effort, change efforts will revert to the norm. One change-maker who had led an initiative to substantially re-envision the model of long-term care provision within an institution, described certain highly resistant senior staff as the most significant single obstacle to meaningful change – more significant than costs, training, logistics, physical infrastructure, regulations and collective agreements or any other factor that she had anticipated as a barrier.

Advocates have described a situation where governments are so dependent on major providers and other large institutional stakeholders to maintain the fragile existing system, that these actors have an outsized influence on policy directions and opportunities. This exacerbates the voicelessness of those directly impacted by long-term care and constrains the options for change. It is important that the major institutional players have a seat at the table and input on reform, but many of those working to advocate for those directly impacted perceive that their voices are marginalized in the policy conversation.

> *"The undue influence of the multi-national LTC companies and their allied companies in the real estate, financial, and development sectors who support them in being able to hire highly paid lobbyists – often previous government staffers and political operatives - has skewed LTC policy to their benefit rather than the benefit of residents and older adults in general. The interrelationship between key players in LTC and government continue to create undue influence on LTC policy today."*
>
> Interview

6. Ontario's Long-Term Care Covid-19 Commission, Final Report (April 30, 2021), http://www.ltccommission-commissionsld.ca/report/pdf/20210623_LTCC_AODA_EN.pdf

As a result of this investment in the status quo, there is relatively little interest in thorough-going reform. The incentive is to make adjustments to the current model, in a way that does not disturb existing interests, rather than to re-envision the sector and deliver something more in line with the future that older adults and their families want.

Societal Ageism

Almost every person that *Re:Think* interviewed pointed to societal ageism as a major underlying factor in the ongoing dysfunction of our long-term care system. It is ageism that enables us to tolerate the poor quality of life that residents of LTCH may experience in their final years and dismiss the stories of abuse and neglect, and ageism that allows us to justify the ongoing lack of investment in and attention to this sector. [7]

> *"[The key barrier is] ageism. There is always time and money and attention for things that people care about… And what we have seen is that older people are not important. And to the degree that some older people are important, what we have seen is that frail older people are not important, people who have dementia – and that is overwhelmingly the population of long-term care – who are older in the area of aging – so at that deepest intersectional point where aging and other forms of discrimination exist."*
>
> Interview

Ageism has been defined as

> *a belief system, analogous to racism, sexism or ageism, that attributes specific qualities and abilities to persons on the basis of their age. Ageism may manifest with respect to older adults in attitudes that see them as less worthy of respect and consideration, less able to contribute and participate in society, and of less inherent value than others. Ageism may be conscious or unconscious, and may be embedded in institutions, systems or the broader culture of a society.* [8]

Ageism, in this case, intersects with ableism. There can be an assumption that because residents of LTCH are frail and living with significant cognitive, physical and other disabilities, their lives are of no further value and are not worth living. As well, because the residents and workers in long-term care are disproportionately female, gender may also play an intersecting role.

Ageism and ableism allow us to think that residents of LTCHs have "had their time", or "don't know the

7. Leonora (Nora) C. Angeles, "Why the Disconnect Between Knowledge and Policy Action in Long-Term Care?" Policy Options (July 2020) https://policyoptions.irpp.org/magazines/july-2020/why-the-disconnect-between-knowledge-and-policy-action-in-long-term-care/

8. Law Commission of Ontario, *A Framework for the Law as it Affects Older Adults: Advancing Substantive Equality for Older Persons through Law, Policy and Practice* (Toronto: April 2012).

difference" between good and poor quality care. They enable us to disregard the ways in which persons with cognitive impairments express their distress, or to assume that depression is inevitable in older age rather than addressable. It allows us to justify unnecessary suffering by arguing that it would cost too much to provide a good quality of life for older persons who are frail or living with disabilities. It encourages us to turn our eyes away from what we know in our hearts is not only inhumane but morally unacceptable.

Our long-term care policies are reflective of our cultural attitudes. There is considerably more investment in the hospitals where people spend short period of time for episodic care than in the homes where people live round the clock, for months or years. People continue to live – and die – in long-term care homes where there are not even automatic sprinkler systems in case of fire. There has been, it has been noted, no real political price to pay for the ongoing neglect of long-term care and the consequent suffering of older persons and their families[9]. As a long-term care resident pointed out to the Commission of Inquiry "the general overall attitude of the general public and people who deal with long-term care, et cetera, must undergo a massive change…. It is time we started being treated as people." [10]

> *"[A key barrier to change is] ageism resulting in discrimination, violation of older adults' human rights, and the inability by policy makers, government and opposition members, and the government bureaucracy to embrace philosophies that would promote older adults' continued inclusion in the community are at the root of why long term care has not changed. Buzz words are used and lip service paid but fundamental changes are not made."*
>
> Interview

Policy Complexity

The long-term care system, as briefly described above, is immensely difficult to grasp and to navigate. It is challenging to simply understand the functioning of the current system, let alone reform it. Any one of the challenges in long-term care – improving infrastructure, diverting resources to home and community care, strengthening human resources, improving leadership, shifting to more person-centred models, or improving compliance with minimum standards – is a significant policy challenge. To understand the interactions of these components, and to design reforms that will improve the system as a whole, is a daunting task.

The system is not only complex, it is also extremely fragile, as the pandemic demonstrated. It is constantly operating at the edge of crisis, working in outdated facilities, with limited resources, and consistently short-staffed among ever-increasing demands.

The combination of complexity and fragility makes reform especially difficult. The effects of change in any one aspect of the system may have unpredictable or undesirable effects in other parts of the system. For

9. Steven Lewis, "The Pandemic and the Politics of Long-Term Care in Canada", *Policy Options* (May 2020) https://policyoptions.irpp.org/magazines/may-2020/the-pandemic-and-the-politics-of-long-term-care-in-canada/

10. Deputation of the Ontario Association of Residents Councils to the Long-Term Care Covid-19 Commission, September 28, 2020.

example, long-awaited pay raises for PSWs in LTCHs added to human resources pressures in a home and community care system that already faced severe challenges in recruiting and maintaining staff, undermining broader efforts to improve and expand care in the community. There is justifiable concern that the transition period for any major change could have severe adverse consequences for extremely vulnerable residents. Risk aversion is understandable where miscalculations can have dire consequences.

> *"People say, it's too hard, and they give up. Or they say, we already know the problem, why are we still talking about it?"*
>
> Interview

The Challenge of Advocacy

Several of those interviewed highlighted the challenge of burnout within the LTC sector and among advocates in particular.

Unsurprisingly given its high demands, low prestige and relatively low remuneration, there is high turnover within the long-term care sector.[11] Seeing the flaws and challenges within the system, many 'vote with their feet'. This reduces the number of people with the expertise and relationships within the sector to position them to press for change.

> *"Now I have an entire Tim Horton's by my house that is literally staffed by PSWs because they just don't want to work in the sector anymore because they don't feel appreciated. They feel undermined. They are not respected. Like I mean, no one in any profession would stay long, right, regardless."*
>
> Deputation to the Covid-19 Long-Term Care Commission
> Ontario Personal Support Workers Association

> *"The high turnover. [Staff] get poor pay and poor hours, so they don't get to know people. You get good ones, and they get burned out, because they get taken advantage of because they do more. They can't survive. Or they get driven out."*
>
> Interview

11. The cycle of staff burnout and turnover has been covered in multiple reports. The issues are succinctly summed up in Ontario's Long-Term Care Covid-19 Commission, Final Report (April 30, 2021), http://www.ltccommission-commissionsld.ca/report/pdf/20210623_LTCC_AODA_EN.pdf

For those working with LTC who are seeking change, advocacy must take place off the side of desks that are already overburdened by the pressures of this sector.

Because of the entrenched challenges of spurring meaningful change in this sector, advocates tend to burn out. When, after years of effort, they see the same challenges, the same conversations and the same failure to implement change, it is difficult to persevere.

> *"The most important lesson learned is that unless the systems established to act as checks and balances work (ie., the police, Crown attorneys, the Ombudsman, the Ontario Human Rights Commission, the Opposition, the Press) that it is a waste of time to continue because the powers (corporate and union and their allies) aligned against individuals are too great to proceed."*
>
> Interview

Summing Up

There are multiple barriers to meaningful change in long-term care. These barriers interact with and reinforce each other: for example, policy complexity contributes to the challenges of advocacy for residents, families and frontline workers, and the challenges of advocacy in turn contribute to burnout.

Considering these barriers, we can see why reform efforts have either been unsuccessful, or when implemented, have had less impact than hoped. Changes in policy that are not accompanied by meaningful change in culture will lead only to surface reform, leaving untouched the deeper problems. Reforms that are not driven, first and foremost, by the voices, priorities and hopes of residents and their caregivers will not make a meaningful difference where it counts. Top-down approaches to reform will run into the opposition of entrenched interests or will become mired in system complexity. Reform efforts that cannot demonstrate positive impact will exhaust and demoralize those advocating for change, leading to a cycle of disengagement and despair.

There is no doubt: change is a challenge.

This may sound like a counsel of despair, but it is not. Alongside the barriers interviewees identified reasons for hope and positivity, and new approaches to reform.

7 PROMISING APPROACHES TO REFORM

In working towards a better future for long-term care, we can build from existing strengths. Despite the challenges, considerable work has been done to build the preconditions for change. Recognizing these assets can provide us with a strong starting point.

A vision of the future exists. As with any policy area, there are differences of opinion and approach. Different groups will place priority in different areas. However, a broadly shared vision of the future can be articulated. It includes:

- Greater supports in the community, including meaningful supports to family and friends who provide care and supports, to allow as many older adults as can and as wish it, to age in the community
- Long-term care homes that are human scale, smaller in size and more intimate in approach
- Approaches to care and support that are flexible to meet the needs of diverse individuals and communities, but that are grounded in principles of dignity, autonomy and respect, and that aim for human flourishing to the end of life; these approaches will create not only better care, but better workplaces
- Long-term care that is connected to and accountable to communities, which have the tools to hold care to high standards
- Long-term care that is designed to be resilient in the face of inevitable challenges.

The evidence has been gathered. Extensive research has been conducted to understand the current state, the best practices from around the country and around the world, and how we can get from here to there. For example, an international and interdisciplinary SSHRC-funded project, *Re-Imagining Long-Term Residential Care*, led by Dr. Pat Armstrong of York University, worked to identify promising practices and approaches to long-term care from across Canada and around the world.[1] The recently formed National Institute on Ageing at Ryerson University has identified long-term care as a central focus. Its reports include a comprehensive examination of what is required to enable the future of long-term care in Canada, an analysis of the future cost of long-term care in Canada, and a proposal for long-term care at home.[2] There is no shortage of reports and recommendations, nor of examples of better alternatives. There is no need to wait: change can begin now.

1. *Re-Imagining Long-Term Residential Care, an International Study of Promising Practices,* https://reltc.apps01.yorku.ca/

2. National Institute on Ageing, https://www.nia-ryerson.ca/reports

There is broad support for reform. As noted at the outset of this report, the impact of long-term care on the lives of Ontarians can be said to be universal. Almost everyone will at some point be a caregiver for an aging friend or family member, or will need care themselves. The revelations of the pandemic have strengthened the public understanding of the shortcomings of our long-term care system, and clarified the case for reform. Among key stakeholders, there is an eagerness to see significant change. As well, despite the challenges of advocacy, there are respected organizations that have worked for many years to educate, mobilize and support community and make the case for change. Non-profit, grassroots organizations like Concerned Friends of Long-Term Care and CareWatch have worked persistently to raise awareness of system challenges and to advocate for change.

The Ontario Caregiver Coalition brings the voice of family caregivers to a range of issues that include the crisis in long-term care. The Advocacy Centre for the Elderly (ACE), a specialty legal clinic focused on the needs of low-income older adults, has a long track record of individual and systemic advocacy that is rooted in the experiences and perspectives of older adults. The legislative mandate for Residents and Family Councils within long-term care homes has created an important opportunity for those most directly impacted by the long-term care system to share their experiences and raise their voices.

Building on these assets, on an understanding of the barriers to reform, and on the insights of the change-makers that we interviewed, we propose the following five approaches to system change in long-term care.

Elevate New Voices

While the conversation around long-term care policy continues to be dominated by key stakeholders and experts, it has become more common for forums to include direct participation by residents of long-term care, users of home and community care, or the family and friends who provide them with vital supports. The Long-Term Care Covid-19 Commission of Enquiry, for example, made significant efforts to create opportunities for residents, families and community members to participate, and highlighted their voices and concerns in its interim and final reports.

That this has been possible is due to the longstanding and ongoing efforts of organizations like Seniors for Social Action, Concerned Friends of Long-Term Care, CareWatch, the Ontario Caregiver Coalition and other grassroots organizations to organize and enable the voices and perspectives of their community members. Organizations like the Advocacy Centre for the Elderly (ACE) take seriously their accountability to older adults themselves in their advocacy efforts. And of central importance, the Residents' Councils and the Family Councils have played an essential and increasingly recognized role in empowering those most directly affected by Ontario's system of long-term care.

> *"Well supported Residents' and Family Councils make a huge difference, and can raise important issues like well-being, visitation, and advancement of rights."*
>
> Interview

As well, the voices and experiences of frontline workers are essential to the conversation.

> *"And PSWs know more about the residents' care and what the residents need than a management level because they are not with that resident every day, and they keep saying, We keep telling them that certain situations won't work. They need to listen to us. And just like you have the collective voice of the residents, to try and make a good home, you also need to have that collective voice of your team members. They are doing it every day."*
>
> Deputation of the Association of Residents Councils to the Covid-19 Long-Term Care Commission

There are opportunities to build on this important work. These organizations and others like them do considerable work with often very limited resources. Collective Impact approaches, which identify successful principles for intentional collaboration towards solving complex social problems, could be more extensively applied in this area, to coordinate and amplify existing change efforts among organizations that are centred in direct experience.

It was evident during *Re:Think's* interview process, that, as marginalized as users of long-term care are in general, there are communities within that group that have even greater barriers to participation. It has been observed that age has a 'flattening' effect on social identities, so that age is seen as the dominating characteristic of older persons. However, differences actually accumulate over the life course, and have a profound impact on the experience of older age.[3] Indigenous older persons, those from cultural, linguistic or ethnic minorities or who are racialized, and LGBTQ+ older adults have all been largely invisible in the conversation about the future of long-term care. However, taken together, these make up a large and growing proportion of older Ontarians. While there are common needs for all users of long-term care, these older adults also have specific needs and challenges. They may also have insights and ideas to share, from which all could benefit.

> *"In terms of systemically, we are still moving at a snail's pace. There hasn't been much done to acknowledge that queer and trans folks also get old and will need support in a way that may be different and may not necessarily fit within our current models of care and our current understandings of care."*
>
> Interview

3. Law Commission of Ontario, *A Framework for the Law as It Affects Older Adults: Advancing Substantive Equality for Older Persons through Law, Policy and Practice* (Toronto: April 2012) at 97-98.

Indeed, there is much that the long-term care reform movement can learn from the experiences of other movements for social change, whether from the grassroots activism of the LGBTQ+ movement, the successful de-institutionalization strategies of the Community Living movement, or the success of the women's movement in reframing struggles that were seen as personal and private into issues of social justice. Part of elevating new voices is developing strategies to sustainably energize these communities around opportunities for change.

While it is true that extensive research has been undertaken into the issues surrounding long-term care, newer forms of research, such as participatory action research, can play a valuable role in understanding and engaging lived experience and more marginalized communities. There is still a paucity of research into the experiences of Indigenous, LGBTQ+ and racialized older adults and their families in the long-term care system. Qualitative research, and in particular, participatory action research, can illuminate little understood experiences, broaden the conversation, and support momentum towards change.

Pathways forward:

- **Examine how Collective Impact approaches could be applied to amplify existing efforts towards reform**
- **Bring more diverse voices and experiences into the conversation, to facilitate learning and collaboration**
- **Examine models from other grassroots change movements to identify approaches that could be adapted to the long-term care context**
- **Use participatory action research to bring the voices and experiences of those directly affected into the conversation**

Demonstrate Positive Options

Perhaps understandably, the narrative around long-term care is often one of despair. There is a set of assumptions that underlie that standard narrative – that old age defined by the experience of decline is inevitably and unremittingly difficult; that due to their extensive needs for supports and medical care frail older adults are doomed to institutionalizing approaches; and that more positive approaches to long-term care supports are too costly or difficult to implement.

These narratives become themselves impediments to reform. And while it is true to say that old age can bring many difficulties and that providing supports in a positive and life-enhancing way is challenging, it is manifestly not true that there are no alternatives to the status quo. *Re:Think* has interviewed a number of leaders who are moving forward to demonstrate alternatives that are achievable, transformational, and inspiring. [4]

4. A good starting point for thinking about these alternatives can be found in Moira Welsh, *Happily Ever Older: Revolutionary Approaches to Long-Term Care* (ECW Press: 2021).

> *"If you find the model or models that will provide real quality care, so people can rally round a vision, that is critically important to change."*
>
> Interview

There are many opportunities to better support aging at home, the alternative preferred by most older adults, through improved community planning and design,[5] better supports for caregivers, and more innovative, flexible and extensive home care supports. For example, there has also been increasing interest in taking advantage of, and formally recognizing NORCs, Naturally Occurring Retirement Communities, as a means to bring supports and services to older adults where they are, to create sustaining communities for these seniors, rather than requiring seniors to relocate to access services.[6] Recognizing the benefits of aging at home, governments have been taking some steps to increase investment in and attention to home and community care. [7]

For those who are more difficult to support at home, there are a number of promising alternative models for LTCHs that are more person-centred, focusing on creating environments that are homes in the fullest sense of the word, and working to address the loneliness, boredom and lack of meaning that create so much suffering for residents. The recent book by Moira Welsh, *Happily Ever Older*, presents a range of these alternatives. These include the Butterfly Model, Eden Alternative homes and the Greenhouse Project.[8] Here in Ontario, the Region of Peel has been working to transform all of its long-term care homes into Butterfly Model homes. Ethnic and culturally specific LTCHs often bring a flexible, creative and community focused approach to supports, by the very nature of their mandates. For example, in addition to its well-recognized LTCHs, Yee Hong Centre for Geriatric Care has been increasingly expanding to provide supports in the community, including day programs, housing services, congregate dining and other supports that provide culturally appropriate and high quality care in the community. These are just a few examples of the creative approaches being taken to re-invent long-term care.

Each of these movements focuses on local change, community by community. Change is demonstrated home by home, initiative by initiative, and as positive options are identified, they can be adapted to local conditions and spread. As we see that better options are achievable, older adults and their families are emboldened to ask for more, and organizations are inspired to innovate.

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5. The international Age-Friendly Communities movement provides a foundation of policy and practice for exploring these opportunities: https://www.who.int/publications/i/item/WHO-FWC-ALC-18.4

6. For research and demonstration projects related to NORCs, see the University Health Network OpenLab project on NORCs: http://uhnopenlab.ca/work/labs/norc-lab/

7. For example, in 2019, the Ontario government announced $155 million in additional investments in home and community care, citing the anticipated impact on hospital overcrowding: https://news.ontario.ca/en/release/53696/ontario-expanding-home-and-community-care-services.

8. These are models of "person-centred" or "emotion-focussed" care. They differ somewhat in their approaches, but share broad philosophical commitments to providing holistic supports, prioritizing quality of life and developing meaningful relationships among and between residents, staff and the broader community.

Pathways forward:

- **Instead of waiting for top-down, system-wide change, focus on understanding how policy can remove barriers to excellence and foster innovation**
- **Instead of emphasizing the failures of the current system of long-term care, concentrate on identifying, documenting, supporting and spreading positive options**

Connect Care to Community

A key challenge in long-term care is *accountability*.

As was noted above, because of the vulnerability of residents and their families, and because long waitlists prevent meaningful choice, it is difficult, if not impossible, for residents and their families to effectively hold LTCH providers to account. This is perhaps particularly true where LTCHs are operated by large institutions that are accountable to far-off shareholders.

Advocates and policy-makers have attempted to address these dynamics through extensive regulation, in the hopes that clear standards and oversight would ensure that all residents could count on care that met strong, minimum standards. While standards and oversight are necessary in every system that serves vulnerable people, in the LTCH system, this approach has not been effective. Advocates point to the failure of government to truly hold LTCHs to account: homes that fail inspections continue to be allowed to operate, perhaps because, with such a shortage of LTCH spaces, there is no fallback should a home be closed. At the same time, LTCHs raise concerns that the extensive regulatory compliance requirements have led to a 'checkbox' approach to LTC, in which more time and energy is spent achieving and documenting compliance with highly prescriptive rules than in providing direct resident care and supports. We have the worst of both worlds, one in which horror stories of neglect and mistreatment are easy to find, at the same time that administrative paperwork consumes disproportionate resources.

Some of our interviews pointed to the benefits of homes that are clearly accountable either to their residents (as in Greenhouse Project homes, where it is residents who choose their activities, schedules, meals and other key elements of their lives) or to a particular community. Ethnic and culturally specific homes are accountable to the communities that trust them with their elders and contribute to their operations through fundraising. Municipally run homes are accountable through the political process: particularly in smaller communities, the quality of care provided is clearly visible to community members, and municipal politicians and officials are accountable to the constituents and neighbours who visit and use the home, and partially fund it through their taxes.

LTCHs that are connected and accountable to a particular community can benefit in return from the sense of responsibility that the community has to them, whether through volunteerism or fundraising. As well, at the local level, there is an opportunity to connect transformation of the long-term care system to broader efforts to create age-friendly communities, so that long-term care can more truly be part of a continuum of supports that enable Ontarians to age in safety and dignity, while remaining integrated into their home communities.

LTCHs that are community connected also have the opportunity to tailor their programs and services to specific community needs, whether in terms of the types of services provided, or in the kinds of food, activities, observances, or forms of communication used within the home. This focus on specific needs can

be a spur to flexibility and to the development of new ideas and approaches.

Communities can be geographic, but these are not the only types of communities, as is clear from the example of ethnic and culturally specific homes. There may be benefits in exploring how other forms of community can be brought together to support accountable LTCH options. For example, there has been in recent years a growing conversation about how to create LTC that will suit the needs of LGBTQ+ seniors as they age.

Where LTCHs have been developed without connection to a specific community, there can be benefit to exploring how to create that connection. For example, the Eden Alternative Homes in Saskatchewan have been successfully working to reintergrate these homes with the community, whether by connecting and collaborating with schools, or bringing restaurants and community services inside the LTC setting, so that community members are drawn inside the campus and the home regains a place as part of the larger community.

Pathways forwards:

- **Identify and engage communities, geographic and otherwise, to see long-term care as an integral and integrated aspect of their functioning and to develop their own visions for community connected long-term care**
- **Undertake research to understand and promote approaches and structures for community connected long-term care**
- **Identify policy barriers to community connected long-term care, and develop policy solutions**

Change the Culture

Many interviewees emphasized that without culture change, both at the institutional and societal level, no real and meaningful change in our LTC system is possible.

One interviewee, who has been involved in advocacy for older persons and LTCH reform for decades, emphasized that while it is important to change laws and policies, it is fruitless to do so without accompanying changes to attitudes and institutional cultures. As an example, she pointed to the current advocacy focus on instituting a minimum number of staff hours per resident. The current requirements specify that all residents must receive the care and supports that they need to meet the standards set out in the Act and Regulations.[9] If the resources and the culture were in place, this should be clear and adequate. Without the resources and culture, no law will resolve the issue. There are many good laws and policies already in place: the problem does not lie, for the most part, in the legislation, but in the will and ability to implement it.

9. *Long Term Care Homes Act*, S.O. 2007, c. 8, ss. 17 and 18

> *"The first thing is culture. It all depends on the administrator in the home … If their culture is that these are real people, and not just bodies that you serve. So if I go into a place where the staff say "well she's a number 3 (and what they are talking about is Levels of Care forms) and she's a 2, and they don't know any of their names, or they emphasize, we are doing exactly what the Act says", so just focused on the Care Plan and not observing the resident. If that's the focus, it doesn't create a caring atmosphere where staff get rewarded or appraised for treating people well."*
>
> Interview

And indeed, a number of interviewees whose organizations provided alternative approaches to LTCHs noted the ongoing effort necessary to maintain a positive, flexible and person-centred culture.

As well, realistically, achieving thoroughgoing change in our approach to LTC will require change in the broader culture around how we see aging and older persons. Unless, as a society, we truly value our elders, see the opportunity for dignified and meaningful lives among those who are old and frail, and place worth in the work of caregiving, reform is not likely to reach the top of any political agenda, and no government is likely to invest the effort and resources necessary to create something better.

> *"Aging shouldn't be something that you dread. It should be something that you look forward to."*
>
> Interview

Interviewees suggested that one starting point is to re-position long-term care reform away from a health care improvement framing to one of human rights and social justice. A social justice approach to long-term care reform can contribute to broader culture change by provoking new thinking about the treatment of older persons, as well as emphasizing the urgency and the fundamental importance of the issue.

> *"By embracing a new philosophy that values rather than devalues older adults, that is based on respect rather than disrespect, and that offers them choice and support rather than forced placement, a different vision built on empowerment of older adults and their families could be introduced.."*
>
> Interview

There is certainly a foundation for this approach. Two decades ago, the Ontario Human Rights Commission's report on the human rights of older persons, A Time for Action, raised concerns about the lack of funding for community care, and the disproportionate spending on acute care, as opposed to community and LTC, which are essential to the wellbeing of seniors.[10] The United Nations *Principles for Older Persons* outline many principles applicable to the reform of long-term care, including among others, rights to integration and participation in society, to live in environments that are safe and adaptable to changing needs and preferences, to reside at home for as long as possible, and to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility[11]. Recently, the Advocacy Centre for the Elderly, CUPE and the Ontario Health Coalition joined forces to ask the Ontario Human Rights Commission to use its powers to investigate systemic discrimination against older persons in Ontario's health and long-term care systems.

Pathways forwards:

- **Frame reform to long-term care, not as a series of technical challenges such as staffing ratios and funding formulas, but in terms of fundamental rights and values as members of a shared society**
- **When speaking about residents of LTCHs, avoid focusing solely on their limitations and instead highlight their continuing capacities for connection, meaning, contribution and enjoyment, including for residents with cognitive disabilities**
- **Institutional and sectoral change efforts should be understood and implemented using theories and models of organizational change**

Don't Tweak: Transform

Efforts at reform have for the most part focused on addressing particular ills – improving staffing, reducing waitlists, increasing inspections, modernizing facilities. This is a practical approach – concrete, feasible and easy to understand – and respects the difficulties of reforming a system that must continue to operate as effectively as possible during any period of reform.

However, the experience of the past 25 years suggests that this approach, of tweaking and adjusting the current system, does not take into account the fundamentally flawed model under which LTC operates. The current system, despite the many good people who work in it and the considerable resources invested in it, needs a more fundamental re-thinking. This system, as a whole, is institutional as opposed to community-based, efficiency-focused as opposed to person-centred, and disconnected from surrounding communities and systems. Older adults and their families regard entry into the current long-term care system with fear and dread. System pressures and prevailing culture tend to absorb reform into the status quo.

10. Ontario Human Rights Commission, *A Time for Action: Advancing Human Rights for Older Ontarians* (Toronto: 2001), http://www.ohrc.on.ca/en/time-action-advancing-human-rights-older-ontarians

11. United Nations, *International Principles for Older Persons,* G.A. Resolution 46/91

> *"What we need is transformative change in the whole approach to long-term care. We need to change the whole philosophy of long-term care. If we don't, adding more hours of care or nicer buildings won't make a real difference."*
>
> Interview

> *"Incrementalism. The idea that long-term care can be adequately reformed by "tinkering around the edges" is another barrier to change. People will design a new long-term care home, and think they've cracked the code with design, or will initiate a new staff training, or make some other singular change, thinking this one change alone will be sufficient to effect the needed change in quality of life, when wholesale, fundamental change is in fact needed. People need to change the root, not just the branches."*
>
> Interview

What is needed is meaningful alternatives to that status quo. While the onset of frailty and age-related disabilities is a difficult passage, it should not be regarded as the end of opportunities for a good and meaningful life. We can do better than this. It is possible to create a long-term care system that:

- is person-centred, and sees people not patients
- responds to the needs of diverse communities
- respects the rights of older persons
- supports a sense of home and connection to community for all older adults
- enables excellence and innovation
- provides a continuum of supports across a range of settings
- recognizes, values and supports family caregivers and workers within the system

We shouldn't settle for anything less.

Pathways forwards:

- **Focus change efforts on providing true alternatives rather than adjustments or improvements to the current system**

Summing Up

Despite the challenges of creating a long-term care system that truly meets the needs and aspirations of its users, our interviewees expressed a continuing commitment to being part of that change. They pointed to the deep connections of this work to their most profound values, and their belief that something better really is possible.

They were clear, however, that just as the long-term care system itself needs a fundamental re-visioning, so do approaches to reform of that system. Despite strenuous efforts, traditional advocacy and reform approaches have not been successful: new approaches are needed. Change will not come about through more reports repeating the same recommendations, or through more regulations that are not meaningfully enforced, or through more exposés of neglect, abuse or misery in LTCHs.

Interviewees were trying a variety of new approaches, including community engagement, test-case litigation, creation of self-advocacy tools, development of demonstration projects, mobilizing knowledge of promising approaches, or bringing new voices to the table, among others. What they have in common is a commitment to innovation, to putting the voices of users of long-term care and their families at the centre, and to treating our approach to long-term care as an issue of fundamental values and principles.

8 RE:THINK'S ROLE IN CHANGE

The *Lessons Learned* project was undertaken with the intent to support conversations about the how of change to long-term care. The research and the conversations that we have engaged in over recent months have been sometimes troubling, often inspiring and always thought-provoking. In line with our mission, *Re:Think* aims to continue to support efforts to create a just, accessible and responsive long-term care system, building on what we have learned through this project.

In light of our mission, our skill sets, our resources, and the vision of change set out in this report, *Re:Think* will, in the coming months, focus our efforts in three areas: engaging new voices in the policy discussions around the future of long-term care; facilitating connections and collaborations between those working towards change; and developing and sharing new tools and approaches that can support engagement and advocacy from within communities, and demonstrate positive options.

Facilitate Connections

Through our interviews, *Re:Think* has observed that there are many new initiatives and conversations happening that have not yet been connected together. Indeed, because many interesting initiatives are taking place among those newer to the policy discussions and who tend to have limited resources, these individuals or organizations may not yet have the resources to connect with others. Some of our interviewees expressed the need for greater opportunities to learn from and collaborate with others who may share some of their goals, approaches or interests with respect to long-term care reform.

For example, there may be some shared challenges, learnings or approaches to long-term care among LGBTQ+, ethnocultural and Indigenous communities in their efforts to create forms of long-term care that respect the particular histories and experiences of their communities, and reflect community values and culture, as well as in their experiences as smaller constituencies attempting to make their needs and voices heard in a system under pressure.

> *"I find a lot of the best ideas come in collaboration. If we could get those folks who are thoughtful change-makers in a room together, feeding off each other, something really incredible could come off of that. And getting folks with lived experience in the room. Framing it in a way that, we are all here because we know that change needs to happen. Let's see what we can come up with. We all know what change needs to look like. But what steps can we begin to take together."*
>
> Interview

Re:Think will aim to support connection, shared learning and collaboration, initially through events and forums. Its role in this respect will evolve alongside the expressed needs of change-makers.

FIRST STEPS: *Re:Think* will

- **host a Collaboration Event in November 2021 to bring together a small initial group of change-makers to explore what is needed to support connection and collaboration towards change**
- **work towards creating spaces for information sharing, dialogue and collaboration among those with shared commitments to reform of long-term care**

Engage New Voices

Given the vulnerabilities of those most directly affected by the shortcomings of Ontario's long-term care system, connecting with these individuals and supporting them to advocate for change is a significant challenge. It is also essential to meaningful change.

Qualitative research, and in particular participatory action research, is one tool for engaging new voices.

> *"There is a need for and role for research, especially intentional research focused on marginalized people, that lifts the voices of those folks. Lived experience, which is critical, needs to be part of the solution going forward. We need to start listening to folks receiving home care or in residential care, to really listen to their stories -- they have the solutions … Folks are coming up already with their own strategies that we need to start paying attention to and putting funding in those areas. We need more people to listen and start doing."*
>
> Interview

Further work can be done to understand effective means of reaching, engaging and empowering older adults, caregivers and others with a direct personal stake in the future of long-term care. Lessons can be learned from other experiences, with the understanding that these will need to be tailored to the specific needs and challenges of older adults and family caregivers, and to particular marginalized communities within that broader grouping.

> *"There needs to be help with advocacy navigation and problem-solving…. You can't have social justice without some kind of help and support. And by the nature of the people who are [in long-term care], they either can't speak for themselves,*

they are afraid of repercussions, they aren't necessarily aware of what options there are, and they may need help and support to advance their cause or other people's causes."

Interview

As well, there are existing structures and opportunities that can be further developed to expand opportunities for engagement and empowerment. For example, a growing number of communities have been engaging in Age Friendly Communities initiatives, which include participation as a core principle. Within long-term care homes, resident and family councils have played an essential role in empowering those with a direct stake in long-term care and in connecting residents and caregivers with decision-makers.

Re:Think will work to bring its expertise in community engagement and participatory action research to support the elevation of new voices.

FIRST STEPS: *Re:Think* will explore opportunities to:

- **conduct research and outreach to help develop tools and best practices for effectively and meaningfully engaging those with a direct stake in the future of long-term care**
- **where appropriate support particular change movements by sharing our expertise in community engagement**

Develop and Share New Tools and Approaches

In keeping with commitments to demonstrate positive options, and to change the narrative, *Re:Think* will use our expertise in research and knowledge mobilization to identify and share new approaches and practices and promising initiatives. Case studies, for example, can be used to identify key elements of successful approaches, enablers for change, and lessons learned.

Re:Think can also play a role in identifying barriers to the uptake and spread of good practices and initiatives, and proposing policy changes to support communities in being part of positive change.

These approaches also build on *Re:Think's* commitment to beginning at the community level, and supporting communities to develop approaches that meet their specific needs.

FIRST STEPS: *Re:Think* will explore opportunities to:

- **undertake research to understand key elements of successful initiatives, enablers for change and lessons learned**
- **identify barriers to the spread of good practices and initiatives, as well as strategies for addressing these barriers**
- **employ the collaborative and connective approaches referred to above to mobilize learnings**

APPENDIX I: INDIVIDUALS INTERVIEWED

1. SueEllen Beatty (Eden Alternative, Western Canada)
2. Mary Connell (Person-Centred Care Project Manager, Region of Peel)
3. Ashley Flanagan (National Institute on Ageing)
4. Charles Fox and Meladina Hardy (Bearskin Lake First Nation)
5. Gail Kaufman (AdvantAge)
6. George Hartgrove (Senior Pride Ottawa)
7. Julian Morelli (Policy Advisor)
8. San Ng (Yee Hong)
9. Samantha Peck (Family Councils Ontario)
10. Nancy Polsinelli , Commissioner of Health Services, Peel Region; Anne Marie Case-Volkert, Interim Director Long Term Care, Peel Region; Dr. Sudip Saha, Senior Medical Director, Long Term Care, Peel Region
11. Al Power (Schlegel Institute on Aging, University of Waterloo)
12. Daniel Roseman (Senior Pride Ottawa)
13. Susan Ryan (Greenhouse Project)
14. David Sheard (Founder, Dementia Care Matters)
15. Seniors for Social Action Ontario
16. Seong-gee Um (Wellesley Institute)
17. Judith Wahl (Advocacy Centre for the Elderly)
18. Tom Warner (Senior Pride Toronto)
19. Laura Tamblyn Watts (CanAge)
20. Moira Welsh (Toronto Star)
21. Kimberley Wilson (University of Guelph)

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MAKING CHANGE

LESSONS LEARNED FROM 25 YEARS OF LONG-TERM CARE REFORM

Rethinkpolicychange.ca