Correcting institutional deficiencies and funding long-term care differently

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While media attention is rightly focused on the plight of seniors who are dying in residential institutions or are confined to seniors' homes, there is a need for post-disaster preparedness. First, we need to investigate the root causes of the disproportionate impact that COVID-19 is having on people in group living environments. How did we get here? What have we done – or rather what have we neglected to do – to create the conditions for such a massive loss of life to take place? But after the investigation, we must act quickly; there are ways to rectify the situation and put in place measures that will prevent a recurrence of this tragedy and enable vulnerable seniors to live a better life in society.

Canada is aging; we say that often, but we don't realize how rapidly. In less than 15 years, people over 65 will make up more than 25% of the population. Japan is already there, and we will now overtake most of the European states that were once called the "old countries." This population aging is not a social, economic or even health disaster. However, we must acknowledge the facts and adapt our institutions and services to this new reality.

Clearly, we refuse to see our collective aging; we refuse to see our old men and women. We even use all sorts of different words to hide the reality: the aged, the elderly, senior citizens, elders. These euphemisms conceal our deep denial of aging and old people. We continue to behave like a young society, starting with our health care system. Reforms in recent decades have made hospitals even more central to the system and institutions, while elder care at home or in institutions has taken a back seat. In every area – budgets, construction and renovations, managerial concerns, medical or nursing resources, or assistance and support staff – hospitals get top priority.

The COVID-19 pandemic and the disaster it has caused in residential institutions demand concrete action to contain the crisis, prevent a recurrence and better organize services for seniors. First, we need to rectify the situation by deploying immediate solutions that will limit the damage and, most importantly, prevent the scenario from recurring during the inevitable second wave. We must also recognize that the institutional solution is still preferred in Canada because of the history of the creation of health insurance systems. Above all, we must come up with lasting solutions to better serve the elderly, especially those who are becoming less independent, whether they are at home or in residential institutions.

1. Containing the crisis

In Quebec, we are still in the midst of a health crisis in CHSLDs (long-term care homes) and other seniors' residences. As of September 10, 2020, there had been 3,676 deaths in CHSLDs, or 9.1% of their residents. The shortage of personal support workers (PSWs) is only the tip of the iceberg; the causes of this "perfect storm" are broader than that. PSWs are the forgotten members of our health care system. In this complex structure, increasingly focused on hospitals and their technology, we have forgotten the human being who needs care and the human being who provides care. Care encompasses much more than executing procedures; it includes listening, being compassionate and patient, smiling, comforting and much more – all tasks that cannot be measured for productivity targets. This is the essence of PSWs' work, what motivates them and what makes their tasks fulfilling and compelling. Of course, remuneration is part of the solution, but working conditions are just as important, if not more so.

CHSLDs must be not only living environments but also care environments, as they accommodate people with multiple medical conditions. Hence, it is important to have a dedicated and competent team of doctors on site. In the blind pursuit of the goal of returning family physicians to offices, the CHSLDs have been stripped of their medical staff. Nursing supervision, which is essential for planning care and performing professional and technical procedures, has also been diluted. As a result, residents have to be taken to the emergency and the hospital for even the slightest decline in their medical condition, which has adverse effects: contamination, mental confusion, unwanted and inopportune interventions, etc. In addition, the expertise to deal with crisis situations and order the necessary measures to prevent the outbreak or spread of infections is often lacking.

In an epidemic, the availability of protective equipment (masks, gowns, visors), designating compartmented areas, and prohibiting staff from working at more than one site or unit are essential conditions for preventing the spread of infection. Moreover, stable staffing in care units is also a prerequisite for high-quality, humane care, even in normal times. A study by Liu et al.[1] comparing mortality in residential institutions in British Columbia and Ontario identified the formal prohibition of staff mobility as a significant factor in the much lower mortality rate in British Columbia. While Ontario was slow to ban mobility, Quebec did not do so in the first wave and still tolerates it today.

The physical facilities in CHSLDs are often outdated: rooms with multiple beds, shared washrooms, inadequate ventilation, and lack of sprinklers and air conditioning. In these conditions, residents lack a minimum quality of life, and staff do not have a healthy, pleasant work environment. There are also no extra rooms for end-of-life care or isolation of residents when they are infectious. The poor quality of the facilities increases the risks during heat waves and outbreaks. An intensive renovation program is needed to correct these deficiencies and create safe, attractive environments.

Lastly, successive reforms of the health and social services system in Quebec have eliminated local management of CHSLDs. CHSLDs are part of regional superstructures that include hospitals, rehabilitation centres, youth centres and local community service centres (CLSCs). Decision-making authority and management are centralized, and there is no local leadership in each facility. It is fundamental that each CHSLD should have a management team responsible for the specific organization of that institution's services and, most importantly, for quick and effective response to crisis situations.

To prevent a new surge in deaths during a second wave of COVID, we need to rebuild medical teams, improve nursing staffing, recognize the work of PSWs, strengthen measures to prevent the spread of disease, renovate facilities and introduce local management in CHSLDs.

[1] Liu, M., Maxwell, C.J., Armstrong, P., Schwandt, M., Moser, A., McGregor, M.J., Bronskill, S.E., and Dhalla, I.A. (2020). COVID-19 in long-term care homes in Ontario and British Columbia. Can Med Assoc J. doi: 10.1503/cmaj.201860; early-released September 30, 2020.

2. Canada's health care system and the institution-centred approach

The Canadian health care system and the *Canada Health Act* have put hospitals at the centre of the health care structure. While this choice was justified in the last century to meet the needs of a younger population, it is much less appropriate for an older population struggling with chronic disease and disability.

Compared with other industrialized countries, more seniors in Canada and Quebec live in group settings that provide care and services. The percentage of the 65-and-over population living in long-term care is 5.7% for Canada and 5.9% for Quebec, while the average for OECD countries is 4.7%.[2] But Quebec has a particularly high number of people in retirement residences, with more than 100,000 seniors (7%) living in such homes. More than half of the places in retirement residences in Canada are in Quebec. Nearly 20% of Quebec's over-75 population has chosen this collective lifestyle, which groups seniors together in a form of independent self-exclusion from other social groups.[3] These seniors of the so-called "silent" generation seek safety and access to services when needed. Their baby-boomer children also saw it as a practical way to provide their parents with support and safety. While those residences were struggling to fulfil their mandates prior to the crisis, it is clearly nothing but an illusion in light of the COVID-19 outbreaks and the general lockdown that the pandemic has created in these settings.

The popularity of group housing stems from the inability of society and the health care system to provide the necessary home care services for people who are losing their independence. In the absence of adequate home care, the pressure on CHSLD accommodation has increased, and a lucrative market of unlicensed private CHSLDs and retirement residences has developed in a haphazard manner, without government control. However, today's and tomorrow's seniors would prefer to continue living at home as long as they have access to sufficient, high-quality services if they become less independent. This requires a change in the way we look at independence support services: instead of moving people to housing solutions that address their needs, we should be adapting and developing the range of available services and let people live where they have chosen to grow old.

Only 14% of public long-term care funding goes to home care in Quebec and Canada. All other OECD countries put more of their public funding into home care, with Denmark ranking highest at 73%.[4] This lack of investment is a funding choice; the Canadian health care system essentially covers medical and hospital care. As a result, long-term care accommodation from continuing-care hospitals is covered by the public health insurance system, while home care is funded at the margin, at the discretion of each province. Hence, it is easy to understand why the institutional solution was preferred.

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[2] OECD. *Health at a Glance 2019*. https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance_19991312

[3] Hébert R. *Les vieux se cachent pour mourir, 2016*. https://www.ledevoir.com/opinion/idees/464685/les-vieux-se-cachent-pour-mourir

[4] Huber, M., R. Rodrigues, F. Hoffmann, K. Gasior and B. Marin. 2009. *Facts and Figures on Long-Term Care. Europe and North America*. Vienna: European Centre for Social Welfare Policy and Research.

3. Investing more but differently

Investing more in home care will not be enough to effect significant change. In a longitudinal study of all the services used by all Sherbrooke seniors from 2011 to 2015, we observed a significant progressive decline in home care services over the period, from 200,000 visits per year in 2011 to less than 60,000 in 2015. The decrease was particularly significant for those receiving more intensive services. This is especially troubling since the 2013-2014 budget included an additional $110 million for home care, a 20% increase in the base budget. Clearly, that increase did not translate into improved services. Instead, institutions reallocated the funds on the basis of their priorities. At that time, home care provided by CLSCs was funded from the same budget as hospitals and long-term care homes. So the additional funds were used by hospitals. It is easy to imagine that with the 2015 reform, this situation has not improved and that the recently promised investments in home care are unlikely to translate into additional services for home care users. Managers of the current supersystems cannot resist the temptation to reorganize revenue sharing to relieve the rising costs of regular hospital care.

The situation is probably similar for federal transfers for home support. In 2017, the federal government announced an investment of $6 billion over 10 years for home care through health transfers. There is no guarantee that this substantial injection of funding will result in a significant increase in services. The concern is that provinces and institutions have other priorities, with access to hospital care monopolizing their attention.

This means moving away from the current institution-based funding model. Instead, needs-based funding should be put in place for long-term care. This is the principle of public long-term care insurance, which has been introduced in many countries over the last 20 years, including Japan, South Korea and most continental European countries.[5] In those insurance systems, the individual's needs are assessed using a disability assessment tool. A benefit is determined on the basis of the level of need. That benefit is used to fund public or private services chosen by the individual or family members based on the intervention plan developed by a health professional, often a case manager. Some countries even issue a cheque ("cash for care") directly to the individual, who then arranges for the services. The quality of the service providers is assured through an accreditation mechanism, and the quality of the services provided is assessed by the case manager. Those insurance plans are usually funded on a pay-as-you-go basis through employer-employee contributions, a tax on retirement pensions, income tax or other specific forms of revenue (e.g., electricity charges or the abolition of a public holiday).

That is what was offered in Quebec's "autonomy insurance" proposal in 2013, when I was a Cabinet minister in the provincial government. Like most other provinces, Quebec already has a number of resources that would facilitate the rapid implementation of this important reform: an assessment tool that is already widely used for everyone who needs home or residential services (the Multiclientele Assessment Tool [OEMC], part of the Functional Autonomy

[5] Hébert R. "L'assurance autonomie: une innovation essentielle pour répondre aux défis du vieillissement." *Canadian Journal on Aging* (2012), 31(1): 1-11.

Measuring System [SMAF]); a classification system consisting of 14 standard disability profiles (Profils ISO-SMAF) that translate the need into resource requirements and benefits; case managers already deployed as part of the integration of services following the Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA) project; computer tools to support the development of the intervention plan and the allocation of services; and an efficient management organization that is already keen on this type of funding, the Régie de l'assurance-maladie du Québec.[6]

Autonomy insurance meets several needs:

- It ensures equitable public funding for people requiring long-term care and services, regardless of their living environment and service providers.
- It offers a solution to interregional and inter-institutional equity issues in the provision of home support services.
- It establishes public management of all independence support services, whether they are provided by public institutions or private companies.
- It gives users back the freedom to choose their living environment and service providers.
- It ensures the quality of the services offered by public and private organizations and encourages service providers to emulate or compete against each other to better meet needs.

There was to be a specific, protected budgetary program to isolate this funding from the institutions' overall budget. At that time, it was estimated that cumulative annual investments of $100 million to $200 million would be required to meet seniors' needs and adjust for expected population aging. The additional investment projection for 2027 was $1.3 billion, $1.5 billion less than the projections based on the status quo institutional solution.

Following the publication of a white paper,[7] which was well received by all stakeholders, a bill was introduced in the National Assembly in December 2013. Because a snap election was called and the Marois government lost, the bill never passed. The bill was not revived by subsequent governments. The bill is dead, but the idea is not, and the components needed to make it a reality are still present. It is now even more relevant because of the COVID-19 crisis.

In the Canadian system, there are two feasible ways of implementing this form of funding. One option would be long-term care services legislation modelled on the *Canada Health Act*. The new law would set out broad principles that would encourage the provinces to introduce specific funding for long-term care with a focus on home care. If the principles and conditions were met, a federal contribution to the system put in place by the provinces would be provided under the new law. The other option would be to establish a Canada Home Care Benefit, under which the federal government would provide direct federal funding to people who meet certain

[6] Hébert R, Gervais P, Labrecque S, Bellefleur R. 2016. L'assurance-autonomie au Québec : une réforme inachevée. *Health Reform Observer*, 4(1): First article. DOI: dx.doi.org/10.13162/hro-ors.v4i1i.2737
[7] Hébert R. 2013. *L'autonomie pour tous : livre blanc sur la création d'une assurance autonomie*. http://www.assnat.qc.ca/fr/travaux-parlementaires/commissions/csss/mandats/Mandat-24161/index.html

disability criteria. The provinces already have standardized needs assessment tools that could be used to determine eligibility and the amount of the benefit. In any event, no matter which option is considered, negotiations with the provinces are essential to define the contours of the legislation or program.

Conclusion

The current crisis in Quebec's long-term care institutions is the result of the health and social services network's neglect of elderly people who are no longer independent. The CHSLDs are in need of a major overhaul in governance, management, funding, service delivery, and the quality and safety of facilities. Medical and nursing supervision must be enhanced, and working conditions – not just pay – must be improved for PSWs. Facilities need to be renovated, and management and governance need to be reformed.

Canada's health care system must adapt to an aging population. Hospitals should no longer be the focus of priorities and decisions. Chronic diseases require a different approach based on quality home care. The funding of services should no longer be based exclusively on institutions but on the changing needs of users. Public long-term care insurance would help achieve this goal.

Our seniors deserve to grow old at home with the services they need. If we tailor our approach to the funding and organization of services to 21st-century reality, Canadians and Quebecers will choose to grow old at home and will resist the siren song of residences and other places of institutionalized social exclusion. This is the kind of society we want for today's seniors and for the seniors of the future, a group we will all inevitably join.

About the author

Dr. Réjean Hébert is a geriatrician, gerontologist and epidemiologist. After a long career at the University of Sherbrooke, he is now a professor in the Department of Health Management, Evaluation and Policy in the University of Montréal School of Public Health (ESPUM). He was Dean of the Faculty of Medicine and Health Sciences at the University of Sherbrooke from 2004 to 2010 and of ESPUM from 2017 to 2019. He was the founding director of the Sherbrooke University Geriatric Institute's Research Centre on Aging, the Quebec Network for Research on Aging, and the Canadian Institutes of Health Research Institute of Aging. His research focuses on the organization of services for seniors losing their independence, front-line services and patient engagement. He designed and validated the Functional Autonomy Measuring System (SMAF) to measure the needs of seniors and persons with disabilities. He led the Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA) group, which developed and validated an original model of service coordination that improves the efficiency of the health care system while preventing loss of independence among seniors. From 2012 to 2014, he was Minister of Health and Social Services and Minister responsible for Seniors in Quebec. In 2019, he was awarded the Armand Frappier award, a Prix du Québec recognizing exceptional contribution to the organization of research.

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