IRPP
Study

No. 59, February 2016
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Integrating Long-Term Care into a Community-Based Continuum

Shifting from "Beds" to "Places"

A. Paul Williams, Janet Lum, Frances Morton-Chang, Kerry Kuluski, Allie Peckham, Natalie Warrick, Alvin Ying

To address the growing long-term needs of Canada's aging population, governments should expand community-based care instead of simply increasing the number of residential care beds.

Pour répondre aux besoins grandissants de sa population vieillissante en matière de soins de longue durée, le Canada doit développer les services de soins communautaires au lieu d'ajouter simplement des lits en établissement.

Faces of Aging
Les défis du vieillissement

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IRPP Study is a refereed monographic series that is published irregularly throughout the year. Each study is subject to rigorous internal and external peer review for academic soundness and policy relevance.

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ISSN 1920-9436 (Online) ISSN 1920-9428 (Print)
ISBN 978-0-88645-351-0 (Online) ISBN 978-0-88645-352-7 (Print)

Summary

Health care systems conceived decades ago to cure episodic illness are being challenged by the health and social care needs of an aging population with long-term disabilities. In Ontario, for mostly political reasons, the government's response has primarily been to expand the supply of institutional long-term care beds, whereas the most pressing problem is a lack of community care resources that allow people to remain in their own homes and communities. The prevailing policy has entrenched a system that essentially equates care for older people with institutional care. Longer hospital stays for chronically ill patients who cannot be discharged, and their placement in residential long-term care because of a lack of other options, are examples of the resulting inappropriate and costly utilisation of resources.

Patients' inability to perform activities of daily living such as preparing meals or using transportation is the key reason they are being referred to residential long-term care. The authors of this IRPP study argue that if more community support were available, the tipping point at which patients with greater care needs require residential long-term care would be higher, and people would be able to stay at home longer.

Drawing on research in Ontario and overseas, the authors examine some promising community-based rural and urban initiatives. Through the lens of neo-institutional political theory, they analyze the hurdles encountered in attempting to scale up or replicate such initiatives.

The authors say that in order to successfully meet the growing care needs of an aging population, governments will need to fulfill three essential conditions. First, instead of simply expanding the supply of residential long-term care beds, they should plan for "places" within a community-based care continuum, which includes supportive housing, attendant care, adult day programs and home care. Second, they should establish the conditions that enable promising community-care initiatives to be replicated or expanded. Third, they should channel funds based on patients' needs, rather than on the location of care.

Breaking with historical pathways and setting a different course of action can be challenging. Legislation, regulations and funding mechanisms are difficult to change. Typically, care providers want to protect their market share, and decision-makers attempting to reallocate resources face opposition. But it can be done. Where progress is being made, the authors observe, there is a policy framework that supports a community-based continuum of places for care over the longer term.

Résumé

Les systèmes de santé conçus il y a plusieurs décennies pour guérir des maladies épisodiques sont aujourd'hui déstabilisés par l'ampleur des besoins sociaux et médicaux d'une population vieillissante souffrant d'incapacités persistantes. En Ontario, le gouvernement a réagi au phénomène de façon essentiellement politique, ajoutant des lits dans les établissements de soins de longue durée alors que le problème le plus criant est l'insuffisance de ressources en soins communautaires permettant aux personnes de continuer à vivre à la maison. Il a ainsi renforcé un système où les soins aux aînés sont synonymes de soins en établissement. Le tout résulte en une utilisation coûteuse et inadéquate des ressources, comme en témoignent les longs séjours à l'hôpital de malades chroniques qui ne peuvent rentrer chez eux et que, faute de mieux, on finit par placer en établissement de soins de longue durée.

L'incapacité des patients d'accomplir certaines activités de la vie quotidienne, comme la préparation des repas ou l'utilisation des transports publics, est la principale raison de leur placement. Selon les auteurs de cette étude de l'IRPP, de meilleurs services communautaires — pensons notamment au logement avec services de soutien, aux soins auxiliaires, aux programmes de jour pour adultes et aux soins à domicile — permettraient aux personnes ayant besoin d'assistance de rester plus longtemps à la maison et de retarder ainsi leur entrée en établissement.

En s'appuyant sur des recherches empiriques, les auteurs examinent de prometteuses initiatives communautaires rurales et urbaines menées en Ontario et à l'étranger et, à l'aide de la théorie politique néo-institutionnelle, ils identifient certains obstacles s'opposant à leur reproduction à plus grande échelle.

Pour répondre aux besoins croissants d'une population vieillissante, concluent-ils, les gouvernements devront remplir trois conditions clés : premièrement, créer des « places » au sein d'un continuum des services fournis par les collectivités au lieu de simplement ajouter des lits en établissement ; deuxièmement, créer les conditions propices à l'application ou au développement d'initiatives de soins communautaires ; troisièmement, axer le financement des soins sur les besoins des patients et non sur les endroits où les soins sont prodigués.

Certes, il sera difficile de rompre avec le passé pour adopter un nouveau cadre d'action. On ne change pas aisément les lois, réglementations et mécanismes de financement. Les prestataires de soins protègent leurs parts de marché, si bien que les décideurs qui souhaitent réaffecter les ressources se heurtent souvent à une forte opposition. Mais c'est possible, assurent les auteurs : partout où des progrès ont été accomplis, un cadre d'action est venu soutenir la création de placements en milieu communautaire.

Integrating Long-Term Care into a Community-Based Continuum: Shifting from “Beds” to “Places”

A. Paul Williams, Janet Lum, Frances Morton-Chang, Kerry Kuluski, Allie Peckham, Natalie Warrick, Alvin Ying

In Ontario, as in other jurisdictions nationally and internationally, health policy-makers face converging challenges. On the demand side is an aging population and the related shift from illness that can be cured on an episodic basis to chronic health and social needs that must be managed over the longer term (IHME 2013). On the supply side are increasingly stretched hospital-based health care systems. While recent data show that population aging is not in itself a major health care cost driver (CIHI 2014b), these systems are poorly equipped to respond to chronic care needs. As a consequence, they struggle with persistent problems of inappropriate and costly utilization. In Ontario, more than a decade of concerted effort to achieve transformative change and bend the cost curve has produced little reduction in the number of hospital beds occupied by individuals who no longer require hospital care but cannot be discharged because of a lack of community-based care. These individuals, described as alternative level of care (ALC) patients, are disproportionately older and may actually be harmed by lengthy hospital stays, increasing their odds of permanent placement in residential long-term care (LTC) (Walker 2011).

These system challenges are complicated by the continuing decline in informal caregiving caused by the weakening of the nuclear family, women’s growing participation in paid employment, and, particularly in rural areas, the out-migration of young adults (and potential caregivers) who are following education and jobs to cities (Fast 2015; Williams, Peckham, Kuluski, Lum, Warrick et al. 2015; Williams, Peckham, Kuluski, Lum, Morton-Chang et al. 2015). Given that unpaid family, friends and neighbours provide an estimated 70 to 90 percent of the everyday care that older persons require to remain at home, in the coming years there will be even greater demand placed on formal care systems, which will potentially undermine their sustainability (McNeil and Hunter 2014; Peckham et al. 2014; Peckham, Williams and Neysmith 2014; Warrick et al. 2014; Williams, Peckham, Kuluski, Lum, Warrick et al. 2015; Williams, Peckham, Kuluski, Lum, Morton-Chang et al. 2015).

How should health care policy-makers respond? The conventional wisdom is that the growing number of older persons (as well as children with complex medical needs and adults with disabilities who are also aging) will necessitate a proportional increase in the supply of LTC beds in nursing homes and homes for the aged. Indeed, lengthy wait times for LTC in Ontario have been cited as a reason why hospitals cannot discharge patients more quickly (OLTCA 2012).

An alternative view, backed by growing evidence and analysis, is that the real problem is a lack of community-based care. As insightful observers in Ontario and elsewhere have commented, older persons overwhelmingly wish to age at home. Nevertheless, because community-based care is fragmented and inadequate, care pathways too often lead to hospitals and residential

LTC (Donner 2015; Drummond 2012; McNeil and Hunter 2014; Ontario Seniors' Secretariat 2013; Sinha 2012; Walker 2011).

In this study, we consider the case of Ontario, Canada's second-largest and most populous province. Because residential LTC and home and community care (H&CC) exist outside Canada's medicare mainstream of publicly insured, medically necessary hospital and doctor services, there is extensive variation in what provinces and territories cover (Baranek, Deber and Williams 2004; Fierlbeck 2011; Marchildon 2013). To permit any depth of analysis, case studies need to be focused at the provincial/territorial level. Nevertheless, Ontario offers important insights into the challenges inherent in moving away from the approach of increasing the supply of LTC beds to one of developing a community-based continuum of places for care over the longer term. Other jurisdictions are now facing similar challenges as they aim to shift the balance of care toward the community (Billings 2013).

We argue that to meet the growing care needs of an aging population, health policy-makers should now decisively set a course toward providing LTC places — not only beds — as part of a care continuum, which includes supportive housing, attendant care, adult day programs and home care. All or most of these places could be located in the community. This is not a novel idea for Ontario. By the late 1980s, it was already well understood that an aging population would put additional strain and a potentially unsustainable burden on the province's publicly funded health care system. There was also considerable agreement that the solutions should allow people to remain in their own homes and communities and live as independently as possible for as long as possible. A series of policy papers commissioned by governments of different political stripes (Ontario Ministry of Health 1993; Baranek, Deber and Williams 2004) emphasized the need to build a community-based continuum of care. Yet, in the early 2000s, the province invested in 20,000 LTC beds while constraining funding for H&CC.

Through this choice, Ontario reinforced a policy mindset that equates care for older persons with institutionalization and, in doing so, creates a legacy of fragmented and inadequate H&CC. Even though provincial spending on home care has increased faster in recent years than spending on hospitals and residential LTC (Auditor General of Ontario 2015), recent reports continue to characterize care in the community as inconsistent and inadequate (Donner 2015). In response, provincial policy-makers have declared that fundamental reforms are needed (Government of Ontario 2015b), including the possible restructuring of provincial home care agencies within a regional health authority model (Government of Ontario 2015c).

This brings us to the second part of our argument: any such reform must aim not just to restructure providers or increase service volume but also to change the policy discourse and its underlying mindset. Instead of seeing residential LTC beds as the ultimate destination for growing numbers of older persons, policy-makers need to see them as only one, albeit important element of a broader continuum of care places that will allow older persons and their informal caregivers to remain closer to home.

This study is presented in four sections. In the first, we highlight key events in Ontario's historical policy pathway. We contend that while justified as a response to the needs of an aging population, major policy decisions, particularly the decision to expand the supply of institutional beds while constraining community-based resources, were political.

In the second section, we consider the costs and consequences. As findings from research projects conducted by our team across Ontario demonstrate, an inability to perform instrumental activities of daily living (IADLs) — such as preparing meals or using transportation or the telephone — remains a key driver of referral to residential LTC. Nevertheless, for more than a decade, access to community-based prevention and maintenance (known as "before-the-fact" care) has been eroding, as home care resources have been redirected toward posthospital ("after-the-fact") care. We offer three vignettes of promising community-based care initiatives in different regions of Ontario that proactively address the needs of older persons and their caregivers where they live; however, each initiative is facing hurdles as it attempts to scale up and spread.

In the third section, we look to the international literature. As recent research across the European Union clarifies (Billings 2013), efforts to build coherent community-based systems of care over the longer term are never easy, since they must overcome persistent divides between formal health care and social (nonmedical) care, and between formal care and informal care. Where progress is being made, it is usually in the context of an enabling policy framework that supports the creation of places within a continuum of care.

In the fourth and final section, we identify the essential elements of such a framework. These include a clear statement that the goal is to maintain older persons and their caregivers as independently as possible for as long as possible in their own homes and communities — if that is where they want to be. Residential LTC beds are no longer to be considered the ultimate care destination.

Where We've Been: Ontario's Historical Policy Pathway

Our analysis draws on neo-institutional political theory. While this theory has many variants, all argue that institutions matter, and that ideas that dominate at different historical points, and the vested interests they represent, become crystallized in legislation, funding mechanisms, formal and informal policies, bureaucratic regulations, and other political institutions (Hacker 2004; Hutchison, Abelson and Lavis 2001; Morton-Chang 2015; Pierson 1993). Together, institutions embed a historical policy pathway, which makes transformative change difficult to achieve.

Policy stasis and policy change

In the Canadian literature, Tuohy (1999) applies neo-institutional theory to compare the pace and direction of health policy change in three jurisdictions: the UK, the US and Canada. Tuohy contends that in the UK, change has been driven by a powerful national government. In the US, it has been driven by the rise of health care corporations. In Canada, change has been comparatively slow because medicare's underlying implicit bargain, while acknowledging the legitimate role of public governments to fund essential medical care, leaves control over delivery largely in the hands of the organized medical profession. In Ontario, framework agreements negotiated directly between the provincial government and the Ontario Medical Association require professional consent for any substantive reform of the organization and conduct of medical practice. Reflecting this, reform and change in key areas such as first-contact physician primary care have been slow, focusing more on how doctors are paid (for example, through alternatives to fee-for-service such as capitation) than on how care is accessed and delivered (for example, through 24/7 interdisciplinary teams). Recent data show that Canada continues to do poorly compared with other countries in providing timely access to primary care for older persons, leading to avoidable use of hospital emergency departments (CIHI 2014a).

By comparison, Baranek, Deber and Williams (2004) observed that developments in the policy subfield of H&CC during the 1980s and 1990s in Ontario lacked similar constraints and were highly volatile. Successive provincial governments have had considerable scope to impose their widely diverging and often contradictory political agendas because, first, access to publicly funded home care is not required under Canadian medicare, second, providers remain relatively small scale and unorganized, and third, older persons with chronic health and social needs and their informal caregivers are among those least likely to be mobilized politically,

For example, while Ontario included home care under the Ontario Health Insurance Plan during the 1980s, it was removed from universal coverage in the 1990s with little public awareness or debate. Similarly, while the provincial Liberal and New Democratic Party governments preferred not-for-profit delivery, home care was subsequently put to market by a Progressive Conservative government, which aimed to introduce competitive market forces into health care and began by doing so in the area of H&CC, where it faced little overt resistance (Deber and Williams 1995). And when, in the late 1990s and early 2000s, home care agencies publicly voiced concerns about a growing gap between needs and resources, executive directors and boards were summarily fired, to be reappointed if they toed the government line.

Home and community care: A patchwork quilt

The result is that H&CC, which emerged historically as a collection of community-based initiatives to meet local needs, remains a patchwork quilt of programs and services, each with its own entry point, assessment process, eligibility criteria, service offerings, service caps and users fees. As recent expert reports have observed, this results in continuing challenges for older persons who wish to age at home and their caregivers, increasing the likelihood of default to hospital and institutional care (Walker 2011; Donner 2015).

As it now stands, Ontario residents have the right to an assessment by one of the province's 14 publicly funded, regionally based Community Care Access Centres (CCACs). CCACs contract out the bulk of home care services — such as nursing, social work, rehabilitation and personal care — to for-profit and not-for-profit providers on a competitive basis (Auditor General of Ontario 2015). CCACs do not charge user fees, nor do they guarantee that eligible individuals will receive services; there is no universal entitlement to home care. Even medically necessary services such as nursing may or may not be accessible, depending on home care budgets (which vary substantially on a per capita basis across the province), eligibility criteria (which increasingly prioritize people with very high clinical needs) and waiting lists (which between October 2013 and October 2015 included more than 5,000 hospital ALC patients waiting for CCAC home care) (Auditor General of Ontario 2010, chap. 3.04; 2013, chap. 4.04; 2015; Access to Care, Cancer Care Ontario 2015a). CCACs also control queues for LTC beds and in some, but not all, areas of the province, waiting lists for adult day programs and supportive housing.

Individuals who need H&CC may also attempt to access it through a constellation of mostly smaller-scale, local, not-for-profit, volunteer-driven community support services agencies (CSSAs). CSSAs vary widely in terms of access, service capacity and eligibility, and they tend to be thin on the ground in rural and remote areas. While CSSAs focus on nonmedical supports for IADLs (such as meal preparation and transportation), some offer a single service (such as Meals on Wheels), while others offer a more extensive menu that might include adult day programs, Alzheimer’s day programs, supportive housing and attendant care, congregate meals, respite, transportation, homemaking, home maintenance, security checks, home visits, and caregiver support and counselling. Like CCACs, CSSAs provide no service guarantee; unlike CCACs, they are required to charge user fees (usually based on a sliding scale geared to income), creating a perverse economic incentive toward “free” hospital and doctor care.

Alternatively, individuals who can afford it can purchase home care from commercial providers, paying market prices. In contrast to the medicare mainstream, where there is an effective ban on the private purchase of insured services, in H&CC, even medically necessary services such as nursing and rehabilitation care (albeit not medically necessary doctor services) can be purchased commercially. When the ability to pay is exhausted, or when care needs exceed what is available through commercial providers (for example, in private retirement residences), individuals can revert back to the publicly funded system.

When needs outstrip local H&CC capacity (more likely in rural and remote areas, where access to community-based supports is more limited), Ontario residents may be referred to residential LTC by their local CCAC. In 2014, the province funded and regulated 78,120 LTC beds in a total of 627 municipal homes for the aged, charitable homes and nursing homes (both for-profit and not-for profit). Funding for an LTC bed (aside from capital costs) is just over $160 per diem, including a user copayment for basic accommodation of about $57, which may be reduced for those with limited economic means (OANHSS 2015).

Although recent provincial governments have not increased the supply of LTC beds, they have made efforts to shore up existing capacity. In October 2014, in response to public concerns about the quality of care in some facilities, the Ontario government announced a capital redevelopment plan for LTC homes, aiming to bring them up to current standards (OLTCA 2015).

In principle, therefore, Ontario would seem to have in place all the elements of a broad continuum of care. However, as recent expert reports have concluded (Donner 2015; Walker 2011; Sinha 2012; Drummond 2012), in practice, these different elements continue to operate relatively independently with no overall coordinating strategy and few mechanisms to integrate client care across providers and settings. In Ontario, individual provider organizations — including CCACs, CSSAs, LTC homes and hospitals — continue to operate under their own independent governance structures. Each is accountable for the services it provides and for the financial integrity of its organization; none is responsible for ensuring that older persons and caregivers get the mix of services they need to remain in the community.

For example, while many CCAC care managers can and do collaborate effectively with other formal providers and informal caregivers to coordinate services, they directly control and are accountable only for CCAC services (such as home nursing); they can only refer to services offered by CSSAs (such as medication checks, transportation to medical appointments or caregiver respite), even if these are crucial elements of care plans. And, because CCACs contract out most services to third-party providers, they face continuing challenges in ensuring the quality and continuity of services provided in the home (Auditor General of Ontario 2013, 2015).

Similarly, while many CSSA care managers can and do collaborate effectively with CCACs and other community providers to coordinate care on behalf of clients and caregivers, their control and accountability is limited to the services they directly provide. In large urban areas such as Toronto, efforts have been made to coordinate intake and referral across more than 30 different CSSAs (for example, Toronto’s Community Navigation and Access Program[1]), and in some regions, a lead agency has been tasked with the responsibility of managing a particular service such as transportation (for example, Toronto Ride’s SPRINT Senior Care[2]). While promising, such initiatives tend to be the exception (Donner 2015).

Cross-subsystem change

Even if prevailing arrangements are challenging from the viewpoint of the client and caregiver, neo-institutional theory predicts that once these arrangements are institutionalized through legislation, regulations, funding mechanisms and so on, they will become progressively more difficult to change. Not only will providers line up to protect their market share, but funders and decision-makers will be faced with increasingly difficult and contestable decisions if they attempt to reorganize providers or reallocate resources.

Nevertheless, change can still occur. Although it tends to be less well developed, a rising variant of institutional theory looks at the dynamics of cross-subsystem policy change. While this literature is far from unified, it conceives of policy broadly as involving systems and subsystems of state and nonstate actors, who, in a more or less coordinated manner, mobilize formal and informal arrangements within specific issue areas or sectors (Howlett, Ramesh and Perl 2009). Policy subsystems may be composed of integrated policy communities with stable and restricted membership and clearly shared goals, or more diffuse issue networks with less stable patterns of membership and activity. However constructed, subsystems advance ideas about a particular set of issues and develop, implement, evaluate and perpetuate policy arrangements through a particular set of political institutions and policy instruments, be they informational, financial, organizational or authoritative.

For H&CC, which has a common boundary with the much larger and more powerful health care sector (referred to here as the “medicare mainstream”), the dynamics of cross-subsystem policy change seem particularly relevant. Different subsystems may draw on incompatible ideas, deploy policy instruments in inconsistent ways, utilize different political institutions in different venues (Baumgartner and Jones 2002) and possess different degrees of political capital when seeking to resolve disagreements in their favour (Jochim and May 2010). Subfields like H&CC may be able to benefit from policy resources available in the adjoining health care field, or they may have their own resources cannibalized by a more powerful neighbour (see Baumgartner and Jones 2002; Béland 2005, 2007; Kay 2005; Jones and Jenkins-Smith 2009; Jochim and May 2010; Schmidt 2011).

In the case of Ontario, change in H&CC has often been driven by health system needs. For example, while budgets for nonclinical community supports were historically controlled by the ministry responsible for community and social services, they were moved during the late 1990s to the health portfolio, thus boosting total health care budgets, at least on paper, but also making H&CC resources more accessible for health care projects (Baranek, Deber and Williams 2004). As hospital and doctor services have experienced the fiscal pinch of successive provincial attempts to constrain expenditures, H&CC resources have increasingly been diverted away from aging at home and applied to curing hospital problems, particularly stubborn ALC rates (Keven 2009; OACCAC 2007).

Of course, such boundary issues are not restricted to formal care systems; they cascade down to informal caregivers, who, it is important to recall, provide the bulk of the everyday personal, instrumental and emotional support required to maintain the well-being and independence of persons of all ages who cannot manage on their own (Fast 2015; Peckham, Williams and Neysmith 2014; Williams, Peckham, Kuluski, Lum, Warrick et al. 2015; Williams, Peckham, Kuluski, Lum, Morton-Chang et al. 2015). Yet, if resources are concentrated on after-the-fact health care fixes, informal caregivers and their social networks may be left to pick up an even heavier before-the-fact care burden in the home. Not only are worn-down caregivers more likely to agree to a hospital or institutional admission for a cared-for person in the first place, they are also less likely to support discharge back to the community, making ALC problems all the more insurmountable (Peckham et al. 2014; Warrick et al. 2014; Williams et al. 2014; Williams, Peckham, Kuluski, Lum, Warrick et al. 2015).

Shifting political sands

How did we come to this point? By the early 1980s, the challenges of population aging were already well understood: growing numbers of older persons would require more and different care in the future, and their needs could put additional and possibly unsustainable strain on hospital-based health care systems already struggling to contain rising expenditures. It was also recognized that the H&CC sector, which had evolved as an ad hoc mix of mostly local, small-scale services and providers, was not well equipped to meet growing and more complex needs (Baranek, Deber and Williams 1999); it would have to be shored up as a policy field in its own right.

The first concerted attempt to do this emerged from the Liberal government of David Peterson elected in 1985. In 1986, his government proposed a one-stop-shopping model that would see in-home professional and homemaking services remain under provincial health insurance plan coverage, with public funding for nonmedical community supports continuing under the auspices of the provincial ministry responsible for community and social services. However, access to services would be coordinated by a new provincial agency that would broker services on behalf of clients (Ontario Office for Senior Citizens’ Affairs 1987).

Implementation of this model lagged. In 1990, the year of the next provincial election, it was supplanted by a new government proposal to establish service access organizations, provincial agencies that would be single points of access, referral, assessment and coordination for H&CC. Regional budgets would facilitate a rebalancing of resources from professional home care to preventive community supports (Liberal Party of Ontario 1990).

The electoral defeat of the Liberals and the unexpected success of the left-leaning, labour-supported New Democratic Party (NDP) led by Bob Rae brought a new political perspective. Beginning slowly, the new NDP government picked up the brokerage mechanism of the Liberal model, tweaked it a bit and printed it on recycled paper. Henceforth, the government would give preference to not-for-profit delivery, as well as training and manpower adjustment for workers (Baranek, Deber and Williams 1999).

This new model was in turn overrun by broader political forces. In 1993, facing a massive fiscal deficit, the NDP government introduced its infamous social-contract initiative, which imposed a wage freeze and mandatory unpaid days off (“Rae Days”) on public sector employees, thus eroding its traditional base of support in organized labour. In 1994, in an attempt to shore up community-based care and regain labour support, the NDP proposed the creation of multiservice agencies (MSAs) that would effectively remove home care from the provincial health insurance plan (ostensibly to avoid medicalization) (Baranek, Deber and Williams 2004) and extend provincial command-and-control over all publicly funded H&CC, with most services to be delivered by unionized employees. However, because the MSAs would also eliminate many existing community-based providers, these providers now formed an anti-NDP alliance along with the provincial medical association. Although the NDP government passed Bill 173, *An Act Respecting Long-Term Care*, it came too late, as the provincial election of 1995 swept to power the market-oriented Progressive Conservative (PC) Party of Mike Harris.

Even as these events occurred, two parallel policy developments were directing new demands at the community. The first was the NDP’s announcement, early in its term, that it would not issue any more LTC bed licences or provide new funding for LTC. It argued that LTC should not be a first choice of care for older persons and that residential care facilities had sufficient space for people who had to be there. This argument was hotly rejected by the Ontario Nursing Home Association, which represented commercial providers: it argued that it was far easier to find seniors in the community who required LTC beds than it was to find seniors in LTC beds who could have been supported in the community. The association also emphasized, correctly, that if the number of LTC beds were constrained in the face of an aging population, the ratio of beds to seniors would decrease, requiring the government to spend additional money on H&CC (Montigny 1997, 136).

Second, the provincial government also began to put concerted pressure on acute care hospitals to reduce bed numbers on similar grounds — that is, it asserted that unnecessarily high numbers of hospital beds resulted in unnecessary and costly hospital utilization. During the NDP’s tenure, the number of acute care hospital beds declined by up to a third in major urban centres such as Toronto, resulting in shorter hospital stays and earlier discharges, thus shifting an additional and increasing burden onto the community (Gray 1995).

The Community Care Access Centres

In 1996, the newly elected PC government reversed the NDP’s policy direction. It announced that it would use the NDP’s legislation (but clearly not its intent) to introduce a managed-competition model for home care as a means of injecting competitive market forces into the sector and achieving the highest quality at the best price. The promise was that lower costs achieved through competition would pay for new services to meet rising demand. The government subsequently created 43 Community Care Access Centres (later amalgamated into the current 14 CCACs) to serve as regional single points of access for home care as well as for placement to residential LTC (Randall and Williams 2006).

CCACs represented a dramatic departure from the logic of the previous home care programs. Rather than relying on contracts negotiated collaboratively with established not-for-profit providers such as the Red Cross and the Victorian Order of Nurses, the PC reform required that contracts be awarded on the basis of competitive bidding between for-profit and not-for-profit providers. The entry of new for-profit providers was encouraged, since these enterprises would not be constrained by existing pay equity requirements or union collective agreements. Moreover, CCACs would no longer be permitted to provide services directly. Instead, they had to divest themselves of experienced in-house staff who would then, presumably, organize to bid for service contracts (Williams et al. 1999). However, particularly in low-volume, specialized areas like rehabilitation and pediatric home care, and in rural areas where the supply of willing providers was low, prices reportedly rose, prompting reductions in service volume (Randall and Williams 2006; Spalding, Hayes and Williams 2002). Regardless, from a funding perspective, the CCAC reform offered a major advantage; now out of universal health insurance coverage, home care budgets could be capped.

By the late 1990s, CCAC budget overruns were making it obvious that market mechanisms alone would not solve the problem. In response, the province first provided selective CCAC budget enhancements and bailouts; it then insisted that the CCACs manage within their means. In 1999, it introduced *Ontario Regulation 386/99*, which forced CCACs to reduce service volumes and tighten eligibility criteria (Caplan 2005); these criteria directed CCACs to determine whether family and friends or others were able to provide care (Ontario Health Coalition 2003). In 2001, the government announced a funding freeze at 2000-01 levels, leaving an estimated $175-million shortfall between demand and available services (Ontario Health Coalition 2003).

When some CCACs protested publicly about their increasingly stretched resources, the government enacted Bill 130, the *Community Care Access Corporations Act*. This bill effectively fired the volunteer boards and executive directors of all CCACs, left it to the government to reappoint their successors (who would presumably be more willing to toe the party line) and gave the government the right to appoint a supervisor to take over any troublesome CCAC at any point in the future (O’Brien 2001).

Of course, other health care sectors had also felt the government’s bite. In a bid to contain hospitals, in 1996, the Harris government established the arm’s-length Health Services Restructuring Commission (HSRC) with a lopsided two-part mandate: while the commission could and did direct hospital amalgamations and closures, it could only provide advice and make recommendations about restructuring and reinvesting in other parts of the health care system. Nevertheless, the HSRC understood the interconnectedness of its mandate: “We are keenly aware… that continued implementation of our directions to hospitals must be matched closely with timely reinvestments in other services (notably home- and long-term care),” and that “bold steps must be taken quickly to make the elements of the health care system in this province (hospitals, home care, long-term care, primary care, etc.) more integrated and better coordinated” (HSRC 2000).

Beds or places?

The HSRC also generated valuable analysis and insight highlighting the choice between LTC beds and places. For example, a 1997 consulting report conducted for the HSRC emphasized that planning must take into account “the entire continuum of long-term care services in Ontario,” including residential care beds but extending as well to places in supportive housing and attendant care, as well as equivalent places in the community such as adult day programs, and home care. It noted that the “most significant” advice it had received from a panel of experts from across North America related to the need to establish an integrated system of care that would maximize “the social, psychological and physical functioning and the health status of each individual”; facilitate “downward substitution” to the “least restrictive, least intrusive setting possible”; and support families “in their role as caregivers.” In addition, the report stated that “the funding system for long-term care should be unified and funding levels should be determined in relation to the needs of the resident, not the location of care” (HayGroup 1997). The HSRC bought into this advice: in its final legacy report, it reiterated that in setting the balance between residential beds and community-based nonbed places, the number of beds should be minimized (HSRC 2000).

Nevertheless, in 2000, the PC government moved in a different direction. It established a long-term care redevelopment project office to take on operational responsibility for developing or retrofitting 20,000 LTC home beds, the majority of which were eventually awarded to for-profit nursing home chains, increasing their dominance of the sector (Auditor General of Ontario 2002; Berta, Laporte and Vivian 2004). While there was little evidence that this number of beds was justified (Coyte et al. 2002), as Morton-Chang notes (2015), “once built, the new beds needed to be filled.” Government constraints on H&CC funding helped by limiting community-based care options as did regulations “to ensure existing beds in LTC homes are fully utilized.” These regulations required LTC-eligible home care clients (with the exception of those experiencing crisis) to choose as many LTC homes as they wished, although under the “three LTC home rule” that took effect in May 2002, the CCAC would forward only three “approval requests" to LTC home operators. Clients then had to accept an offer of admission to an LTC home of choice within one day or be removed from the waiting list. Moreover, the time frame for actually moving to LTC was short: a person offered a bed "will have five days to move in, not counting the date of notification" (Ontario Ministry of Health and Long-Term Care 2006, chap. 11).

Succeeding provincial governments have resisted further expanding LTC bed capacity, and, as noted, they have increased funding for H&CC faster than for other sectors. Nevertheless, demand has also continued to grow (Auditor General of Ontario 2015), with clients who are not gravely ill increasingly likely to find themselves on waiting lists or deemed ineligible for the publicly funded home care services they once had (Donner 2015). Moreover, H&CC remains fragmented, with over 800 CSSAs providing services under separate accountability agreements in addition to the over 160 for-profit and not-for-profit home care service providers contracted to Ontario's 14 CCACs under 260 separate contracts (Auditor General of Ontario 2015). Even when needed H&CC services are present at the local level, they can be difficult to access and coordinate.

Further complicating this picture, the managed competition process used by CCACs to contract service providers remains frozen. In 2004, motivated by public concerns that market forces had driven down quality without evidence that prices had been similarly depressed or that access had improved, the government halted the competitive bidding process for home care services (Aronson, Denton and Zeytinoglu 2004; Auditor General of Ontario 2015, 51). In 2005, an extensive provincial review concluded that while managed competition should stay, employer reliance on elect-to-work (treating home care workers as casual labourers without employment rights or benefits in a bid to push down prices) should be eliminated because it did in fact compromise quality (Caplan 2005). Bidding was restarted in 2007 but then halted once more in 2008, when two established not-for-profit agencies in Hamilton, Ontario, were eliminated from the bidding process, raising concerns among clients that they could lose their existing support workers whenever the competitive process resulted in a change of providers (Auditor General of Ontario 2015, 51). Since then, home care contracts and provider market share, as well as the often considerable discrepancies in rates paid to different providers for the same services, have remained static. Even at this level, change in H&CC has been curtailed (Born and Laupacis 2012; Auditor General of Ontario 2015).

Whatever happened to aging at home?

In any case, by the early 2000s, health care policy-makers had become increasingly preoccupied with hospital wait times, which had emerged as a lightning rod for debate on the future of universal medicare. Although home care had been identified by a high-profile national commission in 2002 as "the next essential service" (Romanow 2002), the federal/provincial/territorial "10-year plan to strengthen health care," announced in 2004, gave priority to consigning billions of new federal health care dollars to the reduction of hospital wait times in five narrowly defined areas: cancer treatment, heart disease treatment, diagnostic imaging, joint replacements and sight restoration. Any improvements to home care were to be limited to short-term acute, mental health and end-of-life care (Government of Canada 2004).

Perhaps not surprisingly, problems of hospital flow-through quickly overran a subsequent Ontario initiative to bolster preventive and maintenance H&CC capacity. Unveiled in 2007 by a Liberal majority government, the province's four-year, $1.1-billion Aging at Home (AAH) Strategy promised to expand community living options "to enable people to continue leading healthy and independent lives in their own homes." Included were IADL supports such as meal preparation, transportation, shopping, friendly visiting, snow shovelling, adult day programs, and caregiver relief and respite (MOHLTC 2007).

This policy direction was short-lived. While funding for nonmedical community supports had been moved from the Ministry of Community and Social Services to the new Ministry of Health and Long-Term Care in 1999, and thus effectively put into the same funding pot as hospitals, now competition became more direct, since AAH was administered by Ontario's newly created system of 14 Local Health Integration Networks (LHINs), which were also responsible for managing hospital budgets (Bhasin and Williams 2007; Torgerson 2005). The LHINs quickly came under provincial pressure to use AAH's pot of new money to deal with hospital problems. In 2009-10, less than a year after the strategy's rollout, the province ordered that 50 percent of AAH money be used to discharge ALC patients; in 2010-11, 25 percent of the AAH money was held by the ministry for its own provincial-level ALC initiatives, with the remaining 75 percent to be used to address ALC problems at the LHIN level (Government of Ontario 2010).

This upward redirection of resources appears to have had little of its intended impact: in July 2011, the Ontario Hospital Association reported that 14.3 percent of provincial inpatient hospital beds were classified as ALC; four years later, in September 2015, the provincial ALC rate remained at 14.2 percent (Access to Care, Cancer Care Ontario 2015b). Nevertheless, this redirection did not go unnoticed. When asked in 2011 what happened to his government's Aging at Home Strategy, Premier Dalton McGuinty observed that in the future, home care resources "won't be gobbled up by the health system" (Goar 2011).

As Morton-Chang points out (2015), similar cross-boundary forces were also at play in community-based dementia policy. While mounting evidence of the rise of dementia prompted the province to introduce a wide-ranging and proactive Alzheimer's strategy in 1999, this strategy was also short-lived, terminating in 2004. The subsequent Alzheimer's strategy transition project (2004-07) anticipated the scaling down of investments even as needs grew. In 2010, the province introduced Behavioural Supports Ontario (BSO), a project that targeted responsive behaviours such as grabbing, screaming and verbal or physical aggression linked to cognitive impairment. Initially designed as a vehicle for building an "integrated network for people, services and supports, across the continuum of care," its focus soon shifted from maintaining people with responsive behaviours in the community, to managing them once placed in residential LTC (Morton-Chang 2015).

Where We Are Now: Default to Beds

As we noted in our introduction, a series of expert reports have documented the costs and consequences of a historical pathway that has left H&CC fragmented and underresourced.

To review briefly, these include Walker’s 2011 analysis of Ontario’s persistent ALC rates, which emphasized that while high rates are often presented as a hospital issue, the root problem is a lack of community-based care alternatives. Without prevention and maintenance in the community, older persons, most of whom wish to remain at home, can instead default to hospitals and then to permanent placement in residential LTC (Walker 2011, 6).

The expert reports also include Sinha’s extensive 2012 review, which similarly observed that current systems of episodic health care are not well equipped to respond appropriately or cost-effectively to the growing numbers of older persons with multiple chronic health and social needs, who are also among the most intensive users of medical care. To ensure that older persons can stay in the community longer, and that the province does not go bankrupt, Ontario requires a continuum of health and social care that promotes health and wellness; strengthens access to community-based primary care and H&CC; promotes senior-friendly hospitals with timely discharge to home and community; and improves capacity within residential LTC to support short-stay and restorative options and discharge back to the community. Sinha also paid attention to the crucial role of informal caregivers, whose presence “is the reason why so many older Ontarians have been — and will remain — able to age in their places of choice for as long as possible” (Sinha 2012, 15).

A pair of 2015 reports added more fuel to the policy fire. The first, by a provincially commissioned expert panel (Donner 2015), likewise concludes that while Ontario has many excellent programs to keep people at home “if that is where they want to be,” it still does not have a coordinated system strategy. The result is too much variability in access to services, too little accountability for outcomes and a system that “fails to meet the needs of clients and families” (Donner 2015, i). This report also acknowledges the crucial role of informal caregivers, who, it notes, provide about seven hours of help for every two hours of professional care; without these caregivers “our health care system could not sustain current levels of care in the community” (Donner 2015, i).

The second, released in September 2015, is a special report by the Auditor General of Ontario on CCACs. Sparked by political concerns about rising CCAC CEO salaries and apparently high administrative overhead (estimated at just under a third of total CCAC budgets), this report presents a critical perspective on the operation of these provincially funded home care agencies. Among its observations, the report confirms that since 2008, the freezing of the competitive bidding process used by CCACs to contract home care providers has made it almost impossible to change the terms and conditions of existing service contracts or to address continuing inequalities in what providers are paid, even for the same services (Auditor General of Ontario 2015, 51).

In response, the Ontario government has promised broad-scale change. Its road map for home and community care (Government of Ontario 2015d) lists initiatives including the development of a statement of core values to guide the transformation of the sector. It has also given notice that CCACs may be subsumed under Ontario’s regional health authority structure; LHINs, which now fund and administer providers including hospitals, LTC facilities, CCACs and CSSAs, would thus themselves become providers, presumably taking on CCAC home care staff and provider contracts, albeit without the current CCAC management structure. A second direction may prove more difficult: the Minister of Health and Long-Term Care recently observed that to pay for home care improvements, money will have to be diverted away from the physician payment pool (Ferguson and Boyle 2015).

Shifting the tipping point for long-term care: The balance of care

While the extent of future reform and change remains to be seen, the costs and consequences of historical patterns of fragmentation and stasis have been documented by balance of care (BoC) research projects conducted by the authors in 11 of Ontario's 14 LHIN regions (Williams, Challis et al. 2009; Williams, Watkins and Kuluski 2010; Morton-Chang 2015).

BoC projects adapt a planning tool developed in the UK by David Challis and his colleagues at the Personal Social Services Research Unit, University of Manchester (Challis et al. 1999; Challis and Hughes 2002; Clarkson, Hughes and Challis 2005; Hughes and Challis 2004; Tucker et al. 2008). While, as observed earlier, conventional projections of the care needs of an aging population often assume that a greater number of older persons will require a proportionately greater number of residential LTC beds, the BoC emphasizes that the need for such beds will be determined as well by supply-side factors such as access to appropriate, cost-effective community-based care and support from informal caregivers. Other things being equal, where needed formal and informal community-based supports are more accessible, the needs tipping point for residential LTC beds will be higher, and older persons will be more likely to age at home or in homelike settings, even those persons with relatively high levels of need. Conversely, where needed community-based supports are less accessible, the needs tipping point will be lower, and older persons will be more likely to require residential LTC, even at lower levels of need (Williams, Challis et al. 2009; Williams, Kuluski et al. 2009; Williams, Deber et al. 2009; Kuluski, Williams, Berta et al. 2012; Kuluski, Williams, Laporte et al. 2012; Bolin, Phillips and Hawes 2006).

Here, deliberate policy decisions, and not just naturally occurring demographic change, can play a key role. One excellent example, highlighted by UK BoC researchers, was the residential allowance introduced in the 1980s by the market-oriented Thatcher government in the UK. This allowance was, in effect, an economic rebate to local authorities for placing older persons in independent sector (that is, commercial) care homes. By making placement in residential care less costly and redirecting resources away from community-based prevention and maintenance, this incentive effectively depressed the needs threshold or tipping point for LTC admission and made it increasingly difficult to prevent potentially avoidable admissions in the future (Pollock et al. 2006; Clarkson, Hughes and Challis 2005).

Of course, as UK BoC projects have clarified, tipping points may also vary locally due to differences in the balance of institutional and community-based resources present in any defined geographic area and processes for managing access to these resources. This is pertinent to the UK, where local councils play a key role in providing nonmedical social supports for older persons (Challis and Hughes 2002). It also pertains to Ontario, where, as recent reports have emphasized, access to H&CC services may vary considerably within and across regions and be particularly problematic outside of major urban centres (Sims-Gould, Martin-Matthews and Keating 2008; Donner 2015; Auditor General of Ontario 2015).

Ontario balance of care project findings

To investigate how tipping points for residential LTC vary at the local level and why, Ontario BoC projects analyze current assessment data (using the Resident Assessment Instrument — Home Care) for home care clients in a given CCAC catchment area, including those waiting for LTC. They then engage with steering committees and expert panels of local health care leaders and experienced front-line care coordinators from across the care continuum (for example, from hospitals, LTC, home care, community supports, supportive housing and primary care) to estimate the extent to which coordinated H&CC packages, if accessible, could maintain older people at various levels of assessed need safely and cost-effectively in the community (Williams et al. 2009a).

For example, an early project in the Toronto Central LHIN — serving Canada’s largest urban area — estimated that between one third and one half of individuals then waiting for LTC could be diverted safely and cost-effectively to care in the family home or in supportive housing if adequate H&CC resources were available. However, even when needed H&CC services were available at the local level (not always the case, even in different neighbourhoods of Toronto), they could still be difficult to access and coordinate. Here, the presence of informal caregivers was crucial. In addition to providing directly much instrumental, personal and emotional support, informal caregivers were often the glue that held care packages together, since they monitored needs, accessed needed services, interfaced with professional care coordinators and managed multiple services and providers in the home (Williams, Challis et al. 2009a; Peckham, Williams and Neysmith 2014).

Subsequent projects in other parts of the province estimated divert rates ranging from 10 to 40 percent based on conventional service-by-service home care, with higher estimates associated with more integrated and cost-effective delivery models such as supportive housing, where needed services could be more easily wrapped around older persons living in the same building. For example, BoC projects conducted in the North East and North West LHINs concluded that if scaled up and spread, supported housing models already present in those regions could potentially redirect up to two-thirds of individuals waiting for LTC back to the community (Williams, Watkins and Kuluski 2010).

These projects also clarified that divert rates were potential rather than actual, since no region had sufficient H&CC capacity to achieve them. Particularly in rural and remote areas, where H&CC capacity remains stretched, older persons could be LTC wait-listed at relatively low levels of need (Kuluski, Williams, Berta et al. 2012; Kuluski, Williams, Laporte et al. 2012).

Moreover, even when needed H&CC services were present at the local level, they could still be difficult to access due to widely varying entry points, eligibility criteria, service offerings and user fees. A lack of coordinating mechanisms posed particular challenges for individuals requiring multiple services from multiple providers. Although all CCACs and most CSSAs offered care management and care navigation services, these often relied heavily on information, counselling and referral, with older persons and informal caregivers still having to make and manage connections with different providers themselves. Particularly for older persons experiencing cognitive limitations, and their caregivers, challenges of access and coordination could quickly prove overwhelming.

Such factors accounted for the only BoC project to estimate a zero divert rate. Conducted in the South West LHIN, it first considered what would be required to maintain LTC wait-listed older persons who were cognitively intact safely and appropriately in the community; it then turned to wait-listed individuals who lived with Alzheimer’s disease or other dementias. The expert panel convened for the project concluded that although in principle individuals with cognitive challenges could be and often were supported in the community, there was not sufficient capacity to maintain steadily rising numbers outside of LTC. Panellists noted, for example, that while supportive housing had great potential due to the flexible, integrated, case-managed care it could provide, available supportive housing places (at that time) had not been designed for persons experiencing cognitive challenges (Morton-Chang 2015).

BoC projects also confirmed that small things matter. In every project, in every region, lower-level IADLs such as meal preparation, housekeeping, phone use and medication management appeared as key drivers of referral to LTC. Expert panels emphasized that an inability to perform such everyday but essential tasks could quickly lead to social isolation, functional decline, illness and avoidable admissions to hospital and residential LTC.

A related lesson concerns the key role of informal caregivers. As observed earlier, a growing weight of international evidence shows that family, friends and neighbours are the first line of care in the community; they provide the bulk of the emotional, instrumental and personal supports required by individuals who cannot manage on their own (OECD 2011; Fast 2015). While caregivers can provide personal care (such as bathing and toileting), they are more likely to help with everyday IADLs (such as cooking and driving) (Sinha 2013). Thus, where formal IADL supports are more difficult to access, informal caregivers can be left to fill a growing care gap (Williams et al. 2014; Williams, Peckham, Kuluski, Lum, Warrick et al. 2015; Williams, Peckham, Luluski, Lum, Morton-Chang et al. 2015).

Nevertheless, across Ontario, IADL supports have been among the first to go. As CCAC resources are concentrated on discharging hospital patients faster, more people with higher levels of need are referred to CSSAs. When CSSA services are not adequate or accessible, care responsibilities cascade down to informal caregivers and social networks, which may be more or less capable of fulfilling them (Hermus et al. 2012, 28; Williams et al. 2014; Warrick et al. 2014; Peckham et al. 2014). In addition to magnifying existing inequalities, this also increases the likelihood that caregivers will become overburdened and withdraw, making hospitalization and residential LTC all the more likely (Peckham et al. 2014; Warrick et al. 2014; Williams et al. 2014; Peckham, Williams and Neysmith 2014).

A series of four BoC projects conducted in the North West LHIN over a six-year period (2008 to 2014) elaborate these observations. In 2008 (the year of the first project), two-thirds of home care clients waiting for LTC beds experienced great difficulty with IADLs; by 2014 (the year of the most recent study), almost 85 percent did. Levels of cognitive impairment also advanced: in 2008, 60 percent of wait-listed individuals experienced some level of cognitive impairment; by 2014, this had increased to 82 percent.

Geographic differences came into play. In particular, the needs tipping point for LTC referrals appeared consistently lower for individuals living in the sparsely populated and comparatively underserviced rural/remote region outside of the main urban centre of Thunder Bay. Wait-listed individuals in the region were more likely to be cognitively intact than those in the city (25 percent versus 15 percent, respectively), less likely to experience great difficulty with activities of daily living (ADLs)[3] (15 percent versus 31 percent) and less likely to experience great difficulty with IADLs (71 percent versus 91 percent) (Williams, Watkins and Kuluski 2010; Kuluski, Williams, Berta et al. 2012; Kuluski, Williams, Laporte et al. 2012; Kuluski, Peckham and Williams 2015).

The North West LHIN expert panels added important qualitative insights. For example, the 2014 panel confirmed that an increasing volume and complexity of needs in the community stemmed from a combination of demand-side changes, including population aging and the related rise in chronic health and social needs, and supply-side factors, such as an increasing reliance by policy-makers on H&CC to relieve pressures on ALC hospital beds and LTC admissions. Although formal IADL supports were seen to be essential to maintaining older persons and their caregivers in the community, they were increasingly difficult to access (Kuluski, Williams, Berta et al. 2012; Kuluski, Peckham and Williams 2015).

Furthermore, while expert panellists emphasized that many dedicated providers worked collaboratively to overcome fragmentation and use available resources effectively, solutions were often in the form of nonscalable and time-consuming workarounds — in effect, finding ways to do things that were not mandated or funded. Even so, the division of labour between providers had become more pronounced: CCACs now accepted mostly higher-needs individuals — those who required high-intensity posthospital care or who were on the verge of entering LTC — and individuals with lower levels of need were referred to CSSAs and commercial providers, such as retirement homes. This effectively narrowed the needs bandwidth served by any individual provider and multiplied the number of hand-offs between providers as clients’ needs progressed.

Even collaboration related to shared clients could prove challenging. For example, North West LHIN expert panellists reported that when personal support workers (PSWs) contracted by the CCAC made a home visit for personal care such as bathing, they would effectively have to break the rules to do nonpersonal household tasks such as laundry or food preparation, if time allowed. Nor was there any guarantee that the same worker would be able to stay with the same client over any given period, since the PSWs were not CCAC employees. Adding to the mix were providers of other essential supports — for example, transportation, meal preparation and adult day programs — as well as health care practitioners such as family physicians and pharmacists. Particularly for older persons with dementia and their informal caregivers, having to deal with such a sizable and changing cast of characters could foster resistance, drain caregivers and make care plans unworkable.

Of course, there were also many promising practices. Supportive housing, or housing with care, was consistently identified as a preferred option for maintaining even high-needs older persons in the community. For instance, panellists observed that existing supportive housing (originally designed for people with low or moderate needs) could be physically adapted for persons requiring transfers (for example, for toileting) through simple modifications such as ceiling tracks. However, funding had not kept up with rising needs. In fact, because supportive housing had proven so effective, older persons now stayed longer, often to the end of their lives, and policy-makers expected them to stay longer, albeit without additional resources.

The establishment of hub models, which can leverage the resources and infrastructure of a central location (such as a supportive housing building) to serve geographically proximate clusters of people (such as seniors living in the same neighbourhood), was identified as another promising practice. A major advantage of such models is that they do not require large-scale capital investment, since they permit people to stay in their own homes. Expert panellists pointed to a palliative care pilot project in the region that used computer tablets (such as iPads) to link clients and providers together on different sites. They also referred to hub models employed extensively in the disability community that locate satellite offices in buildings with concentrations of persons requiring continuing support and that use mobile intervention personnel (akin to Assertive Community Treatment teams in the mental health community) to serve individuals living within a 10-to-15-minute driving distance who do not require regular care.

Promising practices: Three vignettes

The three vignettes below describe three community-based initiatives identified by BoC expert panels in different parts of the province as offering promise in the effort to support older persons and their caregivers appropriately and cost-effectively closer to home. These vignettes also identify some of the challenges faced in the attempt to scale up and spread.

Vignette 1: Jasper Place, North West LHIN

The first vignette describes a long-established supportive housing provider located next to a 150-bed LTC facility in Thunder Bay, in the North West LHIN. The NW LHIN spans the largest geographic region in Ontario — approximately 47 percent of Ontario’s land mass — although it is home to less than 2 percent of the population (231,000). Approximately 16 percent of residents are 65 or older (in excess of the Ontario average); this is expected to increase to 22 percent over the next 10 years (Government of Ontario 2015a), due, in part, to the continuing out-migration of younger adults (Kuluski, Williams, Laporte et al. 201).

In terms of health services utilization patterns, the NW LHIN has high rates of emergency department and hospital utilization for health issues that could be treated in the community (Government of Ontario 2015a). The NW LHIN continues to report the highest ALC rate in the province (estimated at 27 percent of inpatient hospital beds in September 2015), with more than half of patients (56 percent) waiting for residential LTC (Access to Care, Cancer Care Ontario 2015b).

Owned by the District of Thunder Bay Social Services Administration Board and operated by the City of Thunder Bay, Jasper Place was established in the 1990s; it has 91 single-dwelling units and 9 double units, with capacity for 109 clients. It is a traditional seniors’ supportive housing model combining social housing (rent geared to income) with a 24-hour onsite integrated support services program. Jasper Place offers assistance with ADLs and many IADLs, as well as access to a nurse practitioner who works with clients to maintain optimal levels of health and well-being, avoid unnecessary visits to family doctors and hospitals (for example, by conducting blood or urine tests on site) and postpone or avoid referrals to residential LTC. When clients are hospitalized, Jasper Place follows their progress and works to transition them back to supportive housing as quickly as possible. It also links clients to other community providers (for example, CCACs and CSSAs) and social and recreational supports (such as exercise classes).

Jasper Place’s success is reflected by the fact that clients can — and do — stay longer because of the extensive supports offered. For instance, the needs of residents who develop cognitive or other brain health issues can be met as they increase over time, until they match or even surpass those of LTC residents. Needs levels have also been pushed upward by the 2011 provincial Assisted Living Services for High Risk Seniors Policy, which, as the name suggests, targets older persons at the point of loss of independence. While Jasper Place used to serve a mix of clients with lower and higher care needs, clients now typically enter with higher needs. Current targets set by the NW LHIN specify that 25 percent of clients will have Method for Assigning Priority Levels (MAPLe) scores of 2 or under (low needs); 60 percent will have MAPLe scores of 3 (moderate needs); and 15 percent will have MAPLe scores of 4 or over (high and very high needs, generally comparable to LTC residents). Future NW LHIN targets for low-, moderate- and high-needs clients are 25, 50 and 25 percent, respectively. In fact, Jasper Place already meets these targets: 30 percent of its clients are assessed as being at high to very high levels of need, including individuals experiencing care-intensive behavioural and mental health challenges.

While it has been demonstrated that this supportive housing model can successfully manage individuals with needs similar to or approaching those of individuals in residential LTC, funding anomalies remain. An LTC per diem is about $160; Jasper Place receives about $33 per client per day, including municipal contributions and client user fees (2015 user fees were $10.60 per day for single occupancy and $16.04 per day for a couple to cover 15 meals a week and personal support). This strains Jasper Place’s ability to manage current clients effectively as their needs progress, and it also limits the prospects of developing outreach initiatives to support geographic clusters of older persons living in the community. Moreover, because more clients now enter Jasper Place later and with higher levels of need, transitions are often more challenging and resource-intensive for clients, caregivers and staff, particularly in the case of individuals living with dementia, who may experience difficulty adapting to unfamiliar environments.

Jasper Place faces other conundrums. As noted, it is adjacent to an LTC home that is also owned and operated by the municipality, and its clients can access amenities like the coffee shop and hair salon. However, because supportive housing and LTC fall under different legislation and have different regulations and funding arrangements, there are no formal mechanisms for sharing resources and programming. Nor, because LTC bed queues are managed by the CCAC, is there any guarantee that Jasper Place residents and their caregivers can transition, when needed, to a familiar setting next door. While connected by a common walkway, Jasper Place and the LTC facility remain disconnected as a matter of policy.[4]

Vignette 2: Seniors Managing Independent Living Easily, South East LHIN

The second vignette describes Seniors Managing Independent Living Easily (SMILE), a LHIN-wide initiative in southeastern Ontario aimed at improving access to and coordination of H&CC

services for frail older persons living in the community and their caregivers. The South East LHIN is one of Ontario’s most rural and fastest-aging regions (SE LHIN 2006). It is characterized by higher-than-average rates of chronic conditions such as arthritis, diabetes, high blood pressure and chronic obstructive pulmonary disease among those 65 and older (SE LHIN 2013). In September 2015, its ALC rate for inpatient hospital beds was 19 percent, about five percentage points higher than the provincial average; of ALC patients, almost three-quarters (70 percent) were waiting for LTC (Access to Care, Cancer Care Ontario 2015b).

The Victorian Order of Nurses, Canada, in partnership with the SE LHIN and other H&CC providers in the region, initiated the SMILE program in 2008. SMILE currently serves more than 2,000 clients with an annual care plan budget of $6.4 million.

SMILE clients typically have one or more complex health and social care needs, such as significant cognitive impairment, functional impairment that causes problems with mobility and/or deterioration of health status as demonstrated by hospitalization, visits to the emergency room and/or unscheduled physician visits in the past 90 days. They are also, on average, over 75 years of age, and they often have a chronic disease related to advanced aging (for example, stroke, Parkinson’s disease, arthritis or coronary artery disease) and live alone or with a caregiver who is unable to consistently assist with IADLs (SHS Consulting 2015).

SMILE does not replace existing services and supports; rather, it aims to facilitate access and bridge care gaps for older persons at risk of progressive frailty, premature dependency and institutionalization and their caregivers. To do this, it uses experienced care coordinators equipped with budgets averaging $3,600 per client per year to engage with older persons and their caregivers in a process of identifying unmet needs and priorities; cocreating care plans aimed at maintaining functional ability and independence at the highest level possible; accessing local resources, including those available through nontraditional providers such as neighbours, particularly in rural areas where a full range of services may not be not available through established providers; and regularly monitoring and adjusting care plans as needed.

SMILE emphasizes support for nonmedical IADL needs. Commonly accessed services include household management supports (housekeeping; laundry; shopping; meal preparation and/or cooking; and outdoor chores and maintenance, which are often bundled together) as well as foot care, transportation (to doctor’s appointments or on outings), day programs, respite, shopping, socialization, companionship and emergency medical alarm services. It is important to address a person’s inability to get out during the winter due to uncleared walkways, although this is not health care per se, because this restriction can contribute to social isolation and limit access to food, finances and medical services; it can also contribute to physical and mental decline and increase the risk of hospitalization and loss of independence. In rural areas, a client may need assistance to bring in wood, or a newly widowed man may require guidance on how to prepare meals and do laundry in order to remain independent. As noted, SMILE also allows clients to access nontraditional providers, particularly where formal providers are not available; for example, if meals are an issue, clients may choose to have a neighbour do grocery shopping or prepare familiar foods.

Because SMILE does not provide services directly but helps coordinate and manage access to other service providers (which can include paying user fees to minimize financial barriers to access), it can be characterized as a supported self-management model. In contrast to the classic self-management model, by which individuals receive funding and then access and manage services on their own, SMILE offers continuing professional support. Such support is particularly valuable when older persons and their caregivers require services and supports from multiple providers; when they do not have the personal resources and capacity to navigate and manage services themselves (for example, because of a cognitive limitation, language problems or a low literacy level); or, as is the case in many rural areas of the province, when there are few services to purchase, even if clients have the funds to do so (Peckham et al. 2014; Warrick et al. 2014). SMILE has two main methods of channelling funding to clients: client reimbursement, in which the client pays the provider, provides receipts and is then repaid by SMILE; and provider reimbursement, in which the provider invoices SMILE and the client verifies that services were delivered.

Nevertheless, SMILE faces challenges, including that of ratcheting up service levels to meet increasingly care-intensive needs. This is reflected in changing referral patterns. Initially, most referrals came from other CSSAs or through self-referral from the community; currently, most referrals come via the CCAC. Assessment data show that in 2014, SMILE clients had needs comparable to or higher than those of CCAC long-stay home care clients; moreover, about half of SMILE clients referred from the CCAC had high or very high MAPLe scores, comparable to those of individuals waiting for LTC (SHS Consulting 2015). Nevertheless, only a few SMILE clients have initiated applications for or moved to LTC. Although SMILE is good news for clients and caregivers, who can remain in the community longer, and for the formal care system, because of delayed or avoided hospital and LTC admissions, it now faces the dilemma of having fewer resources available for before-the-fact prevention and maintenance.

SMILE faces other dilemmas. Although SMILE care coordinators collaborate extensively with their CCAC and CSSA counterparts, and increasingly with local hospitals, to identify high-needs individuals and maintain them in the community, there is no mechanism to share resources or to have resources follow the client. For example, if SMILE diverts a high-needs, care-intensive client from hospital or an LTC waiting list, it takes on the costs, but it cannot recoup the savings to reinvest in client care. Moreover, because provider funding is strongly driven by historical patterns and market share, the necessity to ratchet up to meet higher needs within fixed budgets means that SMILE can support fewer clients.[5]

Vignette 3: Assisted living in South Western Ontario, Erie St. Clair LHIN

The third vignette describes an integrated assisted living/attendant care provider located in Windsor, in the Erie St. Clair LHIN. The ESC LHIN, in the southernmost part of the province, is home to 4.6 percent of the population of Ontario, 18.4 percent of whom are aged 65 or older (ESC LHIN 2014). Chronic conditions such as arthritis, hypertension, diabetes and cancer are on the rise, and more than half of older persons have two or more such conditions (ESC LHIN 2013).

ESC LHIN has one of the highest hospital ALC rates in the province, estimated in September 2015 at one-fifth (20 percent) of all inpatient hospital beds in the region (Access to Care, Cancer Care Ontario 2015b). Many are occupied by older persons with dementia and mental health problems who cannot be discharged back to the community due to a lack of appropriate community-based care options (Williams, Peckham, Rudoler et al. 2015).

Assisted Living in South Western Ontario (ALSO) was originally designed to provide a comprehensive range of independent living supports for individuals with physical disabilities and acquired brain injury. In 2011-12, it expanded to serve frail seniors with functional impairments so as to delay or avoid residential LTC and bring those in hospital ALC beds back to the community. It did this through a combination of one-time Ministry of Health and Long-Term Care funding to deliver mobile services to persons with disabilities who required higher levels of in-home care than could be provided through the existing Attendant Care Outreach Program (capped at 21 hours) and new dollars provided under the 2011 Assisted Living Services for High Risk Seniors Policy. In contrast to traditional seniors' supportive housing, which is funded at about $30 per day, ALSO receives about $135 per day, reflecting the higher levels of personal care typically required by persons with disabilities.

These resources have allowed ALSO to develop a well-elaborated hub-and-spoke model spanning nine supportive housing buildings owned by different not-for-profit organizations. In addition to serving clients living in these buildings, ALSO provides mobile and outreach services to clients living in close geographic proximity (within 10 minutes' travel time). While the supportive housing buildings can serve 12 to 15 clients, assisted-living neighbourhoods can serve 30 to 35 clients by leveraging hub resources. A recent initiative extends ALSO's reach to rural areas by assisting clients to hire local providers with support and assistance from ALSO care coordinators. Clients may access other ALSO programs, including vocational and acquired brain injury day programs, crisis intervention and support, Equal Ability (an employment support program), community life-skills training and social recreation.

By serving older persons and persons with disabilities, ALSO effectively overrides the practice of treating individuals who need community supports differently depending on the reason for those needs. In Ontario, programs and services for persons with disabilities and for older persons with continuing support needs have different entry points, eligibility criteria, funding mechanisms and fees. By contrast, ALSO offers 24/7 support, regardless of age, on a consistent basis. Moreover, it does so not only for individuals living in specific buildings, but also for those living in the broader community.

Because ALSO has considerable experience serving clients with high to very high care needs, staff are able to manage a range of specialized and high-intensity care interventions, including feeding tubes, wound care, mechanical ventilation, suctioning, challenging behaviours and palliative care. Over the past two years, it has transitioned nearly 200 people from institutional care settings (including ALC hospital beds and complex continuing care, intensive care and emergency department beds) back to the community.

Paradoxically, its success may constrain its growth. Because ALSO supports clients with very high levels of need, often until death, its client flow-through and its ability to take on new clients are increasingly limited; it cannot, for example, continue to transition significant numbers of ALC patients back to the community or divert individuals from LTC with its current capacity. As a result, its interactions with and visibility to system partners and funders have declined; and, due to personnel changes at provincial and regional levels, decision-makers are now less familiar with ALSO and its successes, and it is thus more difficult to make the case for scaling up.

Nevertheless, ALSO continues to enhance the consumer’s ecosystem through a range of initiatives that leverage local community resources. These include working with faith-based organizations and a local hospice to augment services for palliative clients, and working with local accounting firms to help clients file income tax returns. In addition, ALSO raises funds for groups of clients to go camping or take trips to other cities. It is exploring a partnership with a rural hospital that has offered ALSO and several other community agencies space from which to offer services to rural clients.[6]

Where We Go from Here: Bridging Care Divides

A growing body of comparative literature provides us with valuable perspective on where Ontario fits when it comes to beds and places. A first observation is that while Ontario continues to think about long-term care as related to a particular setting (for example, a bed in a nursing home or a home for the aged), a growing number of industrialized countries instead think about places for long-term care by focusing on what people need to maintain their functional capacity and independence at the highest possible level for the longest possible time, regardless of setting (Billings and Leichsenring 2006; Schulz 2014).

A second observation is that while the logic of beds is straightforward, projects to build care places are inherently more complex. The recent INTERLINKS project, funded by the European Commission and conducted across 13 European Union countries (Austria, Denmark, Finland, France, Germany, Greece, Italy, Netherlands, Slovakia, Spain, Sweden, United Kingdom and Switzerland), clarifies that such projects must aim to span two deeply embedded divides: between health care (medical) and social care (nonmedical) on the one hand; and between formal and informal care on the other (INTERLINKS 2013). Even relatively modest projects to establish mechanisms for interdisciplinary care teams, almost universally considered to be a best practice in the care of persons with multiple health and social needs, can confront layers of professional legislation, regulations and funding mechanisms that establish strict hierarchies and limit collaboration, even among regulated providers. Adding unregulated providers (such as PSWs in Ontario) and unpaid providers (such as informal caregivers) multiplies the challenges (Billings 2013). Nevertheless, in jurisdictions such as Denmark, substantial progress has been made in bridging these divides and promoting, as a matter of explicit policy, the practice of having older persons live in the least restrictive setting possible (Schulz 2010, 2014). As early as 1982, the Danish Elderly Commission recommended that long-term care policy support seniors at home and help them maintain independence and live active lives (Denmark 2014; Stuart and Weinrich 2001). Legislation created in 1988 prohibited the development of more nursing home beds, opening the way for a greater range of aging-at-home options; nursing home beds are now being phased out (Schulz 2014). In 1996, the government added a home reform component that increased the availability of subsidized housing with 24/7 supportive services for older people with more extensive needs. Local governments are now responsible for delivering a range of health and social care services for older persons, including a free choice of care options spanning nursing homes, senior citizen residences, gated communities, protected dwellings, service-enriched housing, day programs and in-home care. People in need of care generally pay the rent but receive publicly funded home help independent of where they live. A basic principle is that the care setting should not dictate the offers of care made to older people (OECD 2011; Schulz 2014).

Also noteworthy is the fact that help with IADLs, including household chores, is not tied to medical care or heavier personal care, such as bathing and toileting. In 2010, of 189,000 Danes 65 and older receiving help, 71,000 (about 38 percent) received it for practical tasks (IADLs) only (Schulz 2014). In this period, about 70 percent of Denmark’s care budget was spent on keeping people at home (Allen et al. 2011).

Informal caregivers are also part of the care mix. Danish caregivers may be paid by municipalities to substitute for formal care providers (in effect becoming public employees), but relatively few are. In fact, Denmark’s rates of caregiver participation are among the lowest of any Organisation for Economic Co-operation and Development member country. From one perspective, this might seem to confirm that more robust formal care systems put less of a burden on informal caregivers (Schulz 2014). However, some observers have instead argued that institutional barriers still remain in the form of restrictions on leave-taking from paid employment and a loss of income and benefits if caregivers choose to move from full-time jobs to part-time, albeit paid caregiving (Pfau-Effinger, Jensen and Och 2011; Schulz 2010; Olejaz et al. 2012).

In other jurisdictions, such as England, efforts to span both formal and informal care divides are picking up steam. In 2012, the coalition government’s *Health and Social Care Act* restated the long-standing policy aim of better integrating health and social care, along with devolving power from the professions through mechanisms such as patient choice (United Kingdom 2012). In 2015, the government announced that to accelerate progress, it would make Greater Manchester the first English region to have full control of its health care budget, emphasizing that municipalities already controlled social care; in April 2016, the region’s Health and Wellbeing Board is slated to take over £6 billion previously controlled by the National Health Service, thus bringing health and social care together in the same pool.

Also in England, this pathway of radically restructuring formal care systems is matched by similarly radical calls to restructure social institutions, including informal support networks, which are seen to be in an increasingly precarious state. A 2014 paper by the Institute for Public Policy Research, a UK think tank, observed that because of factors such as decreasing birth rates and the decline of the traditional nuclear family, “the number of older people in need of care is predicted to outstrip the number of family members able to provide it for the first time in 2017”; families, which already provide the vast majority of care for older persons, will have to increase their efforts by more than half over the next 15 years just to keep pace with rising needs. By

2032, this care gap will widen as the population of older persons increases by 60 percent, with only a 20 percent increase expected in the number of family members able to care for them (McNeil and Hunter 2014). As such, there is an urgent need to adapt social structures already in place, such as family caregiving and public services, and to build new community institutions capable of sustaining the population through the changes ahead, such as neighbourhood networks (akin to Ontario’s proposed community hubs, described later in this study), which can tap into and build collective capacity. This is unlikely to happen on a broad scale if communities are left to do it on their own; rather, it will require “a different role for the state, one that is more about establishing partnerships with families and communities than traditional service delivery” (McNeil and Hunter 2014).

In many countries, efforts to build comprehensive systems of care over the long term tend to be more local. For example, the INTERLINKS project provides a comprehensive listing of good practices in long-term care for older people that do not require extensive system redesign (keeping in mind that most EU jurisdictions already have extensive publicly funded health and social care systems in place). A briefing to the European Parliament highlights the following examples:

- Domiciliary rehabilitation (Germany): multidisciplinary in-home rehabilitation care for older persons who cannot travel to a rehabilitation centre
- Alzheimer’s café (Netherlands): community gatherings where information and education are offered and connections are built between older persons with dementia, their caregivers and providers
- Better Homes, Active Lives (UK): community residences for older persons, with onsite care managers and tailored levels of care, including specialized services for persons with Alzheimer’s disease and other dementias
- Acute geriatric care units (across Europe): specialized units in acute care facilities designed for older persons with multiple needs, which first address acute care needs and then develop coordinated community care plans once acute care problems have been solved
- Buurtzorg — care in the neighbourhood (Netherlands): district block nurses who are responsible for the entire care process (from assessment to formal and informal care provision) for older persons with complex needs who cannot leave their homes (Billings 2013)

INTERLINKS provides little commentary on why such innovative local approaches emerge in the first place, or under what conditions they are likely to scale up and spread, although the presence or absence of an enabling policy framework seems crucial (Billings 2013).

A leading example of a successful local initiative is the oft-cited and extensively evaluated On Lok Lifeways in the US. On Lok was founded in 1972 in San Francisco by a small group of community health organizers who realized that most of their elderly Chinese clients, even those with high levels of need, neither required nor wanted nursing home care. On Lok negotiated access to Medicare and Medicaid funding roughly equivalent to what government would pay if high-needs, nursing-home-eligible individuals actually occupied LTC beds. Instead, building on an adult day program model, the organization assembled a comprehensive suite of supportive services, including transportation and in-home meal delivery, to keep people out of those beds.

Interdisciplinary teams — composed of health care professionals such as physicians, nurses, physical therapists and social workers, but also extending to personal care workers, drivers and family members — are a key mechanism for assessing needs, delivering seamless care and monitoring outcomes. Here the economic incentives align: if clients (the majority of whom have multiple chronic medical problems such as diabetes, hypertension, vascular disease and dementia, as well as social problems such as isolation and poverty) require hospital or residential LTC, On Lok has to pay the cost. If, however, clients can avoid such care, On Lok, in effect, keeps the savings. Thus, underserving clients or ignoring low-level needs is not a good option, since the costs of subsequent institutional care cannot be shifted to these other providers.

In addition to lower rates of hospital and residential care and high levels of client satisfaction, a key outcome has been a progressive rebalancing of investments from illness care (including medical tests and procedures) to health promotion and maintenance (including enhanced transportation, medication management and social programs) (Li, Phillips and Weber 2009).

On Lok has been scaled up to serve more clients in San Francisco, and it has been successfully replicated across the US, including rural Program of All-Inclusive Care for the Elderly (PACE) models that leverage the resources of urban programs through a hub-and-spoke model. As of 2014, there were an estimated 104 PACE replication projects operating in 31 states (PACE 2016). However, most of these remain small-scale initiatives, with the largest serving just over 2,500 clients. A 2011 evaluation of 15 rural PACE models conducted for the US Congress noted that resistance from physicians who viewed PACE as a threat to their patient rosters has been a limiting factor in the expansion of the model (Sebelius 2011).

Other local ground-up initiatives tap into informal care capacity. For example, the Riedlingen Seniors Cooperative, a grassroots seniors’ organization established in Germany in 1991, aims to leverage the capacity of social networks by hiring physically well seniors to provide cleaning, transportation, meal preparation and other low-level supports for frail older persons. The cost is covered by client user fees, with subsidies for those who are unable to afford the care services. Seniors helping in the program have the option of banking service hours for their own future service needs. The cooperative also operates two assisted-housing sites with case-managed services, as well as a day centre that offers a range of services, including personal care and rehabilitation, to the broader community. This model is presented as being particularly useful in rural areas with declining populations because of its capacity to tap into local community networks (Allegro 2009; innovAge 2013).

Even proven initiatives may fail to scale up or spread. For example, the PACE-like System of Integrated Care for Older Persons (SIPA), which operated in Montreal for a relatively short period — from 1999 to 2001 — is still presented in the academic literature as a template for integrating community-based health and social care (Béland 2012). SIPA provided primary health care, enhanced home care services and intensive case management through a multidisciplinary team located within a community health centre. Importantly, SIPA took on clinical and financial responsibility for delivering integrated care; it provided a full range of services, including community health and social services, drug management, and hospital and nursing home care coordination. Moreover, SIPA was a success. While a randomized clinical trial showed only modest net cost savings, since utilization of community-based care rose, SIPA reduced overall acute care hospital and nursing home utilization, and SIPA clients were significantly less likely to occupy costly ALC hospital beds (Béland and Hollander 2011; Béland 2012). However, this demonstration project was not extended. The cited challenges included an inability to demonstrate overall cost savings (with home care costs actually rising, necessitating new funding or a shift of funds from other providers) and poor incentives for family physicians to engage in the care of frail older persons (Béland et al. 2006).

Scaling, spreading, sustaining: The role of enabling policy frameworks

So what distinguishes otherwise promising initiatives that fail to scale up, or simply fail, from those that have staying power and impact? The comparative literature is conspicuously underdeveloped in this area, offering a growing number of engrossing case studies (as we have also done) but saying less about the conditions under which models that arise in one local context can be transferred to other contexts either within or across jurisdictions.

Our reading of the literature and our experience in Ontario suggest that despite the fact that there is well-placed enthusiasm for nimble ground-up initiatives — particularly as a counter to rigid, top-down, cookie-cutter approaches — the ability for individual initiatives to scale up and spread is highly dependent on the presence or absence of enabling policy frameworks. In addition to setting a clear direction and assisting local organizations to overcome often-formidable institutional constraints, such frameworks also mitigate obvious pitfalls of inequality when some communities start with greater needs and fewer resources.

In Greece, KAPI (the acronym for a term that translates as “open-care protection centres for older people”) offers an example (Daniilidou et al. 2003). KAPI was established in the early 1980s as a small group of pilot centres run by volunteers with public financing. These centres provided a range of physical, mental and social supports as well as preventive medical services in familiar environments to older people with the aim of avoiding admission to any kind of institution. Core personnel included a social worker/care coordinator, a nurse, a physiotherapist and/or occupational therapist and a cleaner.

In 1982, KAPI geared up as local authorities in rural and urban areas assumed responsibility. More than 370 KAPI centres were established across Greece. However, the KAPI project’s success relied strongly on situating its centres in larger, economically robust municipalities; a significant number of its centres did not operate fully, since Greece has many isolated rural areas, islands and mountainous regions that are typically less well resourced (Daniilidou et al. 2003; Economou 2010; Florinis 2009).

In 1992, Greece’s health ministry added a second layer to the municipal centres: help-at-home teams. These consist of social workers, sociologists and psychologists who evaluate cases, supervise services, offer their support and/or refer clients to appropriate specialists or alternative services; they also include nurses who offer primary care, drug prescriptions and health supervision, as well as home care attendants who assist with shopping, cleaning and light housekeeping. This program is now running in more than half of the KAPI centres (Mastroyiannakis, Kagialaris and Triantafillou 2010).

A similar layering of responsibilities is now emerging in Japan. While Japan has only recently appeared on the comparative policy studies radar (WHO, Alzheimer’s Disease International 2012; Hayashi 2015b; Whitehouse 2015), largely because most of its academic literature has been written in Japanese, its presence is long overdue. It is the world’s third-largest industrial economy (following the US and now China), and it has the world’s fastest-aging population, due in part to people living longer, but also due to plummeting birth rates and restrictive immigration policies.

Faced with rising health care costs, high numbers of social admissions to hospital and a great reliance on institutional LTC beds, Japan introduced its national long-term care insurance plan (Kaigo Hoken) in 2000; this mandatory plan is universal, and it is funded partly by taxes and partly by mandatory insurance contributions (Campbell 2014). It separates medical care from social care, which, at first glance, appears to be the reverse of what countries such as England are now attempting. However, Japan’s approach has the advantage of ensuring that social care resources are protected and cannot easily be appropriated by health care. When individuals require services, they are certified and classified, by means of uniform and objectively determined criteria that emphasize IADLs, into one of seven categories. Funding is determined by level of need rather than location of care. Because the plan covers both residential services (for example, residential care homes) and community-based long-term care services (such as group homes, day programs, short stays and multifunctional in-home care services), older persons and their caregivers can choose between places and beds. Advice and support is provided by trained care managers, and the client is free to change care managers and providers (Campbell 2014).

Japan’s national policy framework, along with its recently announced national dementia strategy (Whitehouse 2015), has catalyzed a range of innovative community-based initiatives aimed at maintaining older persons in familiar settings. Building on a base of over 4,000 government-mandated local support centres — which are open 24/7 year-round, and which create comprehensive community care packages (including day services, respite, nursing care and regular or on-demand home care) — many of these initiatives look beyond formal services to construct and strengthen informal social networks.

Such initiatives include over 6 million dementia friends — volunteers who receive government training to recognize the cues of people who are lost, confused and/or wandering and then to lead them home safely. Businesses are also engaged. For example, ÆON, a large grocery chain, recently reported that 50,000 of its front-line employees are now equipped to identify and respond to older persons showing signs of dementia, communicate sensitively, follow a checklist and report their concerns. Similarly, many banks have now trained specialized support staff to meet the daily challenges of older persons who have no surviving family members, or whose children live in other cities, and who are having difficulty managing their finances or even withdrawing money from automated teller machines because they forget their PIN numbers (CRNCC 2015).

A crucial factor in the success of these endeavours is that while they operate within an explicit policy framework, they give communities a relatively free hand to establish local initiatives that are flexible and friendly, that leverage local resources and that provide social care, compassion and support (but not medical care, which is left to the professionals). Initiatives include open house drop-in centres offering persons with dementia and their caregivers access to all-day care, including lunch and tea service. Run by volunteers who provide informal advice and peer support for caregivers (backed by a 24/7 helpline), these open-house centres embrace normalization by providing a familiar setting (Hayashi 2015b; CRNCC 2015).

Observers have noted that there are essential considerations for mounting such initiatives; for example, the contribution of volunteers and informal caregivers must be recognized and supported as a key element of the care system (Hayashi 2015a,b).

How We Get There: Changing the Policy Discourse

As we observed in our introduction, industrialized countries are now confronting the converging challenges of aging populations and stretched formal care systems. As people live longer, they are more likely to develop multiple chronic health and social needs that hospital-centric health care systems are poorly equipped to meet on an appropriate, cost-effective basis.

Moreover, countries also face broader social changes, including falling birth rates and a declining proportion of nuclear families, which magnifies the impact of aging, since there are fewer young people (and potential caregivers) coming in at the bottom of the population pyramid. While the grey tsunami has long been anticipated in Ontario and elsewhere, considerably less attention has been paid to the widening care gap that can follow as the traditional caregiver base fails to expand apace with growing needs (Fast 2015; Williams, Peckham, Kuluski, Lum, Warrick et al. 2015). In response, countries such as England and Japan are thinking about ways to bolster informal care networks, even as they rethink formal care systems.

By comparison, Ontario has been slow off the mark. As recent expert reports highlight, the province continues to struggle with the costs and consequences of a nonsystem of H&CC, in which older persons can default to costly and potentially avoidable hospital and residential LTC (Donner 2015; Drummond 2012; Sinha 2012; Walker 2011). Our historical review suggests that this is the result of almost three decades of conflicted policy decisions that have left the sector internally fragmented, underresourced and a target for cost shifting. In contrast to the medicare mainstream, H&CC has no entitlements; its terms and conditions vary widely, and there are few consistent standards. While market competition is effectively prohibited under medicare, competitive forces were deliberately inserted into home care as a way of driving down prices — although because of the collateral political damage, the competitive bidding process remains frozen along with existing provider contracts. User fees, seen through the lens of the *Canada Health Act* as a barrier to reasonable access, are accepted as fair play for vulnerable persons and their caregivers in the community, establishing a perverse incentive for using “free” hospital and doctor care.

Nor has Ontario made determined efforts, beyond recently creating an unpaid work leave policy, to validate and support informal caregivers. For the most part, policy-makers remain preoccupied with problems at the tip of the health care iceberg, especially double-digit ALC hospital bed rates, which show few signs of improving, in spite of massive infusions of resources. Paradoxically, by concentrating resources at the tip, they push a greater burden of care downward to the community and onto the informal caregiver base, which includes many older caregivers who are themselves in need of care. Not only are discouraged caregivers more likely to accept hospital or LTC admissions for cared-for persons in the first place, but they are also probably less likely to support discharge back to the community, making ALC problems and LTC waiting lists all the more intractable (Williams et al. 2014; Williams, Peckham, Kuluski, Lum, Warrick et al. 2015; Williams, Peckham, Kuluski, Lum, Morton-Chang et al. 2015).

What are the prospects for change? Institutional theory tells us that once embedded, historical pathways are hard to change. Canadian medicare, while providing universal access to medically necessary hospital and doctor care, also narrowed conceptualizations of health and health care, pushing ideas about nonmedical community supports to the policy margins, where they remain, in spite of a seismic shift in population needs. In Ontario, deliberate policy choices similarly reinforced the idea that residential LTC beds are the ultimate care destination for older persons, with community-based places a distant second. In fact, as we consistently heard from BoC expert panels in different parts of the province, experienced front-line professionals, including hospital discharge coordinators, were not always aware of or willing to risk unfamiliar community-based care options, even when these were available.

Of course, it’s not simply a matter of ideas. The divides between health and social care, and formal and informal care, as well as between LTC beds and places, are powerfully buttressed by legislation, regulations and funding arrangements. Moreover, as Evans and others have noted, once established, such divides are often staunchly defended by professions, bureaucratic offices and providers that stand to lose market share in the face of change (Evans 2011; Lazar et al. 2013). Seen from the perspective of interests, beds are more than a care setting for older persons; they are also the source of good jobs, sustained departmental budgets and corporate profits, all of which could be negatively impacted by any rebalancing of resources toward the community.

Nevertheless, institutional theory and international experience tell us that change can and does occur. As we have discussed, many recent changes in Ontario have been arguably counterproductive to the extent that they have stripped resources away from before-the-fact aging at home in favour of after-the-fact post-hospital care, in the process reducing the likelihood that growing numbers of older persons with multiple chronic care needs and their caregivers can continue to live independently in the community.

Other changes are occurring. The international literature observes, and our Ontario vignettes demonstrate, that a growing number of ground-up initiatives offer promise in terms of addressing individual and system needs. Although demonstrating proof of concept, these remain mostly at the policy margins. It seems unlikely that these small-scale and usually resource-strapped initiatives can by themselves overcome deeply embedded divides to propel the broad-scale system changes that recent expert panels in Ontario believe are needed.

Three essential steps

Step 1: Plan for care places

Consultants for Ontario's HSRC had this one pegged more than 15 years ago when they observed that to know how many beds you need, you must first decide what role you expect residential beds to play in a broader continuum of places (HayGroup 1997). Saying "no new beds," as recent Ontario governments have done, may be a move in the right direction, but it has to be paired with a clear statement of where everyone is expected to go. If you think only about beds, you will end up asking how many. If you think of places, you should ask how many and where.

Researchers at the Manitoba Centre for Health Policy provide an excellent example of how this broader conceptualization can inform real-world policy and planning. In their projections of the future supply of personal care home beds in the province, they emphasize that those determining rates of bed utilization must consider "care that could have been provided by other means such as supportive housing or expanded home care." They adopt the terminology of "bed equivalents" and conclude that "after the first boomers turn 85, between 5,100 and 6,300 extra bed equivalents will be needed in personal care home beds, supportive housing and expanded home care." Importantly, they also note that such projections should take into account informal capacity: "As more Manitobans have fewer children — or none at all — the extended network of family members able to care for aging relatives will decrease," again impacting on the formal system and numbers of bed equivalents (Houlden 2012, 1).

Although such ideas are abstract, the policy literature emphasizes that they can and often do play a crucial role in defining policy problems and developing solutions. Canadians have witnessed this recently in relation to key issues such as indigenous rights, immigration, sexual harassment and the right to die — in these areas, new ideas have pushed policy in new directions. In areas such as climate change and support for aging populations, the prospect of looming crisis opens a window of opportunity for us to rethink how we do business.

Step 2: Affirm the role of public policy

As our review of the international literature suggests, when change occurs at a system level, and not just in local pockets, it is because government enables it. This is not to argue that we need heavy-handed, top-down bureaucratic solutions; rather, it is to argue that governments should establish the conditions under which promising ground-up initiatives, such as those depicted in our Ontario vignettes, can scale up and spread.

Japan's Orange Plan for dementia care provides a helpful illustration. Rather than specifying a cookie-cutter template, it identifies seven pillars or principles to guide the creation of dementia-friendly communities, support family caregivers, encourage cooperation and remove institutional barriers within government and between providers, incent intergenerational projects and give people with dementia a greater voice. This, in turn, stimulates the spread of innovations such as training for front-line bank tellers, grocery clerks and garbage collectors who interact with persons with dementia and their caregivers on a daily basis, and the emergence of grassroots initiatives such as the dementia open houses (Whitehouse 2015; Hayashi 2015b). The establishment of professional-free zones where medical care is not required or provided likewise validates and mobilizes informal social networks, including those of well older persons who can help their peers with a higher level of needs, and of schoolchildren who can learn to identify and assist older persons who appear to be lost or in need of assistance (CRNCC 2015).

Such an approach could do well in Ontario, not only to inform an emerging dementia care strategy (as noted, the province does not currently have one), but also to guide its anticipated reform of home and community care. Instead of taking a top-down approach and reorganizing providers, policy-makers might begin with a clear statement that care should be provided in the least restrictive setting possible, and that older persons and caregivers should be permitted to choose freely between community and residential places. This would propel the development of services that fit people rather than making people fit services.

This does not mean that government should simply leave it to individuals and communities to fend for themselves, since communities with the greatest needs — including those in many rural and remote areas, as well as emerging cultural communities in urban centres — are the least likely to have the necessary resources; so this approach would compound existing inequalities. This is not the case in Japan, where the government, through its dedicated long-term care insurance system, mandates that every municipality have a local support centre staffed by trained professionals whose job it is to connect older persons and their caregivers to their choice of services and providers (Campbell 2014).

Such flexible approaches can also forestall time-consuming debates about what a standardized basket of services should contain, since it seems unlikely that exactly the same services will ever be available in every community, and since various formal and informal services (for example, Meals on Wheels, congregate dining, home help with meals and meal preparation by neighbours or family caregivers) can often be substituted for one another to achieve the same goal (such as good nutrition). This type of flexibility would also allow us to sidestep interminable discussions about whether self-management, supported self-management or professional care management should be adopted as the best approach to care, since each may be appropriate depending on the capacity and willingness of older persons and their caregivers in different places and at different points to manage care themselves.

As our Ontario vignettes demonstrate, promising local initiatives are already showing that flexible approaches can work. A good measure of the success of SMILE and these other initiatives can be attributed to their capacity to match needs and resources at the local level. In rural areas, help from neighbours and community organizations such as the Legion are well accepted; in urban areas such as Windsor, hard hit by an economic downturn, housing to create new supportive community places is more readily available.

A related and promising policy direction is the development of community hubs in Ontario. Aimed broadly at communities and groups experiencing unmet needs (for example, indigenous people, rural communities, persons with disabilities and older persons), hubs are similar in concept to the new community institutions proposed by the Institute for Public Policy Research in the UK (McNeil and Hunter 2014). The logic is that by gathering together (or co-locating) services and providers at a single point you can identify local needs, promote collaboration, build community capacity and eventually provide one-stop access to the services required by people of all ages to stay healthy and independent in their communities (Lum 2014).

Importantly, hubs have been mandated by Ontario's Premier, lending considerable political weight to the initiative. In her 2014 mandate letters to the ministers of health and long-term care, education, and municipal affairs and housing, the Premier directed them to develop jointly a community hubs policy to "reflect the perspective of health and wellness" and promote collaboration on "shared responsibilities" within government. The bones of this policy have subsequently been identified by a special advisor, who, in consultation with community stakeholders, recently made numerous recommendations for actions to "make community hub development easier and more sensitive to community needs" (Pitre 2015). Internal provincial barriers to hubs (familiar, as well, to those involved in H&CC) include lack of coordination within the provincial government and between provincial and municipal governments; conflicting policies; program silos; uncoordinated funding; unclear forms that are time-consuming to fill out, as well as confusing eligibility criteria; and programs and services that are not client-focused. Proposed solutions include establishing a provincial lead for community hubs; creating incentives for agencies and organizations that demonstrate integrated service delivery; simplifying transfer-payment accountability requirements to increase funding flexibility and reduce administrative burden for service providers; working with the information and privacy commissioner to leverage existing work to establish protocols that protect privacy while allowing appropriate sharing of client information; and evaluating the effectiveness of current and planned provincial integrated service delivery projects to identify opportunities that might apply to community hubs (Pitre 2015).

Step 3: Follow the money

As we have seen, care funding in Ontario varies extensively across locations: while the province pays about $160 a day (including a resident copayment) to keep people in LTC beds, its funding for supported housing places, even places occupied by individuals with needs comparable to those in LTC, averages just over $30 a day. The clear message is that policy-makers are willing to pay considerably more to keep people in beds than to keep them out of those beds in the first place.

To overcome such imbalances and encourage the creation of new care places, we concur with the expert advice given to Ontario's HSRC in the late 1990s: that funding should be based on care needs, not location of care (HayGroup 1997). As noted, Japan's long-term care insurance system provides individualized funding linked to assessed needs, with older persons and caregivers given the choice of services and providers. On Lok in the US similarly receives funding for its clients comparable to what they would have received in residential LTC. As our Ontario vignettes suggest, while unequal funding can strain the capacity of community-based providers and slow the development of innovations such as community outreach and supportive neighbourhoods, equal funding can also drive their emergence.

International experience demonstrates that such approaches can produce desirable outcomes at the individual and system levels, particularly if funding is tied to accountability. As we have seen, PACE models receive funding for clients who are long-term-care eligible, roughly equivalent to what it would cost to place them in a nursing home bed. Since On Lok takes responsibility for all care costs, including the costs of hospital and LTC admissions, the clear incentive is to find the most effective ways to keep people well and independent in the community. Operationally, this also spurs the adoption of organizational best practices, including interdisciplinary teams, integrated client records and early assessment. Furthermore, PACE models are now adapting to the requirements of rural areas by leveraging technology and resources from urban hubs.

In the US, policy-makers have shown that even less-encompassing financial incentives can do much to encourage the emergence of innovative care models. For example, a series of federal initiatives enabled by the *Affordable Care Act* of 2010 are aimed at helping states reduce their reliance on residential beds. Among these, the Balancing Incentive Program targeted 13 states that were spending more on institutional LTC than on community-based care equivalents. It supported their efforts in reaching a balancing benchmark where community-based services accounted for at least 50 percent of total long-term care spending. In addition to encouraging PACE-type models, this program stimulated a general expansion of community-based services and supports, including homemaker/home health aides, chore services, personal care assistance, nursing care, respite, training for family members, adult day programs and day treatment (Lester et al. 2015). Similarly, the Money Follows the Person programs offer greater choice to Medicaid beneficiaries related to where they live and receive care by facilitating successful transitions from residential to community settings. In 30 participating states, providers were given the opportunity to test new service innovations on a small scale; states that performed better on key outcome measures used this flexibility to ensure that clients received appropriate and timely care in the community (Denny-Brown et al. 2015).

Some Closing Thoughts

In thinking about the future of care over the longer term in Ontario and elsewhere it is easy to get caught up in the missteps of the past. While documenting these missteps, we conclude that they did not occur simply by chance; many resulted from deliberate policy actions and inactions on the part of successive governments. Paradoxically, this can be seen as good news, since it demonstrates that policy-makers can now take a lead role in steering us back toward needed change. Even if policy-makers have no control over population aging and the rise of chronic health and social needs, they have considerable choice about how to respond.

There is a lot to be optimistic about. In Ontario, recent expert reports and our own BoC projects in various regions have identified numerous ground-up initiatives that, in addition to providing exemplary client-centred care, are leveraging and building formal and informal capacity in urban and rural areas. As our vignettes demonstrate, there is no lack of commitment, innovative ideas and energy to make things happen. However, the vignettes also show that existing small-scale local initiatives are unlikely to be able to drive system change on their own; they require an enabling policy framework.

Ontario's 2015 road map for home and community care lays out key elements of such a framework. It anticipates the development of a statement of values (which we hope will include choice of providers and care settings); the creation of a levels of care framework (which will ideally go beyond assessment to allocate funds on the basis of need); expanded caregiver supports (which international experience suggests can be fruitfully extended to bolster informal support networks); and capacity planning (which we think should encourage the emergence of a full continuum of residential and community-based care places).

Finally, although emphasizing the importance of community-based care, we do not wish to diminish the crucial role of residential beds; as we have noted, no jurisdiction internationally, including gold standard Denmark, has eliminated beds. What others have done, and what we think Ontario and other jurisdictions would also benefit from doing, is to see beds within the more encompassing discourse of places for care over the longer term. Not only does this give policy-makers and planners greater scope to think creatively about a continuum of residential and community-based care, but it also avoids mechanistic planning formulas that ensure that LTC beds continue to be considered apart from, and sometimes in opposition to, community-based alternatives, and vice versa. This approach also allows LTC homes to begin to think more creatively; many are already doing so. They can offer communities greater access to their considerable assets (for example, kitchens, meeting spaces, expertise and programs) and, in turn, draw more fully on rich community resources, including caregivers, younger and older volunteers, and social networks.

Acknowledgements

This study was supported by a research grant from the Ontario Ministry of Health and Long Term Care (MOHLTC) to the Health System Performance Research Network (HSPRN#06034). The opinions, results and conclusions reported in this study are those of the authors and are independent from the funding sources. No endorsement by the MOHLTC is intended or should be inferred.

We wish to extend our thanks to the executive directors of the three community agencies highlighted in this study for taking the time to provide valuable insights not only into their own agencies, but into the broader policy context. They are Lynn Calder (ALSO), Lori Cooper (SMILE) and Donna Ostrom (Jasper Place). Of course, any errors of interpretation are the authors' alone.

Notes

1 For more information, go to http://cnap.ca/.

2 See http://sprintseniorcare.org/transportation.

3 ADLs or activities of daily living are personal care tasks such as bathing, dressing, personal hygiene, eating, movement and mobility (such as moving from a bed to a wheelchair). IADLs or instrumental activities of daily living are required to maintain independence; they include preparing meals, shopping, driving, using a telephone, and managing finances and medications.

4 For additional information on Jasper Place, go to http://www.thunderbay.ca/Living/Older_Adults/Homes_for_the_Aged/Jasper_Place.htm.

5 Additional details on SMILE are available at http://www.von.ca/en/hastings/service/seniors-managing-independent-life-easily-smile.

6 Additional details on ALSO are available at http://www.also-group.org/.

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About This Study

This study was published as part of the Faces of Aging research program under the direction of Nicole F. Bernier. Copy editing was by Mary Williams, proofreading was by Barbara Czarnecki, editorial coordination was by Francesca Worrall, production was by Chantal Létourneau and art direction was by Schumacher Design.

A. Paul Williams is full professor of health Policy at the Institute of Health Policy Management and Evaluation, University of Toronto. His research highlights options for integrating community-based health and social care for vulnerable groups and communities, including older persons, persons with disabilities, and children with multiple chronic needs.

Janet Lum is full professor of politics and public administration and associate dean of research and graduate studies in the Faculty of Arts, Ryerson University. She co-chairs the Canadian Research Network for Care in the Community.

Frances Morton-Chang is a gerontologist and post-doctoral fellow at the Institute of Health Policy Management and Evaluation, University of Toronto. Her academic and professional experience includes community, hospital and residential long-term care, disease-based charities and research programs. Her research focuses on the mix of resources required to maintain frail and cognitively impaired seniors safely in the community.

Kerry Kuluski is a scientist at the Lunenfeld-Tanenbaum Research Institute in the Sinai Health System and assistant professor at the Institute of Health Policy Management and Evaluation, University of Toronto. Her research focuses on the experience and optimization of care for mid-life and older adults with multiple chronic needs and their caregivers.

Allie Peckham is a PhD candidate and research associate at the Institute of Health Policy Management and Evaluation, University of Toronto. Her work focuses on the intersection of formal and informal care and policies aimed at supporting that intersection in the home and community care context.

Natalie Warrick is a PhD student and research associate at the Institute of Health Policy Management and Evaluation, University of Toronto. Her focus is on the delivery of home and community services to informal care providers of people with dementia.

Alvin Ying is manager of the Canadian Research Network for Care in the Community (CRNCC). The CRNCC promotes collaborative, community-driven research and knowledge mobilization in home and community care.

To cite this document:
Williams, A.P., J. Lum, F. Morton-Chang, K. Kuluski, A. Peckham, N. Warrick and Alvin Ying. 2016. *Integrating Long-Term Care into a Community-Based Continuum: Shifting from “Beds” to “Places.”* IRPP Study 59. Montreal: Institute for Research on Public Policy.

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IRPP
1470 Peel Street, Suite 200
Montreal, Quebec H3A 1T1
Telephone: 514-985-2461
Fax: 514-985-2559
E-mail: irpp@irpp.org