EDITORIAL – May 5, 2021

Creating Change in an Entrenched Long-Term Care System: Lessons from the Past

How to make significant change in long-term care is a huge challenge. Long-term care in Ontario has been entrenched for over 40 years, even though older adults do not aspire to be institutionalized. This entrenched system has withstood numerous scathing reports and inquiries, including the recent Commission Report, and yet little has changed. Most people would agree that this is a broken system.

Neither the federal government nor the provinces are showing the kind of leadership we need. The recent Commission Report fails to recommend alternatives that could have made a significant difference to the lives of our vulnerable elders. Also, advocacy for change remains limited and divided.

So how can an entrenched system like this be changed?

Drawing on past successes in other fields may provide some important answers. Related experiences can provide us with lessons in our efforts to transform long-term care from an institution-based system to a personalized, community-based system.

Two historic Ontario movements for change created system change in significant ways. These efforts suggest possible strategies and approaches that can be considered for long-term care reform as we continue our advocacy for change.

The Deinstitutionalization Movement

In the 1970's, there was a growing advocacy movement in Ontario to close institutions for people with development disabilities. At that time, organizations that represented people with disabilities, family leaders, and journalists like Pierre Berton were beginning to raise concerns about conditions in institutions (Berton, 2013).

This advocacy led to the *Williston Report*, submitted to the government in 1972, which recommended that institutions be phased out (MCCSS, 2018). In 1977, the Ministry of Community and Social Services implemented its first five-year plan in the aftermath of the Welsh Report of 1973 (McCauley & Matheson, 2016), to reduce the number of people in institutions and to provide expanded community living opportunities. By the early 1980s there was a growing body of

research, mostly from the United States, that was showing the benefits of people living in the community.

By this time, there was significant momentum for change within the deinstitutionalization movement, as family groups, Community Living Ontario, as well as researchers all called on the government to accelerate their deinstitutionalization efforts. The principle of normalization, articulated by Wolf Wolfensberger, also played a significant role in expanding people's thinking about community alternatives (Wolfensberger, 1972). Over the next 25 years, until 2009, numerous institutions were closed, with an expanded community living movement throughout the province.

The Direct Funding Movement

In the mid-1980s, the Attendant Care Action Coalition was lobbying the Ontario government for a direct funding program for people with physical disabilities. As a result of this advocacy, the government commissioned a *Review of Support Services for Ontario*. This research, completed by the Centre for Community Based Research, was a comprehensive study that presented 40 recommendations, including the need for a Direct Funding program (CCBR, 1988).

Following the release of this report, the Attendant Care Coalition was able to convince government to fund a three-day retreat, which brought together 130 people, including people with disabilities, family members, researchers, and government policy analysts. This collaborative planning event was key in turning momentum into policy change. Within three years, the government had passed legislation to create a Direct Funding program for people with physical disabilities.

Lessons About Change

There are several lessons we can draw from these two successful movements for change in Ontario. We can also reflect on these lessons in terms of creating change in long-term care.

First, to build momentum for change, you need a *catalyst or a trigger* to start the process. In both our examples, there was wide-spread criticism of the status quo and a deep concern with current conditions. Similarly, the pandemic has shone a light on very disturbing conditions in long-term care. This has been a trigger for broad awareness of the need for change. The recent Commission Report could have been a huge catalyst for actual change but fails miserably in this regard.

Second, you need *research* to illustrate that alternatives are not only feasible but are also doable. In both examples, key reports with compelling evidence played significant roles in accelerating the change that advocates were calling for. With long-term care, we have growing research around the world on alternatives. As

illustrated by the Commission Report, there has been little acceptance of this evidence in Ontario and even less understanding of how this research can help create real change.

Third, you need a somewhat *unified advocacy effort*. In both examples, over time there was incredible momentum for change as the movements broadened to include a variety of stakeholders. Also, there were numerous grass roots groups that were committed to the vision of these movements. Currently, advocacy for long-term care alternatives is limited and divided. There continues to be a lot of advocacy for improvements in long-term care facilities, and except for SSAO, few provincial or grass roots groups endorsing significant change and genuine alternatives. Elders themselves, if they organized, could be a force to be reckoned with. We know that comprehensive advocacy will be needed to keep the heat on governments, who are currently very wedded to the status quo.

Fourth, you need *leadership* within the advocacy movement as well as within government. In both examples, there was incredible leadership from families, people with disabilities, researchers, and community service providers. It is noteworthy that when the governments showed leadership, it started with civil servants and eventually included politicians. With long-term care, SSAO has demonstrated powerful leadership in dissecting the problems and outlining solutions. To date, there has been little buy-in from the Ontario government, although both opposition parties have been showing interest in alternatives to long-term care institutions.

Fifth, you need to understand the *power dynamics* that are at play. In both examples, advocates knew that their main adversary was government, who they had to persuade to change their perspective and priorities. The power relations in long-term care in Ontario are more complex, with well-funded corporations having enormous influence. For various reasons, unions and governments seem to be beholden to the corporations' agenda. System change will require a very strategic approach that considers complex political and economic factors.

The history of social movements demonstrates that understanding these five elements of change is vital. We know that creating system change is challenging and cannot be accomplished with only one or two elements. Although the current situation with long-term care can seem discouraging, these five elements can provide a way of thinking as we move ahead with our advocacy. It is also wise to remember that previous deinstitutionalization efforts took years to take hold. We therefore need a sense of urgency as well as patience as we keep working for a future that we know is right for our elders and ourselves.

References

Berton, P. (September 20, 2013). *Huronia: Pierre Berton warned us 50 years ago.* https://www.thestar.com/news/insight/2013/09/20/huronia_pierre_berton_warned_us_50_years_ago.html

Wolfensberger, Wolf (1972). *The Principle of Normalization*. Toronto: National Institute of Mental Retardation.

CCBR (1988). *Review of Support Services for Ontario*. Centre for Community Based Research, Waterloo, ON www.communitybasedresearch.ca

McCauley, K., Matheson, D. (2016). PERSPECTIVE: From institution to community living, to social inclusion – unrealized policy promises. https://oadd.org/wp-content/uploads/2016/12/41022_JoDD_22-1_v10f_3-9_McCauley__Matheson.pdf

MCCSS. (2018). The evolution of government policy and legislation: the 1970s. https://www.mcss.gov.on.ca/en/dshistory/legislation/1970s.aspx