

Long-Term Care Is Not a Solution for Younger Adults with Disabilities

A Call to Action



Community Living Ontario believes that every person has the right to live in a home of their choosing, with others they choose to live with, in the broader community – a right that is guaranteed by [Article 19](#) of the UN Convention on the Rights of Persons with Disabilities.

Unfortunately, this right is far from being realized in our province. Ontario has a long history of housing people with physical and developmental disability, cognitive impairment, and mental health issues together in controlled-access facilities. This practice continues in the present day despite substantial research showing the negative effects of the approach on cost and quality of life.

In developmental services, long-term care (LTC) is serving as an outlet valve for an overburdened and waitlisted disability support system. In a recent [report](#), a group of Ontario-based researchers showed that more than 2,200 people with developmental disabilities aged 19-65 spent time in a LTC facility between 2010 and 2016, accounting for 3.5% of this population (jumping to nearly 10% among people with Down Syndrome). In comparison, just 0.2% of people without developmental disabilities in this age range spent time in LTC.

This problem is not limited to people who have developmental disabilities. The Ontario Centre for Learning, Research & Innovation in Long-Term Care has [estimated](#) that 7% of all LTC residents are under age 65:

- ◇ 2,500 are in their early 60s;
- ◇ More than 2,300 are in their 50s;
- ◇ About 500 are in their 40s;
- ◇ LTC settings across the province house people as young as 19.



People are often placed in LTC facilities because disability-related supports and home care services are inadequate. At the same time, LTC facilities do not receive additional funding to accommodate younger residents, and struggle to develop programs to keep them active and engaged. Further, once placed in LTC, funding models often change, and young residents may lose the supports they had access to while living at home or in developmental service, mental health, or other specialized housing.

As the [Toronto Star](#) has noted, “younger people end up in long-term care when they require ‘round-the-clock assistance or can no longer cope in their own home, whether it’s the result of a stroke, a serious brain injury, developmental disability, progressive types of MS or other degenerative illnesses.” This is also an issue among younger adults with mental health issues.

Many media articles have covered this issue, and most have profiled at least one younger adult living in LTC. In these stories, the people interviewed talk about the emotional challenges of high death rates, loneliness stemming from a lack of shared experience and understanding with other residents, the danger of physical attacks from people experiencing dementia, and the more general emptiness and malaise of nursing homes.

The young adults stuck in long-term care are a distressing reminder that, despite advances in Housing First policy and federal investments in affordable housing, the supportive housing system in Ontario is drastically insufficient to meet existing need.

What Can We Do About It?

There is widespread opposition to the broad and increasing recourse to and investment in LTC facilities in Ontario. For example, [Seniors for Social Action Ontario](#), [C.A.R.P.](#) and the [Ontario Health Coalition](#) have mounted serious critiques of the province’s LTC system. SSAO has identified many worrying issues, including persistent underinvestment in home care and the oversized influence of international for-profit companies on public decision-making processes.



The shortage of affordable and accessible housing, and of health and social services required to support people to live and age in a home of their choosing, is one of our most complex and intractable problems. We will not address our province's over-reliance on LTC unless it becomes a major priority at the highest levels of the provincial government.

Community Living Ontario strongly believes that we need to move away from large-scale institutions for all vulnerable populations. We wholeheartedly agree with the recent MCCSS [Reform Engagement Discussion Guide](#)'s focus on "creating sustainable options for the long-term that give people more choice and control over how and where their needs may be met," and note that [the grand majority](#) of older Canadians want to avoid the LTC system if at all possible.

We know that many people have been placed in LTC facilities with their best interests in mind, given the limitations of other aspects of support systems for vulnerable Ontarians. Unfortunately, in the process they have been placed in harm's way in a system that was not designed for their needs.

To reduce our dependence on long-term care facilities, we need clear policy and programs that prioritize a concerted push for small-scale housing options bolstered by unpaid/natural supports, which will reduce pressure on existing systems. We also need to significantly increase support for family caregivers, and to address the funding disparity between LTC and home care.

If you would like to join Community Living Ontario in pressing the provincial government to take a new direction on supportive housing, please contact Shawn Pegg, Director of Social Policy & Strategic Initiatives at Community Living Ontario, shawn@communitylivingontario.ca.

June 2021