INFORMATION BULLETIN: ALTERNATIVES TO INSTITUTIONALIZATION

BELGIUM'S APPROACH TO KEEPING PEOPLE AT HOME

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Preamble

Ontario's system of long term care is fragmented, unduly reliant on institutions and corporate-controlled care, and places too little emphasis on locally controlled, community-based non-profit care in the community that would offer older adults and their families real choices.

In this report readers are introduced to a system of care in Belgium far superior to our own. While not perfect, it does feature components rarely, or not available in Canada or in Ontario that would be of real benefit to some individuals and families.

Anyone will tell you that when it comes to trying to find a way to keep aging loved ones or people with disabilities of all ages at home rather than institutionalizing them in a nursing home, the task feels almost insurmountable. Families are exhausted just trying to make their way through the maze of eligibility requirements, rules and restraints, splintered services and supports, to try to get anything near what they and their loved ones need.

Many do not even know exactly what they do need because they are unaware of what a loved one's symptoms actually mean. Do they have a hidden health condition? Are they struggling with the impact of trauma that is causing them anxiety and depression? Could some of their challenging physical ailments be better addressed? Are they on too many medications, or not the right ones?

Even if Home Care is organized, it may be restricted by bureaucratic requirements, professional care providers may not be available especially in rural areas, or workers may not even show up. There is no one available to troubleshoot when problems arise, and often exhausted family members are left on their own to try to address these systemic problems.

Belgium's Comprehensive Approach

Belgium has a 21st Century long term care system with several components that Canada's and Ontario's do not. Like many European countries, it spends more on home care than Canada does, and needs to spend even more to further prevent institutionalization. However, it does have some care components that Canada, and especially Ontario, could use.

With 5% of its population over 80, projected to grow to 10% by 2050, Belgium spends more of its share of Gross Domestic Product (GDP) than is the average for Organization for Economic Cooperation and Development (OECD) countries. Canada spends much less.[1]

"In 2018 more than two million people were aged 65 years and over in Belgium, representing 19% of the country's population. According to the Belgian Federal Planning Bureau, this proportion will further increase to 21% in 2025 and will come close to 26% by 2050" (For A Healthy Belgium, 2018).[2]

Like many European countries, Belgium has placed an emphasis on developing care services at home for its aging population in an effort to postpone or prevent institutionalisation. It has greatly increased funding for home care, and limited capacity in institutions through moratoriums on new beds.

Belgium has two main types of residential facilities – homes that provide nursing and personal care services for people with mild to moderate challenges in their activities of daily living or cognitive abilities, and nursing homes which are reserved for individuals who do not require hospital care, but who do need considerable ongoing assistance. Compared to other OECD countries Belgium still has a higher number of long term care beds – something that it is felt could be addressed by even higher levels of in-home care (For A Healthy Belgium, 2018).

What are the differences between Belgium's system and Canada's?

- Belgium's long term care system is divided between health insurance (which Canada does not have) and help for municipalities and regions to allow localization of long term care services and supports (which Canada also does not have).
- Belgium's model has made better integration between health care and other long term care services for people with more complex needs possible. In other words it has built a bridge between medicalized (hospitals, doctors, nurses, institutions) to social care programs in the community (in-home care, community-based residences, day programs, assistance with activities of daily living and home repairs, meals etc.).
- It also has a means of measuring the quality and outcomes in long term care services (BeIRAI) which ensures that funding is more likely to be spent in the right way (OECD, 2013). Canada,

[1] "The 1.3 percent of GDP Canada now allocates to LTC falls well short of the OECD average of 1.7 percent. Worse, our spending relative to GDP has barely increased despite the surge in the number of seniors. Worse still, the measly 0.2 percent of GDP Canada spends on home care is one of the lowest allocations to home care in the OECD. And even worse than that, the ratio of more than 6 dollars spent on institutional care for every dollar spent on home care is one of the most imbalanced resource allocations in the developed world." Pg. 3 https://www.queensu.ca/sps/sites/webpublish.queensu.ca.spswww/files/files/Publications/Ageing%20Well%20Report%20-%20November%202020.pdf

[2] This roughly parallels Canada's own over 65 demographics. "In 2014, over 6 million Canadians were aged 65 or older, representing 15.6 percent of Canada's population. By 2030—in less than two decades—seniors will number over 9.5 million and make up 23 percent of Canadians." https://www.canada.ca/en/employment-social-development/programs/seniors-action-report.html

and especially Ontario lack the means to measure long term care quality, or to even enforce legislated standards in long term care (Pedersen et al, 2020).

Belgium's long term care system rests on the following components:

- Comprehensive assessment by experienced professionals;
- An integrated care plan tailored to the needs of each individual irrespective of where they live;
- An identified case manager attached to the person;
- Day to day support services;
- Educational support;
- Systematic follow up.

How does this system differ from Ontario's?

- In Ontario most families have no clue where and from whom comprehensive assessments might be available. Even if they manage to access them, there is no guarantee that any of the other care providers will pay any attention to them because the multi-disciplinary assessment teams have no authority to order specific assistance for someone.
- Most people living at home do not have person-directed care plans – plans that reflect their personal wishes as well as what is contained in comprehensive multi-disciplinary assessments. In many cases when it comes to in-home care, they have to accept whatever hours they can get as decided by others, and scramble to fill gaps because home care services are rationed and unreliable.
- A comprehensive case management program is not available across Ontario for older adults. Case management is a patchwork quilt – available in some places but not in others, so there is no one to help elders and their families navigate the mystifying labyrinth that is long term care in Ontario and many other provinces and territories.
- Day to day support varies depending upon geographic area. Home Care is set up in a very bureaucratic way, is often unreliable, and geared more towards rationing services than to providing them.
- There are endless waiting lists for many community-based programs and almost no linkages between community care delivered by non-profit organizations, hospitals, and the medical system that would allow referrals for community support rather than just Home Care or a long term care institution.
- Educational support is only now being made available through the community paramedicine program. Much better emotional support, education, and training could be offered to family caregivers who may be suffering detrimental mental health effects of 24/7 caregiving. In-home service providers may also benefit from added educational support by nurse practitioners, occupational therapists, physiotherapists, pharmacists, and trauma counsellors in order to build capacity for both family and professional care providers. Community health

centres could play an important role in this if there were enough of them. Additional respite services are vital.

- Follow up support is generally not a priority so crises develop, are unaddressed and exacerbated, generally resulting in unnecessary hospitalization and/or subsequent institutionalization.

In sharp contrast to Ontario, Belgium has done something remarkable.

Its National Institute for Health and Disability Insurance (NIHDI), a Federal program, started funding "bottom-up" services and supports that targeted frail older people living in their own homes. The goal was to reduce the risk of institutionalization, while keeping family caregiver stress and strain low, and maintaining or increasing individuals' quality of life.

Universities got involved and evaluated the effectiveness of specific interventions as they were being introduced, using both qualitative and quantitative methods. Older adults' voices were actually reflected in the studies (de Almeida Melo et al, 2016).

What did they find?

For individuals with fewer complexities, case management with psychological support and rehabilitative interventions like occupational therapy prevented institutionalization. Occupational therapy interventions, which included home adaptations, even on their own also reduced institutionalization.

For those with higher levels of complexities those receiving case management in smaller residential settings with rehabilitation were at much less risk of being institutionalized.

Case management support for those with complex needs that provided support to informal caregivers combined with other support services such as day programs was also found to be very effective in preventing institutionalization.

Intensive "supportive caregiving interventions specifically designed to meet the unique needs of frail older people and their caregivers" revealed significant positive effects for people with moderate to severe cognitive decline (de Almeida Melo et al, 2016).

Surprisingly, older adults receiving night support at home had higher levels of institutionalization, something that is important to know when planning funding for services. The comment that accompanied this finding is important. "The current study results showed that older people with moderate to severe impairment who received night support at home with full supervision had a higher risk of institutionalization and death than people in the comparison group. This might be because of comorbidities, which could not be controlled for in the analysis. This intervention did not show an effect in delaying institutionalization, but it may have had an effect on decreasing the burden of informal caregivers by offering respite care during the night. More research is needed to confirm this" (de Almeida Melo et al, 2016:5).

What Did an OECD Analysis Find About Belgium's Approach?

It found that in Belgium, long term care is considered a health risk and that institutional arrangements are considered a medical model of care delivery.

The Federal government is responsible for older adults with more severe care needs, while regions handle care for people with less intense care needs.

Belgium has a Geriatric Nurse Certification and this is required in most regions in order to become a director of nursing. It also uses a specialised care professional to coordinate the care of persons with dementia.

Build the Institutions and They Will Come

One very important finding in the research is that it is true that people follow funding. In other words, build institutions and you will find people to put in those beds. "In countries which provide extensive public institutional care services such as Sweden or the Netherlands, chances for NHA (nursing home admissions) in the last year of life are almost 2.5 times higher than in countries with restricted public spending on institutional care such as Portugal, Greece or Poland" (Stolz et al, 2019).

Ontario Is Way Behind

Comprehensive case management and linkages between hospitals, doctors and community care providers make Belgium's system more humane, as does regular follow-up and the provision of education and support to caregivers. All of these prevent hospitalization and subsequent institutionalization and reduce the stress on family caregivers.

Having academics study which systems work best and provide feedback to government, and the use of the BeIRAI data gathering system has also given policy makers and program planners better information about how to meet the care needs of older adults.

Sadly Ontario has none of these components operating in any kind of uniform way across the province, and the people who suffer are those who require care and their family caregivers.

Ontario especially needs a transition planning system where planners located in community organizations with broad knowledge of the kinds of services and supports available work with individuals who are at risk of being institutionalized - either from home or hospital - to obtain vital assessments, and help organize a client-directed care plan where the individual's wishes take precedence.

Offering families the support of a transition planner <u>not connected</u> to a hospital eager to empty beds or to a long term care facility eager to fill beds, would provide needed advocacy support as well as knowledge of resources available so that individuals and families would not need to try to navigate the long term care system on their own during a stressful time.

Belgium's approach while not ideal, does offer some components to consider that may be useful in helping Ontario to reduce its high level of reliance on institutions and promote transition to a more person-directed and community-based model of home care.

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