KICK-STARTING REFORM IN LONG-TERM CARE

Over the last 20 years, numerous commissioned reports have called for reform and improvements to long-term care. This *Policy Options* feature series aims to better understand the reasons for the decades of inaction by governments, and to start a conversation on how to ensure officials tackle the system failures through fundamental reforms.

Guest editor Colin Busby, director of the Institute for Research on Public Policy's Faces of Aging research program, asked some of Canada's top experts in long-term care to ponder some key questions: Why have our governments not taken serious action? Will this time be different? In setting out an ambitious and realistic action plan for fundamental reform, what should be the top priorities for governments in the short term?

The series was accompanied by a series of webinars featuring several of our contributors, as well as the authors of recent publications for the IRPP's Faces of Aging program and its Centre of Excellence on the Canadian Federation.

COUP D'ENVOI À LA RÉFORME DES SOINS DE LONGUE DURÉE

Depuis 20 ans, de nombreux rapports ont préconisé en vain de réformer et d'améliorer notre système de soins de longue durée. Ce dossier d'Options Politiques examine les raisons d'une si longue inaction des gouvernements afin d'inciter nos décideurs à mener une réforme de fond en s'attaquant aux causes profondes des défaillances du système.

Le rédacteur en chef invité Colin Busby, directeur du programme Défis du vieillissement de l'IRPP, a demandé à certains des meilleurs spécialistes des soins de longue durée au pays de réfléchir à quelques questions clés : Pourquoi nos gouvernements ont-ils négligé de passer à l'action ? Les choses seront-elles différentes cette fois-ci ? Quelles doivent être les priorités à court terme d'un plan d'action à la fois réaliste et ambitieux qui réformerait en profondeur les soins de longue durée ?

Ce dossier était accompagné d'une série de webinaires auxquels ont participé plusieurs de nos collaborateurs ainsi que les auteurs des dernières études sur ce sujet du programme Défis du vieillissement et du Centre d'excellence sur la fédération canadienne de l'IRPP.

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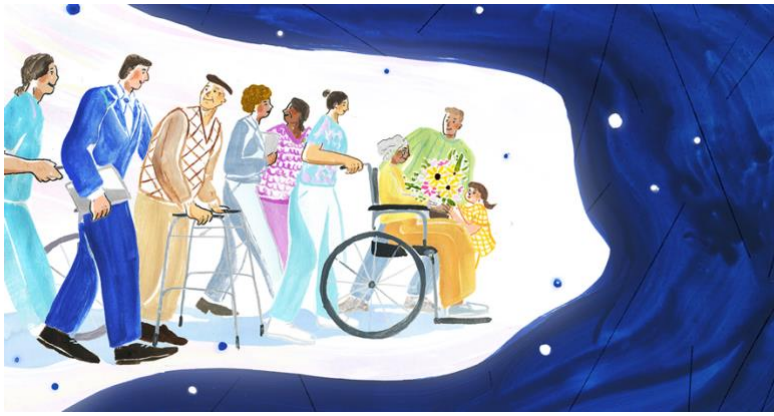


Smart regulations for long-term care would focus on helping the workforce

Long-term care reforms should focus on structural changes such as staffing levels, rather than regulations designed to control the actions of staff.

PAT ARMSTRONG

Although vaccinations have dramatically reduced COVID-19 cases and deaths among long-term care (LTC) home residents during the pandemic's third wave, the main danger going forward for Canada's frail older adults is that the lessons learned from this crisis will not lead to the major reforms. These lessons are not new to policy-makers – they've been documented in countless public commissions and research studies before the pandemic – but very little has been done to act on them.

We do not need more studies to act. We need policies that ensure a better-trained, better-paid, better-appreciated workforce in LTC homes, as well as a better regulatory enforcement to help these workers and to ensure improvement in the quality of care for our frailest citizens.

A history of inaction on LTC reforms

There are many reasons why inaction has been common.

One is that reforms will be costly. But the costs of inaction are much greater. These costs are borne by residents in terms of low-quality care, by families who worry about their loved ones, and by staff who are over-stretched. Rather than investing in fixing these problems over the longer run, governments have resorted only to emergency responses to patch up the problems.

Another reason for inaction is that care in this sector is done mainly for older women by women, many of whom are racialized and/or newcomers to Canada. In our male- and youth-oriented culture, little value is attached to older women or to the care work traditionally done by women. The skills involved are ignored and undervalued.

A third reason is the assumption of family responsibility and the idea that such care was always provided by families in the past. Leaving aside the fact that many older people do not have families, this assumption ignores the fact that many more people are living longer with complex care needs, so families in the past did not have to provide the kind of 24-hour care now required, and that private households can be unsafe places for care. Moreover, we have closed many of the chronic care, psychiatric and rehabilitation hospitals that provided care in the past. We do not like to think about old age and when we do, we assume that we will be able to survive at home.

Prioritize the LTC workforce and regulatory enforcement

To address the crisis in LTC, provincial and territorial governments need to increase the number of staff and ensure that they have appropriate, continuing, work-time training. More than a decade ago, when resident needs were less complex, various studies indicated that there should be a minimum of at least four direct care hours per resident per day. This number refers to the hours when staff are providing care, not the total number of hours worked by employees doing other administrative tasks or those paid but absent due to leave. No provincial/territorial jurisdiction has established this minimum, let alone the more than six hours that current research recommends because of the more-complex needs today of residents in LTC homes. We need to significantly expand training opportunities to reach such minimums.

Retaining staff is just as important as hiring more staff. That requires improved working conditions. Turnover rates in this sector are high even in non-crisis times, with negative consequences for the continuity of care. The temporary wage increases offered during the pandemic recognized that wages are too low in this sector. The pandemic-induced requirement that staff work at only one location further highlights that many had been forced to work multiple jobs to make ends meet, rather than having full-time employment.

Worker absences due to illness and injury in LTCs are among the highest in all industries, even prior to the pandemic, in part due to unsafe working conditions. The Canadian Forces documented the heavy demands and risks involved in the work, as well as the lack of appropriate equipment and technology. Moreover, these reports emphasized the inadequacy of food, housekeeping and laundry, revealing how essential these are to resident health and to the work that the nursing staff does.

We also need smarter and better-enforced regulations. Research by an international team centred at York University showed that, across North America, major failures in care quality that were exposed by the media resulted in more, and more detailed, regulations. These regulations were primarily directed at the actions of staff rather than larger issues of inadequate staffing. Meanwhile, responding to these regulations meant that staff had to spend more time documenting progress towards meeting these regulations, which took away from their already limited time to provide care to residents.

Badly designed regulations further reduced the flexibility of staff in responding to the individual needs of residents. Some regulations, such as one requiring that residents be in the dining room for breakfast at a specific time, can mean both overload for staff who have to rush to get every one up and dressed and no choice for residents who would rather sleep in. Moreover, inspections exposing deficiencies too often do not lead to improvements because enforcement is either limited, absent or based on unverified data produced by the LTC home.

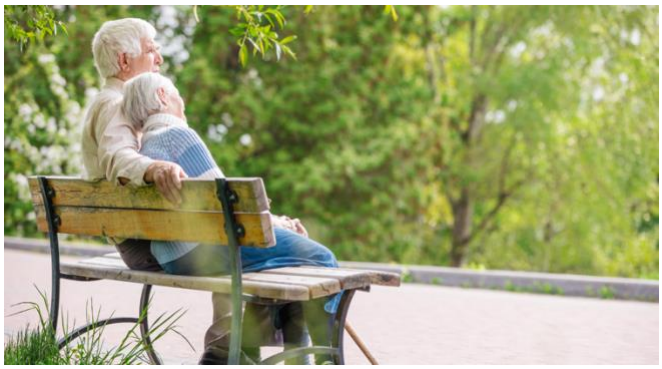
The smarter regulations that we need should focus on structural factors that promote quality, such as minimum staffing levels, the promotion of in-house services and requiring appropriate physical environments. Implementing regulations means working with homes in supporting them to meet the regulation requirements. In developing regulations, governments also need to recognize both medical and social needs – balancing safety and risk, for example, in determining personal contacts during the pandemic.

Reforms must provide conditions for better care

The conditions of work are the conditions of care. Canada's government must offer higher compensation, more full-time and more permanent part-time work for the entire range of staff, as well as investments in modern equipment. We must promote greater continuity of care, teamwork and a healthy work environment. We must do this to support residents and their families to help them lead dignified lives late in life.

If governments do not act now, then when?

Réformer les soins et les services offerts aux personnes âgées au Québec



Le gouvernement doit ouvrir trois grands chantiers pour remédier aux lacunes en matière de soins aux personnes âgées, mises en évidence par la pandémie.

RÉJEAN HÉBERT

La pandémie de COVID-19 a frappé de façon importante les personnes âgées, surtout celles en perte d'autonomie qui résident dans les établissements d'hébergement et dans d'autres lieux de vie collectifs. En effet, à la fin d'avril 2021, 8 520 (79 %) des 10 809 décès dus à la COVID-19 sont survenus dans des centres d'hébergement et de soins de longue durée (CHSLD), des résidences de ressources intermédiaires (RI) ou des résidences pour aînés (RPA). Le Québec se démarque tristement à cet égard : en appliquant le taux de mortalité observé dans le reste du Canada, on peut estimer à plus de 5 300 le nombre de décès en surplus survenus au Québec.

Cette hécatombe résulte de la gestion inadéquate de la pandémie lors de la première vague, alors que les lieux d'hébergement se trouvaient dans l'angle mort du réseau de santé. Mais les causes profondes se situent bien en amont de la pandémie. Au cours des 30 dernières années, les soins et services offerts aux personnes âgées n'ont pas reçu l'attention qu'ils méritaient, compte tenu du vieillissement très marqué de la population québécoise. Pourtant, plusieurs rapports, commissions, politiques et plans d'action (voir le tableau ci-dessous) soulignaient l'importance d'améliorer les services aux aînés, mais sans que des actions conséquentes et cohérentes aient suivi.

L'offre d'hébergement

Dans les années 1980, on a créé les CHSLD en modifiant le statut des « centres d'accueil et d'hébergement » et en y ajoutant les lits de soins prolongés des hôpitaux. On abolissait ainsi la règle selon laquelle 10 % des lits des hôpitaux devaient être réservés aux soins prolongés. Le Rapport Arpin (1999) puis le Rapport Castonguay (2008) recommandaient de diversifier l'offre d'hébergement et de faire davantage appel au privé. Le Rapport Clair (2000) proposait un rattrapage financier pour les CHSLD et une intensification de l'offre de soins. Le Plan stratégique 2005-2010 du ministère de la Santé et des Services sociaux (MSSS) comportait l'objectif d'augmenter de 2,5 % les heures travaillées dans les CHSLD et de doter ces établissements d'un plus grand nombre de professionnels. En 2008, le rapport suivant la consultation publique sur les conditions de vie des aînés recommandait aussi d'améliorer la qualité de vie dans les milieux d'hébergement.

Dans la foulée des réformes des soins de longue durée de 2003 et de 2015, les CHSLD ont perdu la gouvernance et la gestion propre de leurs établissements, puisqu'ils ont été intégrés dans des structures regroupant aussi les hôpitaux et les autres établissements de santé et de services sociaux. Ces réformes ont consacré l'hospitalocentrisme du réseau de santé en laissant les CHSLD à la marge, tant pour la dotation de personnel que pour l'attribution du financement. En avril dernier, le MSSS a rendu publique

la Politique d'hébergement et de soins et services de longue durée qui, au-delà de principes et d'orientations générales, ne comprend aucune mesure concrète pour améliorer la qualité et l'intensité des services. Une étude de Roxane Borgès Da Silva et ses collaborateurs, qui paraîtra sous peu, montre que, de 2001 à 2019, l'écart entre les besoins et les services fournis dans les CHSLD est passé de 22 à 30 %. Le financement des CHSLD en dollars constants n'a augmenté que de 45 % au cours de cette même période, soit à peine 2 % en moyenne par année. Si l'on tient compte du vieillissement de la population, le financement des CHSLD a en fait diminué petit à petit au cours des deux dernières décennies.

Le recours au secteur privé pour les soins de longue durée s'est accentué au cours des dernières années en raison des stratégies d'achat de places par les établissements publics dans des CHSLD privés ou des RPA. Cette privatisation progressive de l'offre d'hébergement soulève des questions sur le contrôle des fonds publics et sur la surveillance de la qualité des soins offerts.

Tableau

Principaux rapports gouvernementaux traitant des soins et services de longue durée offerts aux personnes âgées

Année	Rapports	Auteurs
1988	*Rapport de la Commission d'enquête sur les services de santé et les services sociaux*	Jean Rochon, président de la Commission
1999	Rapport du groupe de travail : *La complémentarité du secteur privé dans la poursuite des objectifs fondamentaux du système public de santé au Québec*	Roland Arpin, président du groupe de travail
2000	Rapport de la Commission d'étude sur les services de santé et les services sociaux : *Les solutions émergentes*	Michel Clair, président de la Commission
2003	Politique de soutien à domicile : *Chez soi : le premier choix*	Ministère de la Santé et des Services sociaux
2005	Rapport du Comité de travail sur la pérennité du système de santé et de services sociaux du Québec : *Pour sortir de l'impasse : la solidarité entre nos générations*	L. Jacques Ménard, président du Comité
2008	Rapport du groupe de travail sur le financement du système de santé : *En avoir pour notre argent*	Claude Castonguay, président du groupe de travail
2008	Rapport de la consultation publique sur les conditions de vie des aînés : *Préparons l'avenir avec nos aînés*	Marguerite Blais, ministre de la Famille et des Aînés ; Sheila Goldbloom et Réjean Hébert, coprésidents de la consultation
2012	Politique sur le vieillissement : *Vieillir et vivre ensemble : chez soi, dans sa communauté, au Québec*	Marguerite Blais, ministre responsable des Aînés
2021	Politique d'hébergement et de soins et services de longue durée : *Des milieux de vie qui nous ressemblent*	Marguerite Blais, ministre responsable des Aînés et des Proches aidants

Les politiques de soutien à domicile

Bien que les lois canadiennes sur l'hospitalisation et la santé ne couvrent pas les soins et services à domicile (à l'exception des services médicaux), la *Loi sur les services de santé et les services sociaux* du Québec a d'emblée inclus ces services dans la couverture publique tout en mettant sur pied des établissements dédiés à cette fin : les centres locaux de services communautaires (CLSC). En 1979, la première politique de soutien à domicile a confirmé le rôle de ces établissements dans la prestation de soins et de services à domicile. Ceux-ci couvraient les soins infirmiers et d'assistance, de même que les

services professionnels en nutrition et en réadaptation. Cette politique établissait clairement la gratuité des services à domicile.

Le virage ambulatoire effectué au milieu des années 1990 par le ministre Jean Rochon visait à réduire le nombre de lits dans les hôpitaux en diminuant les durées de séjour et en transférant certaines interventions en milieu externe. Les économies réalisées devaient être investies dans les services à domicile. Cependant, l'objectif du déficit zéro établi lors du sommet socioéconomique de mars 1996 est venu détourner ces fonds. Le budget des services à domicile, loin d'augmenter, a plutôt dû absorber les nouvelles activités ambulatoires générées par la réforme. Les soins et services à domicile à long terme destinés aux personnes âgées et aux personnes handicapées ont donc été réduits.

En 1996, le gouvernement créait le Programme d'exonération financière pour les services d'aide domestique (PEFSAD), qui subventionnait une partie des services dispensés par les entreprises d'économie sociale en aide à domicile (EESAD). Il instaurait aussi l'allocation financière appelée « chèque emploi-service » pour encadrer la rémunération des travailleurs engagés directement par l'usager pour des services à domicile. Le Rapport Arpin (1999) préconisait de recourir davantage au secteur privé pour les services à domicile. Le Rapport Clair (2000) recommandait que l'on augmente considérablement les ressources publiques de maintien à domicile. C'est aussi à cette époque que le gouvernement a créé le crédit d'impôt pour maintien à domicile.

En 2003, le MSSS publiait sa politique de soutien à domicile intitulée *Chez soi : le premier choix*, qui énonçait clairement que le domicile doit être la « première option à considérer » et que la priorité doit être accordée aux choix des individus. Elle proposait aussi le principe de neutralité financière en vertu duquel le choix de l'usager n'est pas associé à des avantages financiers. Malheureusement, la stratégie nationale de soutien à domicile et le plan d'action qui ont suivi n'ont jamais permis d'atteindre ces objectifs. En 2012, le Protecteur du citoyen critiquait d'ailleurs sévèrement les services de soutien à domicile en dénonçant l'exclusion de certains usagers, le plafonnement des heures de service, la disparité d'accessibilité selon les régions, les délais d'attente et la réduction effective des heures de services. Bien que les plans stratégiques du MSSS de 2005 et de 2010 prévoyaient que le nombre d'usagers augmenterait et que l'intensité des services de soutien à domicile devrait être accrue, force est de constater que ces intentions ne se sont pas matérialisées.

Le Rapport de la consultation publique sur les conditions de vie des aînés (2008) recommandait une amélioration substantielle des services de soutien à domicile et une bonification du PEFSAD. En 2012, la politique *Vieillir et vivre ensemble* réaffirmait l'importance de vieillir chez soi et d'y recevoir les services nécessaires. Les deux plans d'action de cette politique, celui de 2012 et celui de 2018, prévoient aussi des bonifications des soins et des services à domicile.

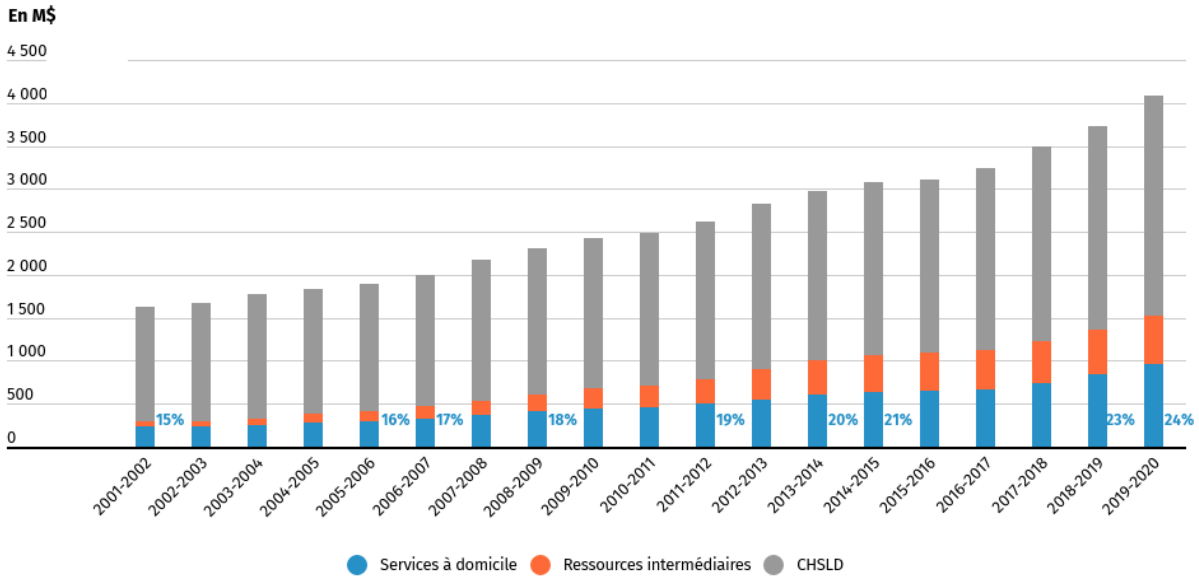
Le financement du soutien à domicile

Malheureusement, entre 2001 et 2020, les investissements dans les services à domicile au Québec n'ont représenté que 15 à 24 % du financement public des soins de longue durée (voir figure ci-dessous). En comparaison des pays européens, qui consacrent à ces services près de la moitié du financement — le Danemark y investit même 73 % de ses dépenses en matière de soins à long terme —, le Québec fait piètre figure. Les investissements ont à peine suivi l'inflation et le vieillissement de la population, sauf entre 2013 et 2015 et depuis 2018, où l'on note une nette augmentation. Une étude sur les services à domicile reçus par les personnes âgées à Sherbrooke montre cependant une diminution importante et progressive des visites à domicile de 2011 à 2015, et ce, même si une hausse importante (20 %) du budget a eu lieu en

2013-2014. Il semble que ces fonds additionnels aient plutôt été affectés à d'autres priorités dans les établissements fusionnés, sans doute à l'hôpital, où les besoins sont toujours criants.

Figure

Évolution du financement des soins et services de longue durée offerts aux personnes âgées du Québec, 2001-2020



Source : Données obtenues par l'auteur du ministère de la Santé et des Services sociaux pour le programme-services Perte d'autonomie liée au vieillissement (PALV) et le programme Soutien à l'autonomie des personnes âgées (SAPA).

Le mode de financement des soins de longue durée pose problème : les fonds qui doivent y être consacrés sont compris dans un budget global que le gouvernement attribue aux établissements et qui sert à financer l'ensemble de leurs missions. Dans ce contexte, il est illusoire de penser que, même en exigeant une reddition de comptes rigoureuse, les services à domicile puissent se développer pleinement. La neutralité financière prescrite par la Politique de soutien à domicile ne peut être mise en œuvre. C'est pourquoi, dès 2000, la Commission Clair recommandait la création d'un régime capitalisé d'assurance contre la perte d'autonomie. Le rapport notait qu'il « est illusoire de penser que le système actuel ou le seul redéploiement du budget des hôpitaux vers le maintien à domicile permettra de réaliser l'importante transition proposée ».

Cette idée a été reprise par le Rapport Ménard (2005), qui suggérait une capitalisation partielle. Le Rapport Castonguay (2008) rejetait cependant cette solution et conseillait au gouvernement d'investir plutôt dans les établissements. Pourtant, une telle assurance de soins à long terme a été mise en place dans les pays de l'Europe continentale, de même qu'au Japon et en Corée du Sud. J'en avais fait une recommandation spécifique en 2008, dans mes conclusions du rapport sur la consultation publique sur les conditions de vie des aînés. C'est ce projet qui m'a amené en politique où, de 2012 à 2014, j'ai pu élaborer le projet d'assurance autonomie. Un livre blanc publié en 2013 a fait l'objet de consultations parlementaires et a reçu un large appui. En décembre 2013, le gouvernement a déposé à l'Assemblée nationale du Québec le projet de loi nº 67 sur l'assurance autonomie, mais il n'a pu être adopté, étant donné les élections précipitées de 2014. Cette assurance visait à redonner à l'usager le contrôle du financement des soins et à réaliser la neutralité financière évoquée par la Commission Clair.

L'insuffisance des services à domicile entraîne un recours indu à l'hébergement en CHSLD et en ressources intermédiaires. Elle joue aussi un rôle très important dans la décision des personnes âgées de déménager dans des RPA, où elles espèrent trouver la sécurité et l'accès aux soins. L'engouement pour les RPA est considérable : en effet, 50 % des RPA au Canada se trouvent au Québec, et près de 20 % des personnes de plus de 75 ans y habitent. Cette situation explique en partie le haut taux de mortalité lié à la COVID-19, puisque plus de 2 000 décès (soit 21 %, fin avril 2021) sont survenus dans les RPA, qui ont connu de multiples éclosions lors des deux vagues de 2020.

Les trois chantiers principaux

La pandémie a mis en lumière les défaillances des services aux aînés en perte d'autonomie. Cette hécatombe doit susciter trois actions essentielles pour éviter qu'elle se reproduise.

Nous devons d'abord réformer les CHSLD en améliorant la qualité et surtout l'intensité des services. La gouvernance et la gestion de ces établissements doivent être revues afin de réintroduire une gestion locale et agile. Il faut élaborer des normes sur le ratio de résidents par infirmière, par médecin et par préposé, à la lumière des données probantes et des bonnes pratiques ailleurs au Canada et dans le monde. Il est nécessaire d'établir une stratégie de recrutement et de rétention du personnel qui revalorise ces métiers et améliore la formation. La stabilité du personnel est un élément fondamental de la relation avec les résidents et de la prévention d'éclosions infectieuses. On doit aussi entreprendre un vaste programme de rénovation des installations, en vue de diminuer le nombre de chambres à plusieurs occupants, d'éviter le partage des salles de bain, d'améliorer la ventilation et d'aménager des espaces de vie dignes de ce nom. Enfin, un réexamen du recours au privé s'impose pour mieux encadrer l'achat de places et, surtout, pour assurer la qualité des services.

Puis, nous devons améliorer les soins et services à domicile pour en augmenter l'accessibilité et surtout l'intensité. En déployant pleinement la Politique de soutien à domicile, le domicile devient une véritable option en cas de perte d'autonomie. Il faut que les usagers aient un droit explicite à ces services en cas de besoin, tout comme ils ont accès aux services hospitaliers et médicaux.

Enfin, le financement des soins de longue durée doit être réformé en profondeur. La mise en place d'une assurance autonomie avec un fonds propre est incontournable pour permettre un financement public équitable, fondé sur les besoins des usagers dans le respect de leurs choix. Des projections montrent qu'une telle formule permet de mieux contrôler les coûts liés au soutien des personnes en perte d'autonomie et représente une solution au statu quo actuel, qui repose sur le recours coûteux à des institutions.

Il s'agit donc de trois chantiers incontournables pour répondre aux lacunes mises en évidence par la pandémie, trois chantiers qui nous permettront de corriger la situation affligeante dans laquelle se trouvent nos aînés, dont des milliers sont décédés au cours de la dernière année.

Equitable funding for home care must be part of long-term care conversation

Supporting home care is key to allowing seniors to age with dignity. For long-term care homes, we need better wages and more funding transparency.

ISOBEL MACKENZIE

This pandemic has revealed deep inequities. The socio-economic chasm that exists in Canada is bigger than many imagined, and fixes are necessary. Age inequities have also come to light as elderly Canadians suffered the highest rates of serious illness and death – outcomes that were exacerbated by decades of government decisions that have not valued the quality of life in our final years. It is clear we can no longer ignore calls for reforms that support our ability to age with dignity.

The problems that have come to the nation's attention over the last year in long-term care (LTC) homes for seniors are not new. The issues related to staffing levels, aging facilities, and the lack of affordable, easy-to-manage alternatives to facility care for seniors who want to remain at home have been talked about for years.

The most basic right we have as Canadians is the freedom to decide where we want to live and with whom. We need to support this right with strong government action throughout a person's lifespan. Quality of care needs to be there for those who can remain at home and equally for those who, for whatever reason, must live in LTC homes.

The challenge has always been to create enough public demand to force the government to deliver the funding and the sustained effort required to make real progress on both these issues.

I hope the volume and intensity of public outcry about the nursing home images splashed on screens across this country during the pandemic have finally caught the attention of the majority of Canadians, most of whom have never seen the inside of one of these homes, or personally faced declining health.

Better support for seniors and their caregivers at home

In seizing this momentum for change, policy-makers should first emphasize better support for seniors who want to remain at home. In B.C., the latest data show that two-thirds of new admissions to LTC homes were people who received no home supports for 90 days prior to admission. This speaks to a significant failure in our "continuum" of care. Admissions to LTC should generally follow a trajectory of incrementally increasing levels of support in the community, yet the evidence is telling us the majority of people admitted to LTC homes go from no formal care to full care overnight.

Lurking in the shadows are distressed family caregivers who are clearly exhausted caring for their loved ones with little or no relief from the public system (assessment for admission to LTC show 59 per cent of new residents have a distressed family member). This comes despite the fact the average LTC home resident in B.C. costs the health care system $60,000 per year – more than enough to pay for some significant help at home.

Individual and family financial pressures are one reason why seniors move to LTC. Subsidizing care in the community to the level an individual would receive in a facility seems a logical approach, yet our system provides significantly more subsidy to LTC facilities than home care – a disservice to both the individual needing care and to the taxpayer funding it. However, money is not the only reason a person moves to LTC. Our health-care system is risk-averse and continues to promote the idea that seniors are "safer" in a facility than at home. Perhaps more than anything, the pandemic has put this fallacy to rest.

The risk in LTC is not just COVID-19. Prior to the pandemic, residents risked falls, medication errors, infections, depression, weight loss and overall failing health. Perhaps most importantly, living in long-term care does not, and never will, confer immortality. Quality of life matters and our paternalistic approach to aging forgets that an individual's right to determine their risk tolerance does not have an expiry date. A 30-year-old can engage in risky activities such as riding a motorcycle or climbing Mt. Everest, so why do we question the right of a 90-year-old man to decide he wants to live on his own?

Even if we get home care right, it will not eliminate the need for LTC, so we must reform the system to ensure frail and vulnerable seniors are offered a dignified life in their final years. This will require more money, financial incentives that compel quality, and a willingness to create and use robust oversight and enforcement tools.

There has been much "buzz" about the need to include LTC in the Canada Health Act and/or eliminate all for-profit long-term care facilities. These may be ideas worthy of discussion, but most of us who have worked in the field know they are not the answer to all that is wrong. Further, they have potential unintended consequences and could delay the implementation of broadly accepted, necessary changes. If we want to see change in the foreseeable future, we need to focus on what can be achieved over the next five years.

Recognizing the link between quality staffing, funding, and wages

Better staffing will go a long way to improving care. We need more staff, appropriate staff and consistent staff – the evidence linking these inputs to quality is well-documented. However, there is no magical formula to achieve these metrics that does not include increased wages. The basic economic law of supply and demand applies to every labour market including long-term care. The default "we can't find anyone to hire" can no longer be accepted as the reason for being short staffed. We talk about how rewarding work can be in long-term care and that is true. It *can* be rewarding. However, it also requires work on weekends, evenings and usually a healthy dose of overtime. We will not create a qualified, appropriate labour pool until we create stable full-time jobs with wages that reflect both the value and the difficulty of the work.

Fundamental to any reform is how LTC operators are funded. In Canada, many provinces contract with private operators to deliver the majority of their long-term care services. The virtues of competition and choice are used to support this model. In publicly funded but privately delivered LTC however, we have neither competition nor choice. There is no incentive to be better than anyone else because your funded

bed will be filled regardless. Choice by the consumer is limited, in all practical terms, to whatever bed is available when you need it.

We need to employ the power of economic incentives to ensure that private operators deliver what we need to improve quality of life for residents. The current model financially rewards those who pay the lowest wages, spend the least amount on food, and source the cheapest supply of incontinence products and PPE. We have been seduced by the economic mantra that the private sector is more "efficient" than the public sector, without examining how these "efficiencies" are found and the resulting impact on residents.

It is the public's money that is funding most private LTC operators in Canada. We should post on government websites the detailed revenue and expenditures for each publicly funded care home. Transparency in public sector spending could provide further momentum for reforms. Across Canada, there has been a general reluctance for government to hold publicly funded nursing homes to account. There are no fines issued for non-compliance with regulations and we talk of co-operation and partnerships with the care home operators. The role of government in LTC is oversight and regulation, not a partner to those who run a business. Our partner is the resident who has turned to us to provide them with the care and support they need and can no longer provide for themselves.

We need to shift our focus to the people who live in long-term-care, and the people who love them. Their voices should influence the funding and oversight of LTC homes, with somewhat less influence going to the people who own and operate publicly funded long-term care for frail seniors.

As policy-makers embark upon reforming long-term care, a central objective should be to expand decision-making autonomy to the majority of seniors so that they can choose to remain in their own homes if that's what they want, or to support them when they decide to move to an LTC. That's how we ensure aging with dignity.

Long-term care insurance would better serve Canada's aging population

A universal, public long-term care insurance system would provide Canadians a continuum of care options from care at home to care in institutions.

ITO PENG

The vaccine rollout is giving Canadians hope for an end to the COVID-19 pandemic. But before we contemplate a return to normal life, we must not lose sight of the virus's devastating impact on long-term care (LTC) and the shameful state of our LTC systems. If COVID has taught us anything, it's that LTC and the health issues that often accompany aging are not isolated problems. They are our collective eventuality, and we must collectively build a better support system.

Federal, provincial and territorial governments should work together to put in place a universal, public long-term care insurance system that would provide a continuum of care options from care at home to care in institutions, similar to what several other countries have already done. This would be financed by a mix of premium contributions, general tax revenues and individual co-payments.

Despite numerous government-commissioned reports over the last 20 years – each calling for reform and improvements to LTC – Canada's governments have taken little or no serious action. This may be because population aging is a slow, silent process. People often don't think about LTC until it's too late. Older people are less visible and you can easily ignore them, or assume that you or your family won't ever need LTC services. However, many people develop disabilities – cognitive and/or physical ones – as they age. Now that the pandemic has shown Canadians the failings of our LTC systems, we must reform them before it's too late.

Demographic aging-prompted reforms in Germany, Japan and South Korea

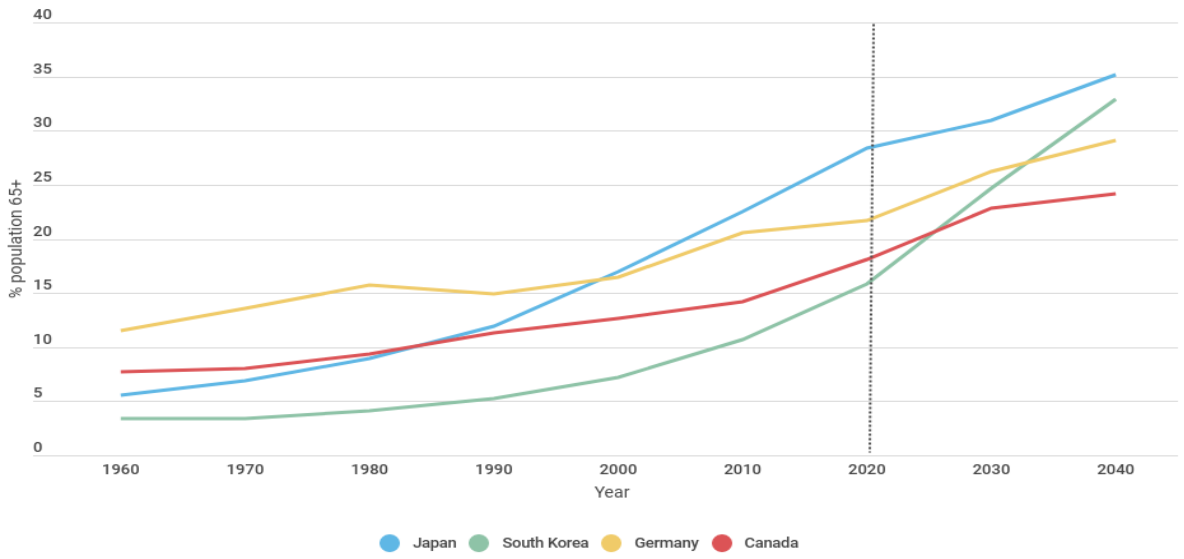
Canada should learn from the experiences of other countries. Germany, Japan and South Korea made fundamental changes to their LTC systems well before COVID-19 hit. They made transformative shifts by replacing their patchwork systems of LTC provided by local and regional governments with universal, national public LTC Insurance (LTCI). In the process, they turned LTC from primarily a private family responsibility to a family, community and state collective responsibility.

These systems are financed by a combination of insurance premiums, general tax revenues and sliding-scale co-payments. They provide a range of services based on one's level of disability. LTCI in all these countries operates on a mixed-market model, with the government setting the regulatory framework for service delivery, the price of services, the licensing and skills training of providers, and overall governance. The benefit of this model is that it capitalizes on the existing service capacity while reforming and building onto it, rather than breaking the existing system and rebuilding a new one from scratch. Germany introduced its LTCI in 1995, Japan in 2000 and Korea in 2008.

The governments in these countries were motivated to reform their LTC systems because they realized that their socio-demographic structures were transforming rapidly, and they foresaw an impending care crisis. The German government had been getting pressure from families and state governments to address LTC issues since the late 1980s. The country's population was getting older, more women were in paid employment, and families were experiencing increasing LTC strain. As state governments were largely responsible for LTC before the LTCI, their resources were stretched, and capacity was overwhelmed by increasing demand. But it was the demographic threshold reached in 1990 – when the number of people over 65 hit 15 per cent of the population – that the government realized it was time for a radical reform. Germany had gone past the point of being an "aging society" – a society with more than seven per cent of its population over the age of 65 – and had become an "aged society," with more than 14 per cent over age 65.

The Japanese government was also under similar public pressures to reform LTC, but it was the "1.57 shock" – the lowest fertility rate in its history – in 1989 that pushed the government into action. Japanese policy-makers were quick to realize the simple equation: (low fertility)+(increasing longevity)=(rapid population aging)=(impending LTC crisis)=(bad economics and bad politics). They also knew that their population was aging much faster than Germany, and they had little time to lose (see Figure 1). They watched and learned from Germany's LTCI reform as they worked on their own.

Figure 1
Percentage Population 65+ — 1960-2040



Source: United Nations, Department of Economic and Social Affairs, Population Division (2019).

South Korea's situation was similar to Japan's. When Korea's total fertility rate dropped to 1.2 in 2000, the government quickly struck an LTC reform commission. Although the Japanese population was aging faster than Germany's in the late 1990s, demographic projections showed that Korea was aging even faster than Japan. Germany introduced its LTCI when its 65-and-over population was 16 per cent; Japan when it was 17 per cent. When Korea introduced its LTCI, the figure was barely 10 per cent, but Koreans knew that their 65+ population would hit 14 per cent by 2018, and was projected to reach 20 per cent by 2026. Today, Canada's total fertility rate (1.50) is not as low as Japan (1.42) or Korea (0.98), but with our

65+ population already at 18 per cent, we are older than those countries were when they initiated reforms.

These countries were also motivated to reform because they wanted to avoid incurring potentially huge health-care costs as their populations aged further. Like Canada, all these countries had universal health-care systems that covered most medical and health-care services. Like Canada, there also had been only limited coverage for LTC because it fell somewhere between health and social services. Before their reforms, all three of these countries witnessed a growing tilt towards institutional care for older people and social hospitalization. This is also a trend we see in Canada.

A public long-term care insurance solution

Policy-makers in the three countries chose universal, public mandatory LTCI, coupled with a rigorous regulatory framework as a prudent policy solution. Not only does LTCI mitigate unnecessary and expensive institutionalization, but it also provides older and/or disabled people with a continuum of care in their home, community and institutions. Moreover, such a system would support healthier and active aging, and would create a new dedicated funding stream for LTC.

LTCI is also customizable. Germany, Japan and Korea each adapted the system to fit their own social, political and cultural contexts. The German government was concerned about public and state support for a national LTCI. To address these concerns, they gave families a choice of cash or service. They also gave state governments a fresh infusion of cash and infrastructural support to provide care services. In Germany, LTCI received enthusiastic support from both the public and state governments.

in Japan and Korea, governments were worried about intergenerational buy-in – why would people in their 20s and 30s support financing a large share of LTCI costs – as well as LTCI's fit with their countries' cultural norms about family caregiving. They therefore set the mandatory insurance premium payment to begin at age 40 to avoid placing a major financial burden on young people. In response to women's concerns – who feared that if benefits were delivered as cash, they would continue to expect women to provide unpaid care – LTCI benefits in these countries provide only services. In both countries, more than 80 per cent of the general public supported LTCI. Families, NGOs, and women's and seniors' groups whole-heartedly endorsed LTCI because they saw that it would relieve the family's – women's – heavy caregiving burden, would allow women to continue working, and even create new employment opportunities.

Canada can customize its LTCI as well. We can set the age of premium contribution to ensure greater intergenerational equity. We can also determine a mix of cash benefits and in-kind care services to meet diverse individual, regional and cultural desires. The most important thing is that we create a universal public LTCI system, with regulations on how benefits can be accessed and used, to ensure accessibility, equity, accountability and quality of care.

The time is now

As Canadians reflect on the lessons from the COVID pandemic, we must boldly reform LTC. We have all the right conditions for a transformative change – a systemic crisis, an aged demographic, families crying out for help, a huge public recognition of LTC needs and expectations for government leadership – and we have models of reforms from other countries to learn from, adapt and innovate. We must act now.

Le système de santé québécois doit se transformer en un système apprenant

Un système de santé apprenant repose sur un large accès aux données, est un chef de file pour mener les changements et effectue régulièrement des analyses de performance.

YVES COUTURIER, FRANÇOIS AUBRY et FRANCIS ETHERIDGE

Les centres d'hébergement et de soins de longue durée (CHSLD) du Québec ont été frappés plus durement par la COVID-19 que d'autres établissements semblables ailleurs dans le monde. Ainsi, parmi les 37 000 personnes hébergées dans les CHSLD de la province, le taux de mortalité lié au coronavirus s'élevait à environ 14,8 % au 7 mai 2021. Cette situation a surpris une partie de la population, mais beaucoup moins les spécialistes, qui étaient las de répéter les mêmes recom mandations aux responsables publics. Depuis des décennies, ils déploraient la piètre qualité des services, le manque de main-d'œuvre et d'équipement, la détérioration de l'environnement de travail, la sous-valorisation du travail des préposées aux bénéficiaires, l'absence d'anticipation des besoins, la prédilection pour une approche d'intervention médicale, la gouvernance défavorable à l'innovation… Il est juste de noter que cette situation n'est pas propre aux CHSLD : elle caractérise aussi de nombreux établissements ailleurs dans le monde qui exercent des missions équivalentes.

En raison du vieillissement relativement rapide de la population du Québec, les politiques publiques portant sur cet enjeu fondamental ont pourtant connu d'importants changements depuis 20 ans ; elles ont suscité les plus grandes réformes de l'organisation des services de santé depuis la création du système des soins de santé moderne, au tournant des années 1970.

Les réformes à la fin des années 1990

Dans la foulée du mouvement international de désinstitutionnalisation, le gouvernement du Québec a en effet élaboré en 2003 une politique publique fondamentale affirmant que le maintien à domicile des personnes âgées en perte d'autonomie fonctionnelle constitue le premier choix de la province. D'une orientation économe, en phase avec le désir des aînés, favorable au maintien de leur participation sociale et faiblement associée aux effets pervers des traitements, entre autres, cette politique n'avait en principe que des avantages. De facto, le pourcentage de personnes vivant en CHSLD est passé en 30 ans d'environ 7 % à 2,6 %, preuve de l'efficacité de cette politique publique. La conséquence clinique de cette focalisation de l'accès aux CHSLD était cependant un alourdissement des besoins en matière de soins et de services à offrir aux résidents de ces établissements. La réforme appelait une transformation fondamentale des CHSLD, notamment en ce qui a trait à la reconnaissance de la charge de travail du personnel et des besoins cliniques des résidents. Or cette réforme n'a pas eu lieu.

Pour que le virage vers le maintien à domicile soit efficace, tant du point de vue fonctionnel que du point de vue clinique, il aurait fallu mettre en place des services de qualité en fonction des besoins de la

population. Or l'écart entre les besoins et les moyens est demeuré abyssal, malgré des réinvestissements que le gouvernement annonçait à chaque budget, au printemps. Le Canada est l'un des pays de l'OCDE qui dépense le moins pour les services à domicile et le Québec se trouve dans le peloton de queue, les soins à domicile ne représentant qu'un peu plus de 2 % de ses dépenses en santé.

À la fin des années 1990, la nécessité de repenser l'organisation des soins de longue durée a néanmoins généré un important effort de recherche. Cette période d'innovations s'était largement inspirée des premiers travaux conceptuels portant sur l'intégration et la continuité des services offerts aux personnes âgées. Parmi les plus notables expériences se trouvaient les programmes de recherche SIPA (Services intégrés pour personnes âgées fragiles) et PRISMA (Programme de recherche sur l'intégration des services de maintien de l'autonomie). Ces deux recherches, parmi les plus citées à l'époque à l'échelle internationale, ont beaucoup nourri la réflexion des décideurs publics québécois et mené à la planification des réformes de 2004 et 2015.

Ces réformes visaient à assurer une meilleure utilisation des ressources hospitalières, à éviter autant que possible les hébergements de longue durée, à combler le déficit en matière d'intervention préventive pour maintenir l'autonomie fonctionnelle, à contenir l'augmentation des dépenses et à résoudre le difficile accès aux soins, qui représente le problème structurel central de tout système de santé et de services sociaux à forte composante publique. Ces réformes prenaient en considération la rapide transition démographique et donc épidémiologique en cours au Québec et le risque d'effondrement du système de santé. Au terme de ce mouvement de réforme, le Québec ne comptait plus que 34 établissements de soins de longue durée publics sur son immense territoire.

Ces réformes, d'une ampleur incomparable à l'échelle internationale, ont été accompagnées d'importantes innovations, comme la création, à partir de 2002, des groupes de médecine de famille — qui n'ont cependant pas complètement réussi à prendre en charge les besoins des aînés —, l'actualisation de la philosophie d'intervention en CHSLD par l'adoption de l'approche milieu de vie — visant à offrir des soins et des services personnalisés et favorables à la santé biopsychosociale des résidents — et l'approche adaptée à la personne âgée en milieu hospitalier — qui aurait dû rendre les hôpitaux mieux adaptés aux spécificités du grand âge. Mais l'approche milieu de vie n'a eu aucun effet réel et l'approche adoptée à la personne âgée a connu une mise en œuvre difficile.

Les réformes prioritaires aujourd'hui

Pourquoi ce volontarisme apparent des politiques publiques n'a-t-il pas réussi à protéger les personnes vivant en CHSLD, alors que les bonnes pratiques étaient assez bien connues ? Il y a des raisons internes et externes à cela. À l'interne, l'organisation des CHSLD est restée fondée en grande partie sur une conception industrielle des soins, directement héritée du modèle asilaire du 19e siècle : la philosophie en matière de soins, les modalités de gestion et l'organisation du travail sont demeurées archaïques et ont ainsi contribué à une certaine inertie des CHSLD face aux effets de la pandémie. À l'externe, c'est tout le continuum de services, qui va de la prévention et de la perte d'autonomie fonctionnelle aux stratégies de compensation, qui n'a pas su mettre en œuvre ne serait-ce qu'une des innovations promues depuis le milieu des années 1990.

Cette incapacité à instaurer des politiques publiques à première vue positives a plusieurs causes fondamentales : le sous-investissement chronique et largement reconnu dans le secteur des soins, le manque d'intérêt pour gérer le changement, une gestion dont la compétence et l'influence sont inégales

(notamment en raison de son affaiblissement découlant de la réforme de 2015) et un réformisme mal focalisé qui privilégie les réformes structurelles plutôt que les réformes managériales et cliniques.

À cela, il faut ajouter les effets désorganisateurs d'une politique ayant de facto favorisé l'expansion du secteur privé dans le domaine pourtant stratégique de l'hébergement. Pensons, entre autres choses, aux résidences privées pour aînés (RPA), qui sont beaucoup plus nombreuses au Québec que dans les autres provinces canadiennes. Par leurs choix opérationnels, en adoptant des pratiques qui ont pour effet d'accroître la perte d'autonomie des personnes concernées, ces établissements contreviennent à certains principes fondamentaux de l'organisation publique des services.

Il découle de cette analyse trois chantiers prioritaires et réalistes :

- Tout d'abord, le Québec doit se doter d'une infrastructure publique de type Qualité Québec comme il en existe en Écosse (Healthcare Improvement Scotland) ou en Ontario, dont la mission consistera à transformer le système de soins de santé québécois en un système apprenant. En plus de nécessiter un large accès aux données, un tel système doit se poser comme chef de file pour mener et gérer les changements, et effectuer régulièrement des analyses de performance. De telles organisations existent déjà au Canada et à l'international. Cette infrastructure aurait pour mission de s'assurer que les innovations soient implantées de manière à répondre aux promesses faites aux résidents.
- Puis, dans un contexte où l'on estime que le Québec comptera chaque année près de 6 000 personnes de plus dans le groupe d'âge des 85 ans et plus, la solution ne pourra pas se limiter à la construction de 600 unités d'hébergement pendant les quatre prochaines années ni à la rénovation de quelques centaines de chambres en CHSLD. L'impact maximal de la vague du vieillissement de la population n'est pas encore pleinement visible, mais le sera très prochainement. Il importe alors de penser les soins de longue durée dans leur globalité et de réinvestir de manière à relever le défi qui s'annonce.
- Enfin, il faut revoir en profondeur la gouvernance et l'organisation du travail dans les CHSLD afin de les rendre conformes aux normes de qualité en vigueur au 21^{e} siècle. Il nous faut développer davantage les potentialités des employés qui jouent un rôle fondamental dans ces établissements : les préposées et les préposés aux bénéficiaires. La crise provoquée par la COVID-19 a mis en évidence à quel point les établissements dépendent de ce personnel. Il importe donc de rendre leur travail plus attrayant et de retenir à long terme les personnes récemment recrutées, notamment en ajustant leur rémunération, mais aussi en veillant à ce qu'elles reçoivent une formation adéquate et en s'assurant de leur bien-être au travail. Pour y parvenir, les établissements doivent reconnaître leur importance en leur offrant la possibilité de participer à la gestion de l'organisation des services.

La COVID-19 a révélé et exacerbé une crise dans les CHSLD qui ne disparaîtra pas avec l'éventuelle régression de la pandémie. Les déterminants sociaux, structurels et politiques des difficultés rencontrées pourraient survivre au coronavirus s'il n'y a pas une prise de conscience profonde de la nécessité de revoir en profondeur les politiques publiques en matière de soins de longue durée. Cette prise de conscience devra d'ailleurs se faire rapidement, à la lumière de l'expérience traumatisante que nous a fait vivre la pandémie.

Moving long-term care from a vicious to a virtuous cycle

Changing the long-term care ethos will require creating national principles, not standards, and transitioning away from a commodified regime.

TAMARA DALY, IVY LYNN BOURGEAULT and KATIE AUBRECHT

Policy-making occurs where opposing ideas, differing values about who should do what, and debate about power dynamics over who should benefit and under what conditions flourish. Some policy issues are more easily resolved and receive broad consensus, if not total agreement. They operate in a virtuous cycle. In contrast, some policy areas never get to a virtuous cycle, and long-term care (LTC) is a prime example of this. Across Canada, it has remained a wicked policy problem, which, as Brian Head reminds us, is characterized by "conflicting values and perspectives, uncertainties about complex causal relationships, and debate about the impacts of policy options."

If we look back only two decades, we might shake our heads, slap our foreheads or break down in tears, angry and frustrated at the countless government commissions, inquiries and inquests, and the innumerable stakeholder and independent academic reports that have been released – only to gather dust. If we retreat longer into the past, our dismay may increase as we recognize that this is a problem we have never gotten right, despite the many proposed solutions.

COVID-19 turned a wicked problem into a deadly one. Doing nothing is not a policy option this time. We recommend a three-faceted, forward-looking approach. We need to 1) implement a new set of national principles based on values to shape seniors' care; 2) recognize, through federal funding, that we share risk for LTC, because a person's needs can progress beyond the capacity of any single family to manage; and 3) enable a shift away from the idea that care is a commodity, toward a recognition that good care requires decent working conditions, as well as greater public oversight, to produce the needed public benefit.

From the vicious….

Why does LTC remain stuck in a vicious cycle?

Part of the policy complexity rests with LTC services being at the confluence of health care, social care, housing, disability and labour, and also crossing multiple levels of government. LTC is a sector that should, but often does not, span ministerial boundaries. While it is mostly adults older than 85 who live in LTC facilities, depending on the province there are also many other adults who reside in them, which can create challenges if the model of care is insufficiently individualized. What is more, LTC sits outside the *Canada Health Act* – it is defined as an extended service – and is therefore not subject to its principles. Each province and territory determines its own funding for LTC and home care.

There is far too little recognition of the extent to which complex care has shifted away from hospitals to LTC in the past two decades. This slow evolution has been traced in report after report, with little recognition that LTC can and should be considered essential. This is especially critical when the demands and chronic-care need associated with diseases like Parkinson's, or neurocognitive conditions such as dementia, progress in ways that can outstrip the capacity of even the most well-resourced individuals and families to provide care.

In addition, LTC facilities as workplaces are associated with myriad problems, as ministries of labour and worker's compensation board reports show. To start, care work is poorly paid, in part due to assumptions that anyone should know how to care for others. There is a lack of recognition of the highly skilled nature of LTC when it is done well; there is a persistent belief that LTC is low-value because it is largely done by an unskilled, mostly female and increasingly racialized workforce. This gendered workforce is provided with only bare supports and resources to do the job adequately, safely and with the sense of fulfillment that many went into the profession seeking. In short, we pay, provide and protect too little and generally expect too much.

There are some very good LTC providers who invest in resident life, their buildings and their workforces and offer high-quality care, but underinvestment by governments and other organizations means that the high-quality ones are good despite the LTC system, not because of it. There are far more LTC providers that are mediocre at best, and abysmal at worst. As a result, there has never really been a golden age for LTC in Canada. But the failure does not rest solely with the providers of care because, in terms of funding, long-term care has always been the sacrificial lamb to our universal acute-care health system, when compared with the funding levels that come from *Canada Health Act*-protected insured services.

Different values may also be at the heart of why LTC is such a persistently wicked problem. To be sure, it evokes strong reactions. Some people are appalled at its very existence and advocate for almost everyone to remain at home, mostly reliant on a kin system of gendered, unpaid care provided by women, supplemented by home-health supports. Others see the provision of high-quality LTC as a crucial resource in a society that values older people. When done well, shared living is not simply about bodily needs, it can also overcome the worst aspects of social isolation, and value women's paid and unpaid contributions.

Finally, there are those who value profit above all else and view LTC as a lucrative market space with very stable, government-backed profits, albeit with high barriers to entry. It is not publicly funded in its entirety. Across Canada, LTC is defined by varying levels of public funding and rules for out-of-pocket payments. To add to this, even in good times, there has been an air of austerity that surrounds it. The sector has never quite shrugged off its poorhouse origins, with the implication that it is undeserving of public funding, or the sense that families are failing to live up to their obligations.

Consequently, given the value- and power-laden fights over who should do what, who should benefit, and under what conditions, LTC languished until it reached an absolute crisis in 2020, when COVID-19 ripped open the doors and shamed us all.

…to the Virtuous

Despite the calamity of the past year, there has never been as much public attention paid to LTC as in this moment, nor have we ever been as close to consensus that we can and should do more to disrupt the vicious cycle in the sector. Below, we raise three facets of what we need to do as a nation to overcome the tragedy that COVID-19 so ruthlessly exploited. First, we must create a set of national principles for

seniors care that are values-based and that recognize the central place of care within our society, not apart from it. National standards, as promised in the most recent federal budget, might be necessary, but they are certainly not sufficient on their own. Standards are usually focused on organizations and providers, so they tend to be more technical and medical. We need values-based principles to which governments must be held to account. Clearly, iron rings do not work, and over-medicalizing LTC is not appropriate either. National principles could build on – but must move beyond – the *Canada Health Act* principles, to recognize the significance of the social and cultural spaces that long-term care residents and workers inhabit.

Second, we must recognize that high-quality, publicly funded LTC has to rest on shared risk – on our interdependence – so we are elevated toward a societal ethos of care. LTC is needed by those with high-care needs, but the "bar" for long-term care needs must incorporate the fact that some people require care sooner; some have fewer social, familial or financial resources to draw on; and some have needs that exceed the capacity of kin and friend networks.

Finally, and most importantly, we must stop commodifying care. Decommodifying care means shifting it away from remunerating a transactional, commodified regime toward offering incentives to providers to innovate and deliver high-quality care; and punishing those who cannot perform. Mediocrity should not be the standard for the provision of high quality care and decent working conditions in LTC. Decommodifying care acknowledges the vital role of public LTC. This means public oversight that includes more robust public reporting of facility-level staffing outcomes and workplace indicators; the generation of health- and social-care data including quality of life, community engagement, improvement and innovation, and comparative system performance indicators; and the establishment of clear reporting of ministerial and operator performance. Meaningful public indicators would move us toward better accountability. National principles could guide policy-makers in their decisions.

Decommodifying care also means identifying how care work exploits gender and racial inequities in society. To address inequities, we must make the conditions of care work not only publicly visible through facility-level workplace indicators but also more highly valued with good working conditions. Care workers deserve good working conditions, which include but are not limited to permanent work, extended benefits, and a living wage. They must also have the resources to do the work and to protect themselves, so the job brings personal satisfaction and minimizes poor work-related health outcomes. Ultimately, the only way to improve care is to ensure more robust public reporting of data.

As we move forward, we must be guided by a set of national principles that build on the idea that we are sharing risk for a challenge too large for any one family to solve on its own, as well as a commitment to decommodifying care for the direct benefit of residents, their families and frontline workers. Until policy-makers acknowledge these three facets to this complex and wicked problem, they will not be able to create the conditions for high-quality care or ensure good working conditions. No matter what national or provincial standards are enacted, what financial incentives exist or what funding algorithms are applied, two ideas are foundational: providing good-quality care is relational and involves treating residents and their families in ways that are not transactional; and ensuring work is decent means providing not only a living wage and job security, but also job satisfaction for care workers.

Resolving the wicked problem of LTC requires multiple levels of government, as well as the broader public and providers, to wake up, stand up, stop shifting the blame and not look away. It will require shifts in policies, practices and philosophy. At least we know one thing: unsolved wicked problems portend even more wicked problems.

Home care should be key part of Ontario's Seniors Strategy

Addressing long-term care staffing and facility issues are just one of the pandemic lessons learned. Increasing home care options is also critical.

BOB BELL

Nobody should forget that Canada set a sad record by leading the world with the highest proportion of COVID-19 mortality that occurred in long-term care (LTC) homes. A new seniors' strategy should take account of pandemic lessons learned and take action that promotes independence for seniors and improves the quality of care. Although aspects of a seniors' strategy can reflect pan-Canadian values, roadmaps to reform should be specific to each provincial health-care system.

In Ontario, the reasons why too many people died in LTC homes has been studied and well- documented. Testimony before the government-appointed Marrocco Commission, an independent inquiry investigating LTC and COVID-19, identified the root causes of fatalities. Empirical evidence points to staffing shortages and facility overcrowding as key shortcomings – issues that should be prioritized in upcoming policy reforms. Further, demographic change and growing demands for LTC services mean we should make major efforts to keep more people independent in their homes and out of facilities for as long as possible.

The Canadian Institute for Health Information (CIHI) analyzed a range of possible factors associated with higher mortality in Ontario LTC during the pandemic's first wave. The analysis demonstrated that there was a higher risk of an outbreak in homes located in public health units not only because of the virus, but also when homes had a medical director present for less than a day a week, where there were critical shortages in personal support workers (PSWs) and a high usage of temporary PSW staff.

Facility overcrowding also had a major impact on LTC mortality. Homes that had three to four residents in a room had a higher risk of infection and mortality than homes that offered private or semi-private rooms. Eliminating four-person bedrooms would have eliminated 263 deaths during the pandemic's first wave, the report said.

Similar to this, it's been determined that for-profit LTC homes are more likely than not-for-profit homes to have three- or four-person rooms. Overcrowding is the underlying reason why for-profit homes tend to have disproportionately higher COVID-19 mortality than not-for-profit homes.

These analyses should convince policy-makers that facility redevelopment and PSW staffing levels and conditions must be urgently addressed to improve the quality of care in Ontario's LTC homes. Fortunately, these issues are already being addressed through recent commitments announced by the provincial government.

Testimony before the Marrocco Commission by the Ontario LTC Association stated that 32,000 of the province's roughly 78,000 beds were located within older homes where three or four residents would share a room. For more than 15 years, successive Ontario governments have stated their intent to redevelop these older homes. But, until recently, little progress has been made with construction of new facilities that conform to modern building standards that enhance infection prevention.

There are many reasons for this historical failure to redevelop. The ministry of health and long-term care could not agree with LTC operators' estimates of appropriate funding for LTC redevelopment. Operators insisted that the ministry financial formula for redeveloping old homes did not provide adequate funding for increasing land and development costs. Operators also claimed that the ministry was overly prescriptive with building standards that increased costs well beyond the funding formula.

In fall 2020, the Ontario government announced a new construction funding program that recognized operators' land and construction costs in redeveloping older facilities or building new LTC homes. At present 38,000 Ontario patients are on the waiting list for a LTC bed, and 32,000 beds in older buildings require redevelopment to meet current infection-control standards. This suggests that Ontario needs to build homes with 70,000 new beds to accommodate both people on the waiting list and the need for redeveloped beds.

Shortly after the new funding principles were implemented, the ministry approved operators' applications to build (or rebuild) more than 20,000 new beds, and major Ontario LTC development was initiated – the first in the last many year. This is a fresh start. The government has committed to provide 30,000 new beds by 2028 along with more than 15,000 redeveloped spaces.

A staffing analysis was undertaken by the ministry of long-term care during the first wave of the pandemic in response to the recommendations of the long-term care homes public inquiry, a government-commissioned judicial inquiry to investigate crimes in Ontario LTC facilities. The outcome of that analysis, combined with staffing challenges experienced during the pandemic, resulted in a government commitment to increase staffing to reach a new average care standard of four hours per-day per-resident in the next three years. This increased care standard will be supported by an increased focus on human resources, which includes better training, recruitment and retention support.

This new approach to facilities and to staffing are important responses to the lessons learned. However, with the population of seniors in Ontario expected to increase by about four per cent annually in the next 20 years, it will be difficult for the system to provide adequate supports for frail elders if LTC facilities are the main option. Most studies of citizen preferences for seniors' supports find that older people would prefer to avoid moving into an LTC home and want to maintain independence in their own residence as long as possible. This preference for staying out of LTC homes has likely increased as a result of the pandemic.

Maintaining seniors' independence in the home means an increased focus on home care. Recent investigations have focused on the opportunity to provide better and more cost-effective home care through recognition of naturally occurring retirement communities (NORCs). NORCs develop as the result of seniors congregating together in communities which serve their needs. Researchers are finding that NORCs in high-rise apartment buildings are growing rapidly in popularity in Ontario cities and that a substantial proportion of urban seniors live in NORCs in cities like Toronto. Recognition of this type of living situation recently enabled Toronto Public Health to deliver mobile on-site COVID vaccination for seniors throughout the city.

The proximity of multiple clients in NORCs permits the efficient delivery of home care and volunteer services for seniors. Home care maintains client independence and is much more cost-effective than care in LTC facilities. Yet, Ontario has not recognized NORCs in developing a home care strategy. Planning to deliver congregate home services to NORCs offers a substantial potential improvement for the province's home care system.

Other elements that should be considered in a new framework for Ontario's Seniors Strategy include investments in community day programs and increased training of various regulated health professionals in geriatric care. Training of primary care physicians and nurse practitioners in geriatric competencies will help to ensure that we have more medical directors and primary care providers in our LTC homes.

Far too many frail Canadians have died in LTC homes during this pandemic. This should prompt a new strategy for seniors' care. The evidence shows that we must focus on facility development and on expanding staffing supports to improve quality and safety in LTC facilities. Given the pressures to come from an aging population, we must increase home care options to reduce the future need for care in LTC homes.

Les soins de longue durée : il faut réformer autrement !

La réforme des soins de longue durée doit s'inspirer de l'esprit d'innovation qui a présidé aux projets menés au Québec et ailleurs au Canada dans les années 1990.

FRANÇOIS BÉLAND

En 1975, le défi qu'allait représenter le vieillissement de la population pour les systèmes de santé était déjà clair : une personne de 65 ans sur cinq aurait besoin d'une combinaison de services sociaux et de soins de santé à large spectre. C'est la notion de « combinaison » qui devait servir d'avertissement. Or les gouvernements ont plutôt continué de privilégier les établissements médicaux et hospitaliers et d'isoler (pour mieux les négliger) tous les soins de longue durée (SLD) destinés aux personnes âgées atteintes d'incapacité fonctionnelle. C'est dans cette négligence généralisée qu'il faut chercher le fondement de la crise qu'a provoquée la COVID-19 dans les établissements d'hébergement.

À la fin des années 1990 et jusqu'au début des années 2000, le Québec était une terre d'innovation en matière de soins de longue durée. Deux projets d'intégration innovateurs y avaient cours : le Système de services intégrés pour personnes âgées (SIPA) et le Programme de recherche sur l'intégration des services de maintien de l'autonomie (PRISMA). Ces projets avaient été soumis à des évaluations rigoureuses et étaient financés en partie par des organismes de subventions de recherche et par le ministère de la Santé et des Services sociaux du Québec (MSSS). Les résultats furent publiés dans des revues scientifiques prestigieuses et diffusés largement auprès des décideurs et des gestionnaires du réseau de la santé et des services sociaux. Ils ont inspiré certains des énoncés de politiques de l'époque et même quelques actions.

Échecs des tentatives de réforme

Plusieurs documents du MSSS ont proposé d'importantes transformations dans le secteur des SLD. Premièrement, le ministère avait planifié de mettre en place le modèle de milieu de vie dans les centres d'hébergement et de soins de longue durée (CHSLD). Ceux-ci, qui étaient au départ des modèles dérivés de l'hôpital, devaient dorénavant offrir aux résidents un milieu de vie aussi proche que possible de celui de leur domicile. Mais ce n'était qu'un écran de fumée. En réalité, les CHSLD ont été dépouillés de leurs capacités de donner des soins médicaux aux résidents sans que les exigences de créer un milieu de vie soient prises au sérieux. Deuxièmement, le projet d'assurance autonomie, qui visait à offrir une protection contre les conséquences des incapacités fonctionnelles, n'a jamais vu le jour. Proposé fin 2013 par un gouvernement du Parti québécois, il a été rejeté en 2014 par les libéraux nouvellement élus. Le jugement fut sans appel et non motivé. Une déclaration lapidaire de Gaétan Barrette, ministre de la Santé à l'époque, le qualifiait « d'exercice le plus cynique de l'histoire du Québec ».

Il ne reste que bien peu de tout cela aujourd'hui. Le MSSS s'est désintéressé des SLD, abandonnant leur développement au secteur privé. Par exemple, le nombre de lits en CHSLD dans le domaine public est passé de 49 000 en 1993 à un peu plus de 37 000 en 2017-2018. Le nombre d'heures de services à domicile fourni par le secteur public n'a pas augmenté entre 2013 et 2018. C'est dans le secteur privé que l'offre

s'est accrue. Les SLD n'ont eu droit qu'à de la rhétorique, et le plus récent document ministériel, Politique d'hébergement et de soins et services de longue durée : des milieux de vie qui nous ressemblent, appartient malheureusement à la même catégorie. Au fil des ans, il y a bien eu des initiatives locales méritoires menées par des gestionnaires et par du personnel engagés, mais ces efforts n'ont jamais atteint le sommet de la pyramide ministérielle.

Le désarroi, les abandons et les décès dans les CHSLD réussiront-ils à jouer le rôle de « moments charnières » qui rendront imparable une réforme du régime d'assurance maladie ?

L'assurance publique et universelle des services médicaux, hospitaliers et diagnostiques est au cœur de la *Loi canadienne sur la santé* de 1984. Cependant, les professionnels de la santé, les gestionnaires des établissements et les responsables régionaux et ministériels ont refusé d'étendre aux SLD la couverture offerte par la loi. Cette conception restreinte de la couverture, laquelle est dominée par une perspective strictement médico-hospitalière et préoccupée par le diagnostic médical, a constamment rétroagi sur les politiques relatives au régime d'assurance maladie au Canada et sur le financement et l'organisation des services offerts par les provinces. Il en a résulté un itinéraire du développement de ces politiques pavé par les échecs des tentatives d'étendre la couverture à d'autres secteurs que ceux inscrits dans la loi de 1984. Le désarroi, les abandons et les décès dans les CHSLD réussiront-ils à jouer le rôle de « moments charnières » qui rendront imparable une réforme du régime d'assurance maladie ?

La pandémie de COVID-19 a été un révélateur des problèmes accumulés au cours des dernières décennies en ce qui a trait aux SLD. En voici les éléments principaux :

- Le financement des SLD s'est avéré insuffisant pour recruter, former et rémunérer le personnel nécessaire pour combler les besoins des bénéficiaires.
- Aucune des interventions et aucun des programmes et des plans d'action relatifs aux infections nosocomiales (dont fait partie le coronavirus), pourtant prévus depuis des années, n'avait été mis en place dans les établissements de soins de longue durée. Les CHSLD ne disposaient d'aucun des moyens qui leur auraient permis d'affronter les éclosions de COVID-19. La surveillance en continu des infections et le suivi serré de la contagion étaient inopérants. La pandémie a révélé la négligence des responsables ministériels par rapport à tout ce qui concerne l'appréciation de la qualité des soins dans les CHSLD.
- L'hébergement a occupé tout le terrain des SLD pendant la pandémie. Les autres types de soins, notamment les services à domicile, ont été largement ignorés pendant des mois avant d'occuper brièvement le devant de la scène.
- Enfin, les CHSLD n'ont pas fait partie des établissements qui ont été mobilisés dès le début de la pandémie pour limiter la contamination. Ils ont été marginalisés, alors que les hôpitaux occupaient toute la place. Ils ont même servi de déversoir pour les hôpitaux, qui ont transféré des patients dans les CHSLD sans prendre de mesures pour protéger ces établissements des risques d'éclosion. Les services à domicile n'ont pas joué leur rôle de surveillants de la contamination chez les personnes âgées à haut risque.

Ces problèmes ont mis au jour les maux qui touchent l'ensemble du secteur des SLD, et chacun y va de sa suggestion pour une réforme de fond. Les enjeux et les défis sont du domaine du financement, de la qualité des soins, de la fluidité de l'accès aux soins, de la prestation des SLD en fonction des besoins des personnes, et de l'intégration des SLD et des services médicaux et hospitaliers.

Principales recommandations

Tout d'abord, les SLD doivent être inclus dans le régime public et universel d'assurance maladie au Canada et soumis aux mêmes cinq normes que les services couverts par la loi de 1984. Et les transferts fédéraux pour les services de santé doivent comprendre les dépenses pour les SLD, selon les règles qui s'appliquent aux soins médicaux et hospitaliers. Le Québec refuse que le fédéral, en échange de son financement, impose des normes de gestion administrative et clinique qui pourraient aller jusqu'à la régulation de la prestation locale de soins. Les normes de la *Loi canadienne sur la santé* s'appliquent à l'économie générale du régime d'assurance maladie. Le Québec, qui les accepte pour les soins médicaux et hospitaliers, n'a pas de raisons sérieuses de s'y opposer. Le fédéral devrait financer les SLD au prorata de la proportion des dépenses en soins médicaux et hospitaliers qu'il assume par les transferts fédéraux et les points d'impôt pour la santé. Un groupe de chercheurs de l'Université de Toronto a estimé cette part à 59,1 %. Les dépenses des provinces en SLD se situant à 22 milliards de dollars en 2019, cela fixerait la part du financement fédéral à 13 milliards de dollars.

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Puis, nous avons aussi besoin d'une véritable politique d'appréciation de la qualité des soins. La déliquescence de la prévention et du contrôle des infections nosocomiales dans les CHSLD ne se serait pas produite si une telle politique avait été mise en place. Les soins et les services étant prodigués localement, l'appréciation de la qualité doit être intégrée au quotidien. La réforme la plus difficile et la plus essentielle doit mettre au centre de la prestation des SLD la qualité et les procédures conséquentes d'appréciation continue. Le personnel de tous les métiers doit être formé aux pratiques gérontologiques et gériatriques ; les équipes locales de prestataires doivent être redevables de la qualité clinique des soins; l'appréciation de la qualité ne se fait qu'en continu, avec des procédures et des moyens intégrés à la prestation des soins.

Des modèles de pratiques et des outils existent à cet effet. Plusieurs établissements de soins de longue durée se soumettent déjà à l'examen périodique d'Agrément Canada. Toutefois, si cette procédure est essentielle, elle ne pourra suffire, comme le montrent les nombreux cas de désorganisation des soins survenus pendant la pandémie dans des établissements agréés. L'ajout de normes fédérales, au-delà des cinq normes de la *Loi sur la santé* du Canada, ne servirait qu'à faire illusion.

Ensuite, les politiques en matière de SLD qui opposent l'hébergement et les services à domicile n'ont pas lieu d'être. Parmi les propositions de réforme, certaines privilégient l'hébergement, d'autres se concentrent sur les services à domicile. L'urgence d'agir peut expliquer ces choix stratégiques. Cependant, on ne peut concevoir les SLD sans tenir compte de l'évolution des incapacités des personnes qui les requièrent. Les situations changent et varient selon les personnes (par exemple, la gravité des incapacités, la faculté de mobiliser des services, la disponibilité de l'aide de proches). Ces trajectoires de soins se moquent des considérations bureaucratiques et des jeux de pouvoir entre ordres professionnels qui président à la prestation des SLD. Une réforme des SLD exige donc de considérer la totalité des soins et des services, qui doivent être intégrés à la trajectoire de soins des personnes qui les reçoivent et non pas l'inverse. Pendant trop longtemps, on a obligé les personnes à s'insérer dans les structures de soins existants et à se conformer aux règles qui assurent leur fonctionnement.

Enfin, on a attribué l'incapacité des CHSLD à réagir aux défis de la COVID-19 à une gouvernance déficiente et proposé de renforcer celle-ci en s'inspirant de modèles de « gouvernementalité ». Il faut plutôt aligner

les modalités financières, institutionnelles et cliniques de la prestation des SLD sur les profils de besoins des personnes qui les requièrent. Les incapacités fonctionnelles ne sont qu'un des divers types de problèmes de santé. Les personnes qui ont besoin de SLD cumulent de multiples maladies chroniques ; elles peuvent être atteintes de maladies aiguës, leur médication est complexe, les symptômes dépressifs et les diminutions des capacités cognitives sont aussi fréquents. L'évolution de l'état de chaque personne suivra différentes voies. Chez certaines, les affections multiples seront légères, leur laissant une bonne autonomie, car la progression sera lente. À l'autre bout du continuum, la progression pourra être catastrophique. Entre ces deux pôles, on observe toute une gamme de cycles d'évolution.

Les soins de longue durée, aussi bien que les services médicaux et hospitaliers, les services sociaux et la réadaptation, les services psychologiques et le soutien à la famille, existent selon de multiples configurations. Séparer ces soins des autres types de services ne fait que dresser des obstacles aux trajectoires de soins et de services. Il faut savoir intégrer autour de la personne et de ses proches l'ensemble des services qui leur sont nécessaires. Dans cette rencontre entre les SLD et les autres secteurs des soins de santé, les SLD doivent être à même de promouvoir les intérêts de leur patientèle, la pérennité des institutions qui en ont la charge, leur accès à des ressources humaines et financières, et leur capacité d'action.

La réforme des soins de longue durée doit s'inspirer de l'esprit d'innovation qui a présidé aux projets de démonstration au Québec et ailleurs au Canada dans les années 1990.

Reforming long-term care requires a diversity and equity approach

Long-term care institutions should be home-like environments, that reflect the growing diversity in the aging population in Canada.

SEONG-GEE UM

Moving into a long-term care home, where nobody speaks your mother tongue or understands your culture, is an uncomfortable reality faced by many Canadians in their later years. As people age, they often revert to their mother tongue and communication with others outside their language group becomes difficult, particularly for those suffering from dementia. For many, it hardly feels like home.

The Chief Public Health Officer of Canada has called for an equity approach in Canada's pandemic recovery plans: an approach that is evidence-based, develops new innovations, spurs action to decrease the impact of the social determinants of health, as well as to improve data, governance and communication. We shouldn't stop there.

As Canada is set to establish its first national standards for long-term care, incorporating evidence and understanding the reasons for disparities experienced by people from diverse ethno-cultural backgrounds who live and work in LTC can help to build a better system for all Canadians. Canada's governments must ensure that the development and implementation of national standards for LTC is guided by an equity and diversity lens.

Inequities in long-term care

Before the COVID-19 pandemic, significant inequities were found among people needing and providing LTC. A Wellesley Institute study highlighted that immigrant seniors, especially racialized immigrants and those with a non-English mother tongue, experienced cultural and language barriers to access quality LTC in the Greater Toronto Area. An Ontario-wide study found that being an immigrant and applying to an ethno-specific home was associated with significantly longer wait times. Family caregivers reported substantial health impacts from having to overextend themselves in balancing work, family and the care needs in supporting seniors who face delayed, or lack of, access to care. A Canada-wide study found that immigrant family caregivers were three times more likely than non-immigrants to report a health consequence from informal caregiving.

The fundamental principle of the Long-Term Care Homes Act of 2007 in Ontario requires all homes to be operated so residents "have their physical, psychological, social, spiritual and cultural needs adequately met." Yet, the Ontario LTC COVID-19 Commission – an independent commission established by the provincial government to investigate the spread of COVID-19 and to provide recommendations on future actions – heard that LTC homes did not always recognize, acknowledge or value residents' diverse needs. This caused some residents from diverse ethno-cultural groups to feel isolated and alienated, which was exacerbated during the COVID-19 pandemic when they were cut off from families who provided essential supports to address cultural and language barriers to receive quality care in LTC homes.

Further, a recent analysis of 2016 census data highlighted the breadth of inequities experienced by LTC workers. Those working in LTC were disproportionately Black and Filipina women who were more likely to be employed part-time than women who work in non-care fields. Women LTC workers made $1,684 less annually than women workers in comparable fields. They also had higher rates of self-assessed "poor" physical health than non-care workers. During the pandemic, particularly in the first wave, work in LTC became more precarious and even dangerous. LTC workers faced greater risks of COVID-19 infections and deaths as many were working in multiple homes to make ends meet, with no proper personal protective equipment. In addition to the personal and societal costs of bad jobs, in health care they contribute to poor quality of care and health outcomes. COVID-19 data analysis by the Canadian Institute for Health Information suggested that LTC homes with critical shortages of personal support workers and a higher rate of use of agency workers experienced more severe COVID-19 outbreaks among residents.

Diversity in LTC reform

The sector must be transformed. For institution-based LTC, there has been growing attention on decades-old advocacy around transitioning LTC into more home-like environments, whether by building more smaller, household-type facilities or making smaller spaces within large institutions. Both our current facilities and proposals for new home-like environments must reflect the growing diversity in the aging population across Canada and especially in urban centres such as Toronto, Vancouver, and Montreal.

When Wellesley Institute asked family caregivers of immigrant seniors, across diverse ethno-cultural communities, about key factors considered when seeking LTC, they highlighted their quest to find the LTC homes where their family members would "feel at home." Many family caregivers described such home-like environments as places where their loved one could speak their first language with other residents and staff, enjoy familiar meals, games and songs just as they once did at home. They wanted a place where their loved one's diverse needs were respected and included in care planning and delivery. Evidence from international research suggests that meeting individuals' cultural and linguistic needs is especially important for the health of people living with dementia in care homes.

In the coming months, Canada's Health Standards Organization (HSO) will develop a national LTC services standard with a focus that reflects current discussions about LTC reform, such as

resident- and-family-centred care that values the importance of respect, dignity, trust, and quality of life with a healthy and competent workforce.

National standards for LTC that include diversity and equity

Building on the promising strategies developed by Canadian and international jurisdictions, there are three key priorities that require immediate, concrete actions to ensure that equity and diversity is embedded in all initiatives leading up to transforming LTC.

First, in developing the new national standard, targeted efforts should be made to meaningfully engage with diverse ethno-cultural communities through public and expert consultations to better understand and address the issues these communities face in receiving and providing quality LTC. In particular, efforts should be made to learn about any existing barriers to meet the expectations set by the current standard (e.g., access to translation and interpretation services). This could be done by, for example, asking diverse groups of LTC residents, families and staff to share their experiences in accessing supports. Building on the current evidence on health inequities, the diverse perspectives gathered in this process should inform the new standard development.

Second, the standard should present clear guidelines for LTC homes to provide a good job to everyone working in each home, with decent pay and working conditions that enable workers to achieve a healthy, thriving life. Amidst COVID-19, some Canadian jurisdictions rightly took steps to improve pay and employment conditions for those working in LTC. For example, in April 2020, the B.C. government implemented a policy making all LTC staff provincial employees – employed full-time at one facility, with pay comparable to workers in public-sector unionized positions. These changes, if made permanent, could be effective in improving the quality of care and the health of all Canadians living and working in LTC.

Third, the standard should set specific goals and outcome measures for health equity. Clear guidance should be presented on how to track and report on the progress on improving health equity for people living and working in LTC. Currently, a lack of data on resident and staff socio-demographic information – such as immigration status, race and ethnicity – limits our understanding of health-equity impacts of the pandemic on people living and working in LTC. Canada has lagged behind other countries in the collection of such data in health care. Enhanced collection and use of socio-demographic data can be a powerful tool in identifying existing gaps and the effectiveness of any interventions in addressing such gaps for diverse population groups. New national standards for LTC present a promising opportunity to establish pan-Canadian standards that promote equitable access to high-quality care. With strong commitments to equity by all levels of government, we can ensure that the long-term care reform improves the health and well-being of all Canadians.

Could down-payment federalism help kickstart reform in long-term care?

Federal-provincial buck-passing has to end, and a new cost-sharing transfer for LTC could work by having half the money up front and half in 20 years.

COLIN BUSBY

The historic decision to create a universal Canadian public health care system in the late 1960s and early 1970s was driven by the federal government's exercise of its constitutional "spending power" – it offered 50-50 cost-sharing transfers to those provinces that created public health insurance programs covering nearly all medically necessary physician and hospital-based services. Long-term care (LTC) services were left out of this initial arrangement. Today, Canadians are facing a moment as consequential as the creation of public health care now that the nation has been exposed to the LTC system's major shortcomings during the COVID-19 pandemic.

The various means adopted over the decades for transferring federal money annually to the provinces for Canadian medicare have proven to be inadequate and have held back needed reforms. However, a new, redesigned federal-provincial cost-sharing transfer for LTC – down-payment federalism – could galvanize much-needed reforms while avoiding past mistakes.

Since their introduction, conditional federal-provincial health transfers have become unproductive. For far too long, federal and provincial governments have been engaged in an endless game of shifting blame and responsibility for our health-care system's inadequacies, with the provinces pointing to the feds' declining share of funding support as the reason for inaction. As a result, necessary health-care reforms languish.

A good idea gone wrong

The creation of our health-care system is regarded by many as Canada's most important policy success. Not long after medicare began, however, concerns about its fundamental cost-sharing arrangement started to emerge. In the late 1970s, the federal government grew concerned about its ability to finance these ongoing commitments, so it replaced its open-ended cost-sharing commitment in 1977 with an unconditional block funding arrangement (under Established Programs Financing provisions). This included converting half of the cash transfer into federal tax points and transferring them to the provinces to enable them to collect more of their own tax revenues to pay for health care. The provinces, however, refused to publicly acknowledge the transfer of tax points and instead complained that the federal government was violating the agreement.

In the early 1980s, in response to public concerns about the growing role of private medicine in the health-care system – and what the feds saw as provincial politicians' unwillingness to appropriately manage it – the federal government reasserted the conditions on health transfers in the principles of the *Canada*

Health Act of 1984. In theory, the feds would enforce the act by withholding some of the annual transfer payments if the CHA conditions were not met. But in practice, such penalties were circumscribed to the application of user fees or extra-billing by physicians.

In the mid-1990s, when the federal government faced a debt and deficit crisis, it unilaterally cut health and other social transfers to the provinces by more than one-third. Any remaining trust between Ottawa and the provinces was irredeemably lost as a result of this decision. As governments' public finances improved in the late 1990s, health transfers slowly started to rise again and culminated with the 2004 Health Accord, whereby Ottawa committed to six per cent annual increases for a period of 10 years in exchange for health-care improvements on a number of fronts (most of which never materialized). This commitment was extended to 2017, after which they have increased in line with average economic growth in Canada, subject to a minimum increase of three per cent each year.

Federal involvement in funding health care, while central in efforts to establish our universal publicly funded system, has become more of a hinderance to progress than a catalyst. Conditions on health transfers to the provinces have two basic flaws: they are less effective in changing provincial governments' behaviour because the money goes into general provincial revenues and are used as provinces see fit, and because they focus more on how the provinces administer and deliver these services rather than on general health and patient outcomes.

What has resulted is blurred accountability and mutual distrust, leaving most Canadians confused as to what level of government is to blame when issues arise. Cost-sharing agreements should therefore be used cautiously, so that voters see health policy issues as purely provincial responsibilities.

With this in mind, a new way of designing conditional transfers is warranted. Long-term care was not part of the original list of health services to be covered by public health insurance. Rather than include it in the *Canada Health Act*, the federal government should embark on a new way of funding long-term care that would spur and facilitate the extensive, medium-term reforms required.

Breaking the stalemate

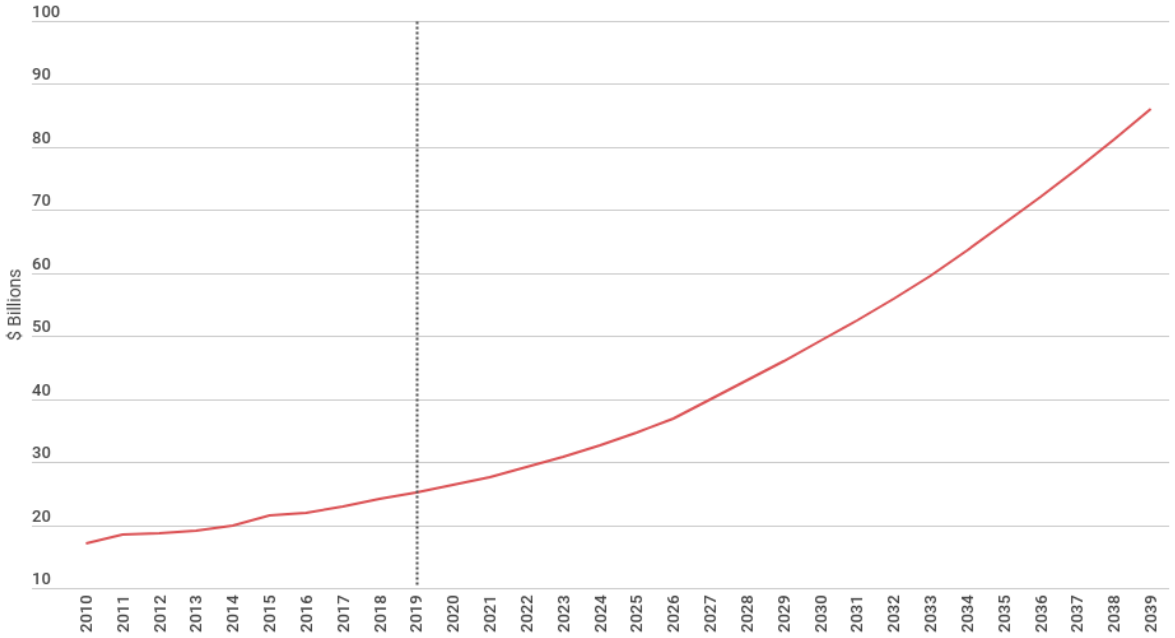
What to do when two sides in a negotiation are concerned about the other party fulfilling its side of the bargain? Simple. Pay half up front, and the other half when the job is done. The feds should negotiate a cost-sharing arrangement with the provinces based on anticipated increases in LTC costs, which will determine the size of the transfer. Governments should jointly set outcome-oriented, not process-oriented, objectives for improved quality of LTC and should develop ways to measure progress toward these goals. Then the federal government should get out of the way.

How would down-payment federalism work for LTC?

Because there is no precise calculation of total LTC costs in Canada, an estimate is required. Canada has comparable provincial/territorial data for public funds spent in LTC institutions, but only has estimates of how much each province/territory spends on LTC services delivered in individual homes. In 2019, the provinces spent approximately $20.7 billion to finance long-term care institutions (according to the Canadian Institute for Health Information's national health and expenditure database). Recent research concludes that roughly 82 per cent of LTC spending in Canada goes to institutions, which means that roughly $4.6 billion in 2019 was spent on public LTC services provided at home.

By adding public spending on LTC institutions to estimates of public home-care spending, total provincial and territorial LTC costs are estimated to be slightly more than the $25 billion in 2019. Assuming these figures will increase in line with the annual growth of the age groups that have the highest need for LTC (those aged 80 and up) as well as government-sector inflation, we can project the trajectory of provincial and territorial LTC institutional costs in the next 20 years. According to this simple calculation, we can expect the costs of LTC to more than triple over the coming 20 years, from $25 billion in 2019 to slightly more than $86 billion in 2039. (See figure 1.)

Figure 1
Provincial/territorial LTC costs (institutional and home care), historical and projected



Source: Author's estimates based on assumptions in text.

But, of course, embedded in this projection is the assumption that the provinces just keep doing what they have been doing in the past, which we know is insufficient in terms of quality of care. All provinces have to invest in improving the quality of LTC services. So, when we add a premium of 15 per cent for the provinces to make necessary improvements to LTC, we get a total expected increase in LTC costs of $70 billion by 2039 relative to 2019. (We get $70 billion by subtracting $25 billion from $86 billion, then adding 15 per cent of the difference.)

If the federal government were to pick up half of this anticipated increase in costs, that means it would need to cover about $35 billion of the public bill for LTC in the coming decades. That would mean transferring to the provinces an additional $17.5 billion this year, then another $17.5 billion in 20 years' time.

How would down-payment federalism advance LTC reform?

Such a transfer has the potential to create clear lines of accountability and give provinces needed funds to bring long-overdue improvements in the quality of care. By focusing related federal conditions on the

data collection of specific LTC outcomes rather than on constraints on how to use funds, the feds would free up the provinces to innovate in the sector.

The feds should demand that the provinces collect and provide LTC data on patient-centred outcomes, such as resident-satisfaction scores, quality of life, and caregiver burnout, for example. The data could be paid for by the feds and should be comparable across provinces and territories. Much like pan-Canadian standardized test data helps educators across the country to identify and discuss good and bad policies, or models of delivering services, these data would perform a similar function for LTC.

An advantage of this new transfer is that it would remove short-term political cycles from the policy realm. With elections roughly every four years, a concern for the provinces is that a new federal government could be elected with a different set of priorities. This would no longer be a major issue with a down-payment transfer.

The only time that the federal government would start to seriously look over the provinces' shoulders would be near the end of the 20-year period, when the second installment comes due. Given the size of the lump-sum transfer, and taking into account any provincial progress toward improved outcomes, it would be difficult for a future federal government to walk away from the deal. At the same time, a province that has not made improvements to LTC would be rolling the dice and would have to face the scrutiny of its electorate if it has not improved its LTC system relative to its peers.

Should the provinces find more cost-effective ways to deliver services – say by providing a greater share of LTC services in people's homes rather than in institutions – and the increase in LTC costs is lower than originally anticipated, the provinces should get to keep the savings.

A new approach to health transfers to help spark LTC reform

Any new transfer must seek to end the blame game between governments and remove the excuse that a lack of financial resources is holding back reforms. Conditions would focus on LTC outcomes and the collection of data to observe progress toward these outcomes rather than have the federal government play an ongoing enforcement role.

The federal government and the provinces should agree on projections of long-term-care cost increases in the next 20 years and what health outcomes should be measured. Then Ottawa should make a down payment and get out of the way. In another 20 years, when the provinces have done their job, then the federal government can settle the remaining tab.

Cash-for-care benefits are key to reforming long-term care system

Other countries are much further ahead than Canada in helping older adults age at home, such as offering direct public transfers to support care.

COLLEEN M. FLOOD

Watching scenes of overcrowding, neglect, suffering and untimely death in LTC homes in the early days of the pandemic was agonizing, and has no doubt reinforced the desire of many Canadians to age in their homes for as long as possible. But the home-care needs of many older adults across Canada are unmet.

Those who do receive publicly funded home-care services report having little control over how their care is provided, a lack of continuity in care, and having to deal with multiple caregivers and a complicated bureaucracy. What's more, many activities such as food preparation and other daily chores don't qualify for public funding. Family members and other informal caregivers are left to fill the gaps. These are often women who report high levels of distress and burnout. To provide better support to Canadians who wish to age at home, policy-makers should look at successful examples in European countries that provide a cash-for-care benefit option – a direct public transfer paid to older citizens (or their caregivers) to support at-home care.

One in five seniors have care needs that could be met at home

According to the Canadian Institute for Health Information, the problems that plague the home-care system – including financial constraints, limited availability of services, confusion on how to access services and lack of responsiveness – drive older Canadians toward institutional care. Between 2012-13 and 2014-15, about one in five seniors who entered LTC institutions had care needs that likely could have been met at home. In Canada about 80 per cent of spending on LTC goes to institutions while 20 per cent is spent on home care, a disparity that may drive some people to opt for institutional care prematurely.
Canada must do better. In a report published by the Institute for Research on Public Policy, my colleagues and I argue that part of the solution is to provide cash-for-care benefits. More than half of OECD countries offer cash benefits to care recipients. These benefits can be used to purchase formal home-care services, to compensate family and friends who provide informal care, and/or to pay for equipment and home renovations.

Empowering care recipients, maintaining autonomy

The experiences of Germany and the Netherlands, where cash-benefit programs are widely used, demonstrate that they can be a practical solution to improving LTC services for those with low or moderate care needs, and can offer many advantages. Better access to home-care services can reduce unnecessary and unwanted admissions to LTC homes. It can also empower recipients to manage their

own care, maintain their autonomy and customize the kinds of supports they receive to their individual circumstances, rather than be squeezed into a cookie-cutter definition of service provision.

But there must be restrictions on how cash-for-care benefits are spent as well as policies that counteract the risks. Both Germany and the Netherlands have introduced restrictions to curb growing program costs and to combat fraud. For instance, in the Netherlands, cash benefits can be invoiced to a centralized personal health budget for each individual, up to an annual maximum, or to pay caregivers based on formal contracts, even if the caregiver is a family member.

Protecting informal caregivers

There's also a concern that offering cash payments for informal care would encourage more working-age women, who already provide the bulk of home-care services, to reduce their participation in the workforce. In Canada, women account for 54 per cent of informal caregivers. According to the most recent estimates, the wages forgone by caregivers due to missing work or working reduced hours totaled $221 million a year for Canadian women between 2003 and 2008, compared to $116 million for men.

Policy-makers should consider providing additional supports for informal caregivers, such as strengthening job-leave provisions, bolstering respite support and supplementing Canada Pension Plan contributions.

The pandemic has demonstrated that new investments are sorely needed to improve the quality and safety of long-term care institutions. We recommend that cash benefits be part of a suite of initiatives that cover the full spectrum of Canadians' care needs, including significantly more investment in LTC homes, better access to formal home care and greater support for informal care. We recommend that provincial and territorial policy-makers target cash benefits to those with low and moderate health-care needs, and that they work with the federal government to implement additional measures to ensure that informal caregivers do not suffer financial setbacks.

Over the next 20 years, both the overall number of older adults and their share of the overall population are expected to rise considerably, putting further pressure on an already strained system. Other countries are much further ahead than Canada in designing policies to help older adults age at home. Canada must catch up quickly.

As attention begins to shift to life beyond the pandemic, we can't lose this window of opportunity to reform long-term care. Policy-makers should move quickly to introduce a new cash-benefit program, with appropriate regulations, to help older adults age at home.

Soins de longue durée : le personnel soignant est un facteur clé

La composition et la gestion du personnel, les conditions de travail et le manque de formation sont parmi les facteurs clés de l'échec des soins de longue durée.

FRANCINE DUCHARME

Lors de la première vague de la pandémie de COVID-19 au Canada, la plus forte proportion des décès est survenue dans les établissements de soins de longue durée, un taux plus élevé que dans des pays comparables. Par rapport aux autres provinces, c'est le Québec qui compte le nombre le plus élevé de décès dans les établissements de soins de longue durée. La COVID-19 a constitué une réelle onde de choc qui a mis en évidence les nombreuses failles des soins de longue durée, notamment en ce qui concerne la sécurité et la qualité des soins, et, bien évidemment, la gouvernance des établissements de soins.

Pourtant, depuis plus de 50 ans, comme l'a souligné le groupe de travail sur la COVID-19 de la Société royale du Canada, nombre de rapports, de commissions et de reportages sur les soins de longue durée ont paru sans qu'on leur accorde vraiment de l'attention. Il aura fallu cette pandémie et ses milliers de victimes pour que les gouvernements s'y attardent. La COVID-19 a donné lieu à des enquêtes et à des recommandations provenant de plusieurs instances, notamment du Protecteur du citoyen, du Bureau du vérificateur général du Canada, du coroner en chef du Québec et même des Forces armées canadiennes, qui ont dû pallier le manque de ressources humaines. La COVID-19 a non seulement révélé le sous-financement des soins destinés aux aînés vulnérables, elle a aussi suscité une réflexion sur les mesures à mettre en place de façon urgente pour assurer l'avenir des soins de longue durée.

Pourquoi cette crise, en dépit des avis des dernières décennies ?

La préparation des interventions face à la COVID-19 était concentrée sur les milieux de soins aigus. Quand la pandémie est survenue, les établissements de soins de longue durée n'avaient pas les capacités requises pour contenir l'éclosion. Quelles sont les priorités qui auraient dû être établies en soins de longue durée ? Quels soins auraient été nécessaires ? Avec quelles ressources et quels équipements ? Aucune stratégie n'avait été mise au point. De nombreux éléments essentiels étaient manquants : approvisionnement en équipement de protection individuelle et formation à leur utilisation ; stratégies de regroupement et d'isolement des résidents, et procédures de surveillance des infections ; capacités de dépistage et de traçage des contacts ; personnel en nombre suffisant et bien formé ; équipe de dirigeants sur place ; politiques relatives aux proches aidants.

En somme, la pandémie a exposé la façon dont sont traités les aînés et les personnes qui en prennent soin. La dévaluation du travail auprès des personnes âgées, la perception qu'il s'agit d'un emploi facile ou de moindre importance qui nécessite peu d'habiletés, de compétences ou d'expertise particulière ont révélé un âgisme certain.

De nombreux autres facteurs peuvent expliquer le désastre qui s'est produit. Un des éléments clés concerne les caractéristiques des personnes âgées et la gestion de la main-d'œuvre dans les établissements. En dépit des changements démographiques prévisibles depuis des décennies, de l'alourdissement de l'état physique et cognitif des personnes hébergées et de la grande complexité de leurs besoins, la composition du personnel de soins n'a jamais été ajustée aux nouveaux impératifs.

Actuellement, les soins sont presque entièrement offerts par des préposés et préposées aux bénéficiaires mal rémunérés qui ont reçu une formation minimale et variable. Ces personnes représentent une ressource indispensable, mais sont néanmoins sans voix pour effectuer les changements systémiques qui s'imposent dans leur milieu de travail. Des professionnels de la santé détenant une expertise, de même que des gestionnaires de proximité, font aussi partie de la solution.

Les ratios infirmière-résidents ont été constamment réduits au fil des ans pour limiter les coûts, mais aussi parce qu'on estime qu'un personnel professionnel dont disposent d'autres établissements de santé, notamment en soins aigus, n'est pas nécessaire en soins de longue durée. C'est dans ce contexte de pénurie de personnel qualifié que les transferts quotidiens, trop nombreux et sans raison, des aînés hébergés dans les établissements de soins de longue durée vers les urgences des centres hospitaliers ont amplifié la perte d'autonomie de ces aînés.

Il est non seulement essentiel de doter les établissements en personnel suffisant et de rééquilibrer les ratios, mais aussi d'engager du personnel qualifié et bien formé à temps complet et sur une base stable. Actuellement, les établissements de soins de longue durée n'ont pas accès ou ont un accès très limité aux services d'une équipe interdisciplinaire de professionnels : ce sont notamment les soins en santé mentale, les soins palliatifs et les soins de réadaptation qui ne sont pas au rendez-vous. Et combien de fois a-t-on limité le débat au « nombre de bains offerts », alors que tant d'autres soins et services sont nécessaires ? Les discours relèvent encore d'une philosophie de « gardiennage » et ne sont pas centrés sur des soins optimaux pour les personnes âgées vulnérables.

La pénurie de personnel, majoritairement féminin, notamment de professionnels qualifiés, les conditions de travail très difficiles et le manque de formation sont parmi les principaux facteurs qui expliquent l'échec dans le domaine des soins de longue durée. Personnel temporaire et à temps partiel travaillant dans plusieurs établissements, agences de placement sursollicitées, heures supplémentaires obligatoires, va-et-vient entre « zones chaudes » et « zones froides » en sont des illustrations concrètes. Et que dire de la gestion des établissements ? Le modèle doit être revu. Une gestion à distance dans des mégastructures est loin d'être optimale, alors qu'une gestion décentralisée, de proximité, aurait permis d'éviter plusieurs dérives.

Bien sûr, d'autres facteurs peuvent expliquer la situation exacerbée par la pandémie. On a invoqué la vétusté des infrastructures où sont prodigués les soins : chambres à plusieurs lits favorisant la contamination, manque d'espace qui empêche la distanciation physique, absence de ventilation adéquate. On attend de nouvelles constructions et des rénovations dans les établissements existants. Le Québec a notamment promis des maisons des aînés, mais, à court terme, leur construction ne constitue pas une solution. Pour améliorer le sort des personnes âgées, il faut certainement plus que de jolis environnements physiques. Réformer et restructurer la composition de la main-d'œuvre et sa gestion est une condition *sine qua non*.

À court terme, les gouvernements à l'échelle mondiale ont élaboré quelques stratégies d'action depuis le début de la pandémie. On recommande, par exemple, que toutes les résidences de personnes âgées soient pourvues d'un plan d'intervention et qu'il y ait une personne clairement identifiée à la tête de chaque établissement, qui devra rendre des comptes. Le personnel devra être stable, des technologies devront relier les résidents à leurs proches et une politique devra permettre aux proches aidants de rendre visite à la personne hébergée de façon. Le gouvernement du Québec a pris en compte quelques-unes de ces recommandations dans son Plan d'action pour renforcer et assurer l'application des mesures de prévention et de contrôle des infections dans les milieux de vie, mais… il y a plus que la pandémie ! Il apparaît clairement qu'une restructuration de l'ensemble des soins de longue durée, tant dans le secteur public que dans le secteur privé (la deuxième vague ayant éprouvé les établissements privés), doit avoir pour but de corriger les négligences présentes depuis trop longtemps.

Quelles priorités pour une réforme des soins de longue durée?
Ce ne sont pas les données qui manquent pour aider à la prise de décision et améliorer les soins. Voici les priorités :

- Un financement suffisant et pérenne des soins de longue durée, provenant tant du gouvernement fédéral que des gouvernements des provinces, en vue d'atteindre des normes d'excellence minimales en matière de soins ;
- Une gestion de proximité des établissements de soins, décentralisée, qui rapproche les réalités du terrain d'une prise de décision rapide et efficiente faites par des leaders compétents qui doivent rendre des comptes ;
- Un niveau adéquat et constant d'effectifs, y compris une variété de professionnels formés (ce qui nécessite des réformes éducatives soutenues par les gouvernements), qui permet de répondre aux besoins des aînés tout au long de l'évolution de leurs besoins ;
- Un financement et un fonctionnement des soins à domicile qui ont été repensés en vue d'une meilleure intégration aux soins de longue durée.
-

La responsabilité des soins de longue durée est évidemment provinciale. Il semble par ailleurs que plusieurs pays font actuellement des efforts afin de créer des cadres de référence nationaux. Sans le soutien financier du gouvernement fédéral, les gouvernements des provinces auront du mal à se doter de toutes les ressources essentielles dans le contexte actuel. Les gouvernements ont donc un important rôle à jouer dans cette réforme urgente : ils doivent fournir un financement adéquat et mettre en place des normes fondées sur des résultats probants.

Un changement dans le mode de gestion des établissements qui, au Québec, à la suite de la réforme du système de santé de 2015, ont été regroupés en mégastructures, s'avère également indispensable : décentralisation, gestion de proximité, diminution des lourdeurs administratives, reddition de comptes. Il faut aussi revoir la composition des effectifs et la formation minimale requise du personnel, de même que la spécialisation en soins de longue durée, pour pouvoir fournir des soins de qualité aux aînés.

Si le Plan d'action du gouvernement du Québec pour une deuxième vague prend en compte quelques-unes de ces recommandations, la question de la main-d'œuvre, qui est cruciale pour corriger la situation au-delà de la pandémie, n'y est pas abordée dans son ensemble.

Force est de constater qu'il n'y a nul besoin d'une autre commission ou d'un énième rapport pour prendre dès maintenant des décisions éclairées qui modifieront en profondeur la façon de prendre soin des aînés vulnérables. Au Québec, la récente politique d'hébergement et de soins et services de longue durée et la

politique nationale pour les personnes proches aidantes offrent quelques lueurs d'espoir, mais encore faut-il que ces politiques puissent se traduire en plans d'action concrets assortis de mesures de résultats. Les données sont disponibles, les actions ont été suggérées; une volonté politique forte est maintenant nécessaire pour en arriver à modifier les paradigmes actuels dans notre société vieillissante et, ultimement, pour contrer l'âgisme qui y règne.

Increases in dementia will drive long-term care reform

Expect a jump in dementia patients as our population ages. LTC strategies with a focus on support for the community and caregivers will be needed.

FRED HORNE

Canada's philosophy and approach to supporting seniors in long-term care (LTC) needs a fundamental re-think, including how, why and when people access LTC. We've just begun to deal with the consequences of a broken system during the COVID-19 crisis, where system failures resulted in tragedy previously thought unimaginable. Facing this challenge head-on means confronting one of the greatest health policy challenges Canada has faced: understanding and acting upon the diverse needs of Canadians living with dementia, now and in the future.

The number of older Canadians who are expected to live with a cognitive disability is set to increase dramatically. The prevalence of dementia in Canada is projected to nearly double between 2020 and 2038, with rapid increases beginning around the year 2030. Already, in 2015/16, 69 per cent of residents in long-term care homes had dementia.

In light of this, LTC reform plans should reimagine the physical design of LTC institutions, how care is provided in those facilities, and find ways to expand and improve home-care services – an underused and much-preferred alternative to institutional care. Finally, and perhaps most importantly, Canada must adopt policies and provide funding to support informal caregivers: family and friends who are essential in any plan to allow seniors to age in safety and dignity.

Several reviews into the devastation that COVID-19 wrought upon residents, families and staff of Canada's long-term care and residential homes highlighted various underlying causes. They include underfunding, overcrowding, aging infrastructure, inadequate staffing and lack of standards. Although this retrospective analysis is important, none of this information is new.

Governments must make immediate investments to address infrastructure issues, improve sustainability and viability of the workforce and make more home-care options available. But increased spending alone is unlikely to change anything: spending on "more of the same" has been the customary response of governments to addressing most health-care issues, and Canadians have more or less accepted that approach without question. A 21st century approach is less rigid and more personalized – focused on funding needs rather than beds – in short, providing the right care in the right place at the right time in active partnership with patients and families.

Decades of inaction in LTC

As a staff member in two provincial health ministries, a consultant working with multiple and diverse stakeholders, a health policy analyst, a health minister, and now a caregiver, I've had nearly 40 years to

think about why it's so difficult to achieve transformation in health care that can benefit all Canadians. Many of the health and social services that support aging fall outside of the original list of Canada's universal health care services and are rarely considered as alternatives to institution-based models. Think about the challenges of accessing meal preparation, housekeeping and friendly visiting for an isolated senior as one example.

Like mental health, public drug coverage and other "orphans" of the universal health care in Canada, understanding LTC and the nature of change requires an honest assessment of how we arrived where we are. André Picard's new book, *Neglected No More*, covers the trajectory of LTC in Canada, from asylums and workhouses to houses of refuge, homes for the aged and ultimately today's long-term care and retirement living options. Picard shows how today's stated policy objectives supporting independence and more home-based care are at odds with the bias of the default institutional approach, now the norm. Attempts at reform in recent years have been largely focused on adaptations to institutional care. Where funding has increased for home care, the focus is largely nursing care with an understandable emphasis on freeing up much-needed beds in acute-care facilities.

A lot of money is on the table for LTC in the near future. For instance, in the 2021 budget, the federal government announced $3 billion over the next five years. The Ontario government announced an additional $4.9 billion over the next four years. Other provinces have announced billions more. What's lacking is clarity about the purpose and measurable outcomes associated with this funding that governments desire to achieve. How will the future be different? In this vein, adapting LTC to a rising number of Canadians with dementia is essential.

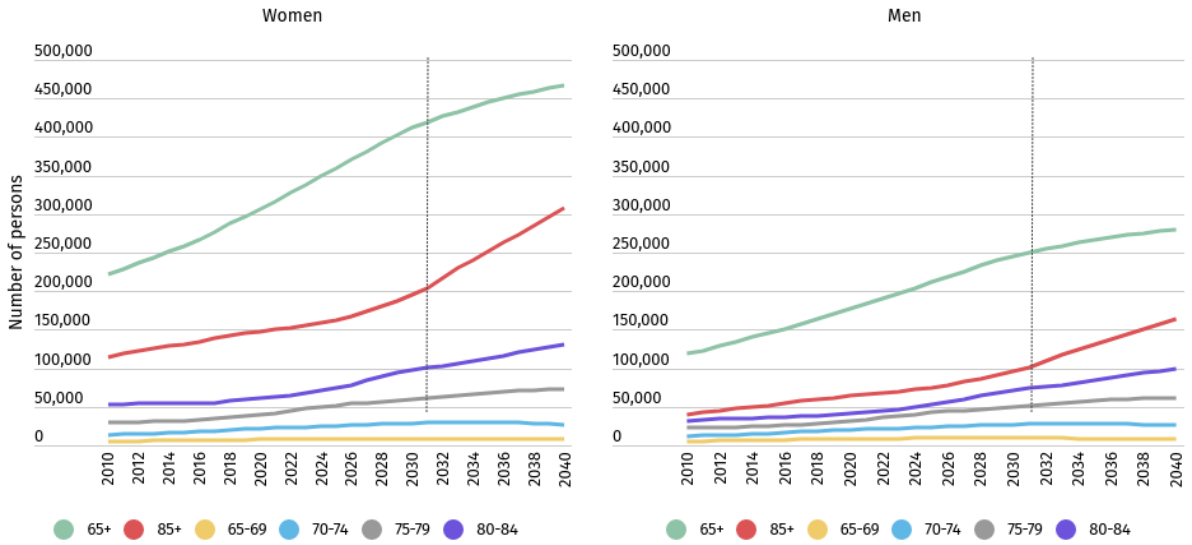
A focus on dementia within LTC – fast growth in cognitive disabilities in Canada

The main risk factor for dementia is age – it is more common after the age of 65. While dementia affects both men and women, women make up approximately 65 per cent of those living with dementia. Their higher proportion is due to their longer average life spans and, as emerging research suggests, their higher incidence of non-modifiable risk factors for dementia – such as genetics.

In a report published in April by the Institute for Research on Public Policy, researchers projected the future prevalence of dementia in Canada by assuming that the most recent prevalence rates of dementia by age and gender (from the Canadian Chronic Disease Surveillance System) would remain constant in the future. With these assumptions, Statistics Canada's medium-case demographic forecasts are used to project the number of Canadians likely to have dementia in each province and nationally.

The results show that the prevalence of dementia in Canada is expected to about double between 2020 and 2038, with sharp increases in prevalence beginning around the year 2030 (figure 1). By 2038, the number of women living with dementia over the age of 85 is expected to surpass the total number of men living with dementia across all age groups in all provinces. At a provincial level, dementia prevalence is projected to be highest in the relatively older provinces in central and eastern Canada.

Figure 1
Prevalence of dementia in Canada



Source: IRPP research calculations as described in text.

What to do?

Canada's policy-makers must prepare for this surge in demand for care and support. They must do so by finding the right balance between providing more and better options to receive care at home, and when that is no longer feasible, provide high-quality facility-based care. For those with dementia who can continue to live at home – and there are many – we need to ensure the health system does not prematurely admit them to institutional care because home and social supports for them and their caregivers are lacking. This will necessitate not only looking at additional funding for home care, but will force deliberate reallocation of funds from institutional to community-based care.

Delaying institutionalization through community-based supports will be critical from both a quality of life and affordability perspective.

There are already some promising signs that policy and funding may be moving in this direction. Alberta's recent continuing care review proposes shifting the distribution of services to a ratio of 70 per cent long-term home care and 30 per cent facility-based care from the current ratio of 61:39. The shift is expected to result in savings of $452 million in annual operating costs and a cumulative capital cost savings of $1.7 billion. Most importantly the review documents expected improvements in quality of care as a result. The challenge for Alberta and all provinces moving in this direction will be to ensure that these savings do not fall into the "black hole" of acute care but rather are strategically reinvested in high-value services that respond to the needs of seniors, especially those living with dementia.

Local governments will also have to prioritize community support services and access to appropriate care networks to reduce the impact of the aging population on provincial health-care services.

For those who need facility-based care, the way in which long-term care homes are built, designed and run must be re-imagined to better accommodate those with cognitive disabilities. This includes providing funding for behavioural support programs, hiring specialized staff, improving staff training and support, all with the goal of maximizing quality of life for residents with dementia.

Of course, caregiver support and resources will be critical. The quality of life we are able to offer growing numbers of citizens living with dementia will depend largely on how well we "care" for informal caregivers who deliver the vast majority of support for diagnosed with the disease, especially in the early stages.

The way forward

Although the shortcomings in LTC were obvious to informed experts and families with loved ones in care long before the pandemic, the difference now is that more people now recognize the lamentable state of seniors care as one of the most pressing issues in Canadian health care. With the growing prevalence of dementia in Canada, LTC reforms must account for the anticipated demographically driven increase in need.

André Picard rightly concludes that the starting point for a meaningful action is neither a lengthy bureaucratic review nor a political blame game, it's about articulating, committing to and ultimately "giving life to our values." A year from now, Canadians expect that LTC reform will be well underway. It's arguably the most important "call to action" since the first days of medicare in this country. Let's hope we're up to the challenge.