COLLABORATING FOR CHANGE:
RE-IMAGINING LONG-TERM CARE
November 18, 2021

ENVIRONMENTAL SCAN

INTRODUCTION

The *Re-Imagining Long-Term Care Collaboration Event* was hosted by Re:Think Policy Change on November 18, 2021. This Event was intended as a starting point for dialogue and collaboration, rather than a comprehensive analysis of any of the many issues raised. Its key purposes were to:

- Create a forum for connection, dialogue and collaboration among organizations and individuals who have been working towards transformation of long-term care
- Explore and share strategies for change and
- Identify opportunities for Re:Think to support the ongoing efforts towards change.

The Event brought together 29 participants, each of whom has made significant contributions towards reform in long-term care, whether as researchers, advocates, thought-leaders, or institutional change-makers. Over the course of a morning, participants collectively engaged in a lively exploration of pathways towards meaningful change in long-term care, supported by a series of panel discussions and by the results of the Lessons Learned research project. Building on the results of the *Lessons Learned* project and the ensuing Report, four key questions were explored through-out the Event.

1. What do we need to understand about the current context in order to make change?

Political context: The suffering in long-term care homes over the course of the pandemic has created significant anger and momentum towards change. However, the multiple jurisdictions at play (local, municipal, provincial, federal) add complexity to reform efforts.

Cultural context: Our approach to long-term care is rooted in ageism, ableism, racism and sexism. It is rooted in the Poor Laws, and as such treats vulnerable older persons as recipients of charity, dependent on the goodwill of others, rather than as persons with rights and dignity. It is a form of systemic injustice.

The current culture is focused on risk avoidance. There is a 'safety rules surplus' in the current system, which cuts older adults off from the community and does not ultimately provide safety. This is entangled with questions of power and autonomy.

Reform of long-term care is also entangled in questions of public/private responsibility, and world views that continue to see care as a private, gendered responsibility.

Systems context: The current system is extremely complex and the issues are often over-simplified. Change will be slow, and will require ongoing effort and resourcing. There was been,

as of yet, little recognition of or effective attention to the particular needs of Indigenous, cultural/linguistic and LGBTQ+ people and communities.

Institutional context: The biggest challenges in the current institutions are boredom, loneliness and helplessness.

2. What are the barriers to and opportunities for meaningful change?

Change must start with a strong understanding of the current system, and where the real barriers and opportunities lie. For example, for most of the challenges facing the system, law reform is not the core need.

Barriers
Political barriers: Powerful entrenched interests mean that key voices that should be part of the conversation are not yet heard; while at the same time, the public often feels confused, and unsure of whom to trust. Given the vulnerabilities of residents, family caregivers and frontline workers, there are significant barriers to advocacy, so that this is rarely a ballot-box issue.

Cultural barriers: Ageism means that issues related to long-term care are rarely seen as a priority within politics and systems.

Systems barriers: A scarcity of resources, arising from the low priority that is placed on this sector, makes it difficult to implement and maintain core reforms. Procurement systems create significant hurdles for non-profit organizations to engage in long-term care, creating a tilted playing field. Jurisdictional complexities create barriers to the creation of quality long-term care options for Indigenous seniors: we need a 'Jordan's Principle' for seniors. Advocacy groups aren't coordinated and are often siloed, conflicting and competitive.

Institutional barriers: Bureaucratic barriers create hurdles for change-makers: we must discover how to plant "seeds for change".

Opportunities

Political opportunities: There is a provincial election in June of next year. As well, ongoing demographic change can strengthen the coalition for reform (with the caveat that most people believe that they themselves will never need long-term care).

Systems opportunities: There is a wealth of knowledge, skills, insights and will towards change: how can we capture and mobilize this? As well, if we can find more effective supports for access to justice, the legal system can offer opportunities for strategic litigation and for advancing individual rights.

Cultural opportunities: There is an opportunity to engage new voices and tell new stories, both positive ("the most dangerous stories you can tell") and negative (the "never again" of the pandemic). Positive stories can set the bar higher, and can help mobilize people towards a realizable vision of the future.

Institutional opportunities: Examples of more positive approaches can be both learning opportunities for other organizations, and a way to 'raise the bar', so that older adults, frontline workers and their families can expect more, and can articulate a clear vision of the world that they want to live in. The efforts to develop new models in Peel Region and in Saskatoon LTCHs point to the potential of cultural shifts within institutions themselves; there are also examples of programs that are effective at supporting older adults who continue to live in communities outside an institutional context.

3. What strategies and approaches will be most effective in supporting change?

From the conversation, five fundamental principles emerged to shape work towards system change.

Start from a commitment to transformation: Because our current system is rooted in ageism and oppression, smaller 'tweaks' to the system will tend to revert to the norm. What is needed is a new approach. An emphasis on more beds, for example, is not a commitment to real change.

Start from the 'ground up': Begin by creating space for voices that are not usually heard and centering lived experience. Inclusive engagement approaches can be a way of shifting power dynamics. Emphasize the diversity of experience and the opportunities for learning from this diversity. Participatory research can be an effective tool in lifting marginalized voices. This can create starting points for building a broad coalition that includes residents, older adults in the community, family and people within the system.

Look to successful movements from the past, and learn from them. This can include the successful coalition for national childcare, the community living movement, Black Lives Matter, and the LGBTQ+ rights movement.

Begin to identify areas of agreement (shared principles), where we can work together. Change will develop through partnerships, relationships and connections, built on shared priorities. This might include:
  • Older adults should have the opportunity to live full, abundant lives, with opportunities for growing and learning, and being connected to the vibrant communities surrounding them, of which they are part. Care should nourish the human spirit as well as the body, and the focus remain on living life, and not on death

- A good system provides wellbeing for everyone – residents, staff, family, communities - with a comprehensive understanding of wellbeing
- The concept of community is central, and all settings must keep older adults closely connected to their communities
- Most older adults want to age in their homes, and wrap-around supports should enable that for as long as possible
- Reform should begin with elder care as a whole, and not strictly on institutions, which are only one piece of the current continuum.

At the same time, we must acknowledge that there are areas of real divergence, and find ways to collaborate where we can, and to be kind where we cannot. These include:
- 'abolition' of long-term care homes, versus 'reform' – is it possible to create LTCHs that are true homes, where people want to live, work and connect?
- Person-directed care versus person-centred
- National versus provincially-focused approaches
- Do we start with culture, or with resources?

Change leadership approaches: leadership should be strategic, shared, and build on the acknowledgement of past heroes and successes.

4. How can Re:Think support the movement towards change?

A wide variety of needs and potential steps were identified for Re:Think's consideration.

Develop strategic approaches: Create a Theory of Change and a Stakeholder Map. Identify strategies for engaging and amplifying the voices of those who have been systematically excluded.

Coalition building: An "Ontario Coalition for Better Elder and Long-Term Care" could coordinate and mobilize advocacy. Begin by educating the public and community and starting to build allies. Create a coordinated forum for collaboration. Develop a shared vision and clear goals for societal change. Create a consensus statement with agreed-upon key actions and ensure that the ask is clear.

Communication and persuasion: Locate stories from residents, caregivers, workers: one model would be the creation of a Speakers Bureau for resident and caregiver engagement. Communicate and promote the most effective models of care, especially non-institutional and including home health options, adult day programs, neighbourhood models. Use social media to build buy-in. Keep communication clean, emotional, practical, hopeful and impactful.

Demonstrate change: Create a pilot project in one community based on most effective model(s).

Political action: aim to make this a 'ballot box issue'. Start by developing clear asks for politicians. Create knowledge tools that measure party platforms against evidence-based recommendations, and that measure government action against government promises. Teach residents, caregivers, workers to be advocates and to learn and practice this in their work, as well as to understand the current system so that they can effectively engage. ICL can sponsor, with partnership, a series of trainings to give voices and advocacy skills. Host Town Halls and invite party leaders to comment and answer questions. There is an opportunity to contribute to the Ontario Liberal Party platform on these issues.

NEXT STEPS

Consistent with our goal of supporting knowledge-sharing and collaboration, Re:Think will disseminate the results of the Collaboration Event, and will continue to engage individuals and organizations in dialogue to identify strategic opportunities to enable change.