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A Roadmap of Noninstitutional Living Options for People with Dementia: "Don't Fence Me In"

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Article

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Abstract

Canadians overwhelmingly do not want to live in long-term care institutions (LTCIs) when they age; yet many end up there for lack of home care, because family care partners burn out, or because they and their professional advisors are unaware of alternatives to institutions. Not only is institutional dementia care riven with problems, it segregates disabled people, thereby abrogating human rights. Because systemic ageism and ableism cloud seniors' care, institutions remain the default option for Canadians with dementia. Yet, decades of deinstitutionalization enabled younger disabled Canadians to live in the community with supports. Why not seniors? We describe a plethora of noninstitutional dementia-care alternatives. We then present a roadmap for considering all relevant care options in service plans, one that incorporates supported decision making by people with dementia. We propose a paradigm shift in how Canada serves its senior citizens – not just the current generation, but those to come, including ourselves.

Résumé

Les Canadiens affirment ne pas vouloir vivre dans des centres de soins de longue durée en vieillissant. Toutefois, beaucoup finissent par s'y retrouver faute de soins à domicile, parce que les aidants familiaux s'épuisent, ou parce que leurs professionnels ne sont pas au courant des alternatives aux institutions. Non seulement les soins institutionnels pour la démence posent problème, mais ils ségréguent aussi les personnes handicapées. En raison de l'âgisme et du capacitisme, les institutions restent l'option par défaut pour les Canadiens atteints de démence. Pourtant, des décennies de désinstitutionnalisation ont permis aux jeunes Canadiens en situation de handicap de vivre dans la communauté. Cet article se veut une description des alternatives aux soins institutionnels pour la démence. Cette discussion est appuyée d'un guide pratique pour envisager toutes les options de soins pertinentes. Le texte soutient un changement de paradigme dans la manière dont le Canada sert ses citoyens âgés.

Understanding institutional living

There is little dignity in institutional life. Residents with dementia live behind locked doors and pace sanitized corridors to the distant sound of televisions furnishing minimalist common spaces, void of personal touches and designed for easy maintenance. Yet, although nearly all Canadians over 65 polled in 2021 (97%) reported not wanting to reside in long-term care institutions (LTCIs) (NIA, 2021), little has been done to challenge the institutional model of dementia/seniors' care, even if reforms and cultural trends have had some success in improving elements of the nursing-home experience (e.g., *Maison des aînés* in Quebec, Sherbrooke Community Centre in Saskatchewan). Still today, LTCIs offer little to endow residents' lives with meaning (Gleeson et al., 2019; Weiner & Ronch, 2003), as they are merely considered objects of costly medical and domestic care tainted by the stigma of sickness and death (Hummel & Tettamanti, 2009). This is even truer for residents living with dementia, a condition causing impairment over time and often misunderstood by laypeople and professionals alike (WHO, 2024). People with dementia are disabled by social attitudes (Shakespeare et al., 2017).

It is paradoxical that, even following media coverage of high death rates in LTCIs during COVID-19's first and second waves (Carette, 2021; Fisman et al., 2020), politicians still support the institutional model as Canada's default option for dementia care. Consequential to this preference, physical safety trumps all other concerns, leading substitute decision makers (whether family members or medical professionals) to prematurely commit people with dementia to locked LTCI units (Ferreira et al., 2015). Family care partners and substitute decision

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makers often resign themselves to the seeming absence of other viable options.[1] For people with dementia, the disadvantages and dangers of institutions are many. They may:

- receive only physical care (with quality depending on staffing levels) when neither emotional nor social care are government funded (Banerjee & Armstrong, 2015);
- contract easily transmitted infections, such as COVID-19 and influenza;
- lack privacy (Tufford et al., 2017);
- lose liberty, autonomy, and dignity (Heggestad et al., 2013; Lai, 2022; Šaňákova & Ĉáp, 2019);
- wear incontinence products instead of being helped to the toilet, resulting in frequent urinary tract infections (Salsbury Lyons, 2010);
- very likely be depressed (Crick, 2019);
- be inappropriately controlled with physical and chemical restraints (e.g., antipsychotic drugs) (Koncul et al., 2023; Lai, 2022; Steele & Swaffer, 2022);
- endure physical and psychological abuse (Lai, 2022; Steele & Swaffer, 2022);
- deteriorate mentally and physically (Steele & Swaffer, 2022);
- likely develop dental problems, leading to malnutrition, weight loss, and frailty (Slaughter et al., 2017; Yoon et al., 2018); and

suffer from lockdowns during disease outbreaks (e.g., COVID-19, influenza) when family and friends are banned, preventing them from receiving support and improved care under their loved ones' monitoring (Koncul et al., 2023).

Yet, although Canadians condemn the state of LTCIs (Lloyd et al., 2014), why do our governments keep funding and building institutions? Compared with other Organisation of Economic Cooperation and Development (OECD) countries.) Canada drastically underfunds home care for seniors (Drummond et al., 2020). Canada's spending on geriatric institutions, as a percentage of GDP, is over five times higher than its spending on home care (Drummond et al., 2020). In 2020–2021, compared with 11 per cent of total provincial healthcare spending going to LTCIs, only half of that (5%) went to home and community care (HCC). Across provinces, HCC spending, as a percentage of 2020–2021 continuing-care budgets varied widely. For example, Newfoundland-Labrador spent the most (42%), compared with Ontario (40%), British Columbia (39%), and Quebec (22%). This yields a provincial average of $300/person on HCC in 2020–2021 (Busby, 2021). Underfunding is compounded by government spending generally flowing to institutional beds or programs, not individual seniors, aggravating the mismatch between demand for seniors' services and supply.

The federal government recently announced voluntary standards for improving LTCIs. More standards will not likely improve care, because even in Canada's largest province, Ontario, LTCI regulations are rarely enforced (Flood et al., 2021). This is also the case in other provinces, such as Quebec (Lévesque, 2022). Very few LTCIs are inspected each year; for example, only 1 per cent in 2018 (Pedersen et al., 2020). With current seniors' demographic growth, LTCI-expansion plans will do little more than replace decommissioned beds (Drummond et al., 2020).

Canadian governments should look far beyond regulating and expanding LTCI, instead, replacing the institutional-seniors'-care model with community-based alternatives. To initiate this trend, we must first understand what drives seniors' institutionalization. Systemic ageism (discrimination based on age) clouds much of Canada's social policies and practices regarding end-of-life services and care-partner supports. Healthcare-quality decline with age is well reported (Nemiroff, 2022). Seniors often encounter paternalistic physician attitudes (Fernández-Ballesteros et al., 2019); therapeutic nihilism (Biskup et al., 2020), stigma (Lagacé, 2010), higher rates of under- and overtreatment (Mistry, 2021); barriers to timely, effective care (Nemiroff, 2022); and, in the face of functional decline, a deficit in alternatives to barren, segregated institutions (Herron et al., 2021).

As a driver of institutionalization, systemic ageism is bolstered by systemic ableism (discrimination based on ability). People with dementia are discredited as active participants in society and, more crucially, as agents in their own lives (Milne, 2010). Through confinement to LTCIs, they experience epistemic and humanitarian injustices. Indeed, within institutions, management of residents with dementia contradicts the United Nations Convention on Rights of Persons with Disabilities (UNCRPD), a treaty that Canada signed. As Steele et al. (2020) point out, "care homes commonly employ a wide range of physical and environmental barriers to movement, including locked doors, lap sashes and belts, bed rails, and segregated wards" (p. 9). These physical constraints compound the widespread use of drugs to control residents with dementia, clearly violating their rights to nondiscrimination and equality as disabled people (Minkowitz, 2006). Ableism also drives exclusionary practices even among institutional residents. Those without dementia avoid interacting with residents with dementia, fearing them as examples of aging's 'physiological failure' (Lévesque, 2022). Institutions' segregation of residents with dementia reinforces societal discrimination against people living with the condition. At every turn, they are denied participation possibilities, let alone feeling they belong. Because LTCIs are concurrently work, medical, and living environments, residents have limited opportunities for meaningful involvement. With hierarchies akin to hospitals, LTCIs deprive residents of citizenship and demote them to low care-planning priority (Lévesque, 2022). They are seen as objects, not subjects, of their care.

In view of the above, the need for LTCI alternatives is not only undeniable but an urgent human-rights remedy (Steele et al., 2020) and taxpayer-cost saver. Individuals contemplating old age unanimously wish to avoid institutions (Lévesque, 2022). Yet, professionals and families lack the tools and knowledge to find other care avenues. Professionals tasked with coordinating care through the lenses of social justice and social change (e.g., social workers) resent this lack (Thériault & Dupuis-Blanchard, 2017). To address it, in this article we aim to:

- give readers a roadmap for considering all relevant care options;
- broaden the options professionals can recommend to seniors and their families beyond institutions;

[1]The dementia village in Hogeweyk, the Netherlands has been replicated in Norway and Australia, and one is being developed in the United States (Plockova, 2023). Living conditions in a Canadian version, The Village Langley in British Columbia (Verve Senior Living, 2024), appear to be better than LTCIs: residents with dementia are able to use amenities such as a store, hair salon, and local cafe at their convenience, unaccompanied by staff, family or friends. However, this privately owned dementia village is expensive ($8,300/month in 2023). Being an assisted-living facility, it may not provide as much medical care as LTCIs do. Although dementia villages may segregate people with dementia from their communities, contravening the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), efforts are being made to add senior residents without dementia and younger residents (Plockova, 2023), integrating the villages better into communities. In Norway's Carpe Diem dementia village, for example, neighbourhood residents can patronize the amenities and walk around the grounds (Plockova, 2023). Institutional elements remain however. Although dementia-village residents may think they are moving around freely, they are under surveillance by village staff, who play the role of store clerks, waiters, and hairdressers.

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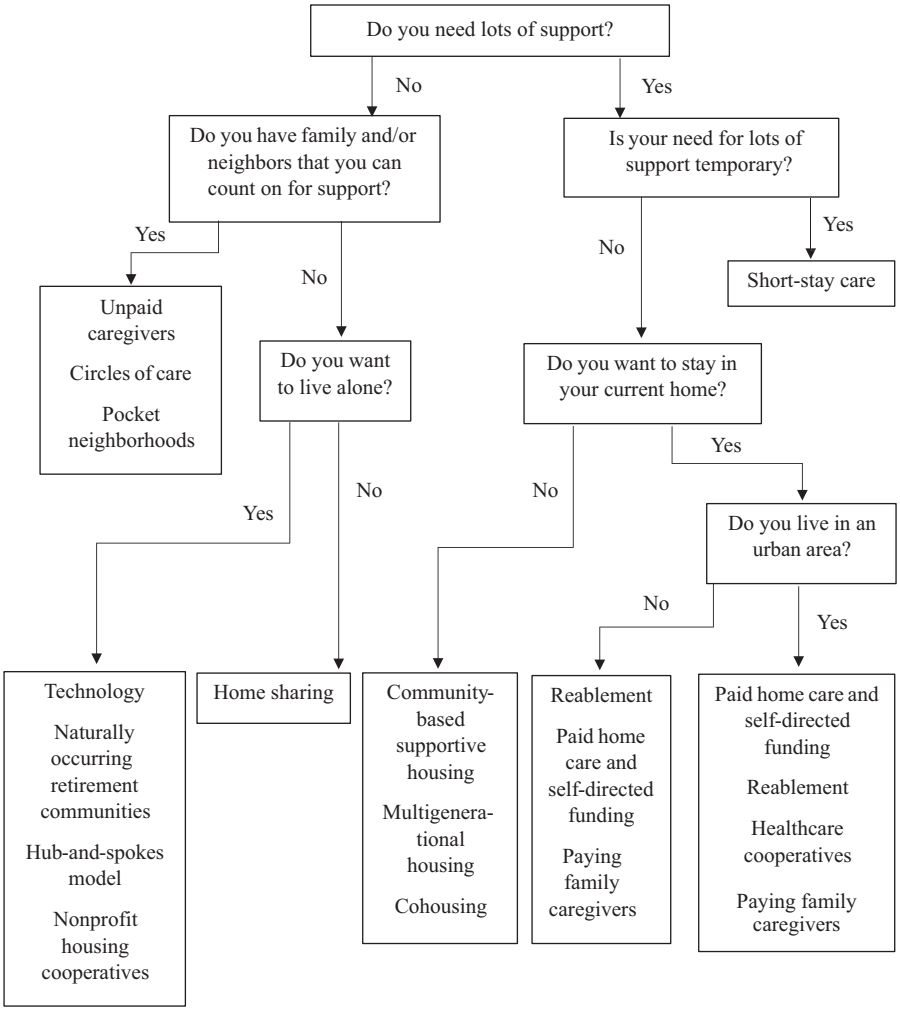

Figure 1. Roadmap of alternatives to institutional care for someone with dementia.

Table 1. Noninstitutional options for supporting people with dementia

Minimal in-home supports	Extensive domestic and medical in-home supports	Out-of-home options
Unpaid caregiving	Paid home care and self-directed funding	Community-based supportive housing
Circles of support	Reablement	Multigenerational housing
Technology	Healthcare cooperatives	Cohousing
Home sharing	Public community-based-care insurance plans[a]	Nonprofit housing cooperatives
Naturally occurring retirement communities (NORCs)	Short-stay care	Pocket neighbourhoods
Hub-and-spokes model	Paying family caregivers	

[a]Not currently available in Canada.

- provide tools that empower people with dementia through supported decision making, rather than the substitute decision making that currently dominates the institutional landscape; and
- discuss both current and potential alternatives to institutional living.

First, we provide a nonexhaustive roadmap (see Figure 1) professionals can use to guide decision making by clients with dementia and their families. We then describe options for supporting people with dementia within their own communities (see Table 1). All these options should be discussed jointly with people with dementia based on their preferences, care needs, social and financial resources.

Our roadmap's foundation is supported decision making (SuDM). This approach recognizes the human right of disabled people to participate in decisions about their lives, with support if needed, under the UNCRPD (Alzheimer Europe, 2017; UN, 2006). Under SuDM, changed capacity need not disqualify someone from participating in their care planning. Instead, creative accommodations can adapt decision making to individuals' current abilities (e.g., supporters listening to nonverbal cues like facial and other bodily expressions). Thus, even as dementia progresses, people

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with dementia can still be heard. SuDM contrasts with substitute decision making (SDM), whereby seniors appoint people "to make decisions on behalf of another" (LCO, 2023, p. 1), concerning, for instance, their health and property. Although integral to conventional advanced-care planning, substitute decision makers poorly predict seniors' preferences (Peterson et al., 2020).

In Canada, younger people with cognitive impairments (developmental disabilities) advocated SuDM as an alternative to guardianship as far back as the 1980s. The 1992 Report of the National Task Force on Alternatives to Guardianship (Panitch, 2008) advocated SuDM as well. It is law in at least six American states and in Peru, Columbia, and Mexico (personal communication, Russell Chloe, Canadian Sociology Association Conference, May 30, 2023). The United Kingdom's Choice and Control policy also incorporates SuDM (Williams & Porter, 2015). SuDM involves listening to the preferences and self-identified needs of people with dementia, including those expressed nonverbally. To listen, professionals can use pictures to explain abstract concepts, involve trusted people (e.g., family and staff) who have listened to their wishes; build relationships well before discussing decisions; allow time for decision making and multiple discussions; and look for verbal and nonverbal signs of anxiety and other signs of disagreement (Oldfield, 2021). To these strategies Lai (2023) adds that professionals can provide information in accessible formats and use assistive devices to facilitate communication. She advocates help for care partners in supporting seniors' decision making by, for example, professionals providing information on how to challenge legal-incapacity decisions made by physicians or courts. We suggest that care partners also receive peer or other support to challenge medical power.

Noninstitutional options for supporting people with dementia

We now describe noninstitutional options currently available in Canada, along with those in other countries. We group the options into (a) minimal in-home supports, (b) extensive domestic and medical in-home supports, and (c) out-of-home supports. See Table 1.

Minimal in-home supports

In planning service trajectories for people with dementia, professionals should attempt to minimize drastic transformations to people's day-to-day lives. Dementia's evolution varies widely (Melis et al., 2019), leaving many people able to live at home with supports. Although dementia eventually causes ability losses, the diagnosis does not mean immediate need for substantial support or institutionalization. Initially, minimal supports are best to avoid disrupting people's lives.

Unpaid care. Unpaid care partners prevent, or significantly delay, institutionalization. They provide physical and emotional support to parents, partners, friends, or neighbours. They may also organize and monitor paid care. Unpaid care partners, therefore, save governments substantially in healthcare costs. Being essential, they are usually included in care plans to fill paid service gaps (Carette, 2021; Lévesque, 2022). However, unpaid care can require a lot from the women who mostly do it. Middle-aged family care partners juggle caring for parents and children living at home (Parry et al., 2023). To accommodate care, they may switch to part-time employment or leave their jobs, leading to increased dependence on their partners, reduced family income, more stress, and worsening mental and physical health (Mar, 2020). These negative impacts are largely tied to insufficient government compensation and workplace accommodation, and to the structural ageism and ableism that shape insufficient seniors' supports (Lévesque, 2022). However, care can be reciprocal and thereby mitigate negative impacts. Seniors may emotionally care for the children/friends/neighbours who provide or organize physical care. In turn, caring for seniors provides meaning, life satisfaction, and closeness (Quinn & Toms, 2019).

Nonetheless, the benefits of unpaid care do not diminish the harms of deficient seniors'-care systems. Professionals should advise unpaid care partners to monitor their physical and mental health and suggest services that can prevent care-partner burnout (e.g., home care, adult day programs, respite care, tax credits, or employment insurance benefits[2]). Some of these options are covered below. In sum, when unpaid care is coupled with appropriate supports and guidance, not only is care-partner burn-out reduced, but the risk of institutionalization drops.

Circles of support. Circles of support bring together groups of friends or community members who weave a personal safety net around a disabled person, who is then empowered through supported decision making (microboardsontario.com). The concept was pioneered by Judith Snow, a disabled Canadian at the forefront of the independent living movement in the 1970s (Davis, 2005).

Overall, circles of support can enable people with intellectual disabilities to live well (Araten-Bergman & Bigby, 2022). In Ontario, circles of support can incorporate as nonprofit organizations called microboards to gain legal recognition, access, and manage services. Unlike a healthcare proxy or power of attorney, "a Microboard is not guardianship or a vehicle for substitute decision making. A Microboard has no control or legal authority over a person's life" (Microboards Ontario, 2022).

In contrast, Quebec has formalized the importance of ally groups for people under protection mandates. As of November 2022, they must be consulted in homologating (legally implementing) a protection mandate (Curateur public du Québec, 2022). While ally groups do not necessarily function as Microboards in Ontario or British Columbia do, protection mandates represent growing societal awareness of the importance of community in supporting people who need financial and/or healthcare proxies.

Technology. Protective technology can allow people with dementia to remain at home without compromising safety or limiting community engagement. Wearable alerts that summon help from a service operator are a growing industry. Although the alerts' functions vary according to brand and price, they generally use a global positioning system and/or fall detection technology that does not require input from the wearer. Devices can be waterproof, linked to other smart devices, and encapsulated in lanyards or bracelets, depending on the person's preferences. Even the cheapest device provides medication reminders, two-way voice communication, and monitoring through cell phones and landlines.

Simpler technology, such as people with dementia carrying cards with their names, addresses, and emergency contact information in wallets, purses, or pockets, or wearing lanyards or bracelets with identifying information, can facilitate a return home if lost. Carrying this information can reassure people who want to be out in the community and their family members. Similarly, medic-alert bracelets tell emergency personnel about a person's

[2]Pay rates are unknown.

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medical conditions, allergies, etc. without the person needing to be articulate or conscious.

Home sharing. Home-sharing programs match seniors who have unused bedrooms in their homes (e.g., after children leave) with housemates looking for low-cost accommodations. Seniors may trade free or low rent for housework or home maintenance. Other benefits for both parties include companionship, security, and mutual caring. As an example, some programs based at universities and colleges match students with senior homeowners (Benzie et al., 2020), who become proxy grandparents for homesick students.

Although home sharing can postpone institutionalization while fostering intergenerational bonds (Bodkin & Saxena, 2017), there are some drawbacks. First, home sharing may not meet seniors' complex or intensive needs, as housemates are more tenants than care partners (Poulin, 2022). However, by mutual agreement, the housemate may organize and monitor paid care. Second, people matched by home-sharing programs may turn out to be incompatible. This can create more distress than benefits, particularly in small homes that lack privacy (Bodkin & Saxena, 2017). Nonetheless, some programs safeguard against this outcome through a thorough acquaintance process. Third, municipal zoning may prohibit sharing one's home with unrelated people. Hence, potential home sharers should seek advice about relevant bylaws before proceeding. Nonetheless, when done well, home sharing cultivates mutually beneficial relationships and fosters stronger community.

Naturally occurring retirement communities (NORCs). Beyond individual homes, naturally occurring retirement communities (NORCs) are apartment buildings where at least half the residents are seniors. NORCs may be buildings that, while not intended as such when built, now house a senior majority or communities exclusively for older adults that are neither retirement homes nor LTCIs (National Institute on Ageing, 2022). Using government or other funding, residents may partner with senior-serving agencies to provide in-home supports at reduced or no cost (Benzie et al., 2020), thereby enabling seniors to continue living, and die, at home.

The potential of NORCs is clear in two examples from New York City. Tenants are provided with personal care, nursing assistance, social and educational activities, housecleaning, and transportation (Cohen-Mansfield et al., 2010; Paying for Senior Care, 2024). Services are coordinated by social workers during home visits, along with nonprofit organizations allied to each NORC. Although NORCs are not considered suitable where constant surveillance is needed, people with early-to-mid-stage dementia can live there for years (Freedman et al., 2022).

In Canada, the Ontario Ministry of Health and Long-Term Care funds NORCs in several City-of-Toronto-owned seniors' buildings.[3] Services are provided by personal support workers (PSWs) and coordinated by registered practical nurses (RPNs). Eligible tenants receive the following services: personal care, navigating the healthcare system, light housekeeping and laundry, medication reminders, safety checks, light meal preparation, health promotion activities and education, and referral to community resources. In addition, the NORC Innovation Centre (norcinnovationcentre.ca) helps Toronto seniors set up NORCs in their buildings. Outside of Toronto, OASIS (oasis-aging-in-place.com) is working with privately owned apartment building residents and owners in 11 Ontario cities and Vancouver to create NORCs. Despite these efforts, NORCs are an undermobilized resource:

> Although more older adults in Ontario live in NORCs than long-term care and retirement homes combined, their potential remains unrealized because little is known about how to successfully create, implement, and sustain supportive service programs in NORCs (Women's College Hospital, 2023, p. 1).

Not only have NORCs gained legal recognition and standardized funding (Cohen-Mansfield et al., 2010), they answer seniors' preference to age at home. By integrating care and redistributing funds from institutions to community services, municipal and provincial governments save money while significantly improving seniors' quality of life (Béland et al., 2006).

Hub-and-spokes model. A variant of NORCs is the hub-and-spokes service-delivery model. Unlike NORCs, this model extends from but is not restricted to individual apartment buildings. Health and social services are based in hubs – buildings housing mostly seniors (SSAO, October 17, 2022). From hubs, supports are provided to seniors in the surrounding community, the spokes (SSAO, November 28, 2022). The hub-and-spokes model has multiple benefits: it (a) serves seniors in various housing arrangements (e.g., houses, multigenerational homes, apartment buildings with few seniors), (b) reduces costs by not requiring new infrastructure to expand clientele, (c) delivers services to communities of seniors, not individuals. The latter service-delivery model is significantly more resource-intensive and complex than the hub-and-spokes approach.

In Ontario, the Peel [municipal] Housing Corporation (PHC) partnered with Peel Senior Link, a community agency, to create a hub-and-spokes network in its buildings. The hub provided 399 seniors with complex care needs and multiple chronic conditions, including dementia, with personal support, food, transportation, and homemaking. Eligible tenants were supported 24/7 and received up to eight hours of care a day. This initiative diverted 116 emergency room visits and prevented the placement of 121 seniors in LTCI (SSAO, June 8, 2021). The hub staff also served seniors within 3 to 5 kilometres of the PHC-owned buildings. Employee turnover was lower than within LTCI, with a greater proportion of full-time staff (SSAO, June 8, 2021).

Although the Peel hub-and-spokes model was successful, the Ontario Government funded it only once (SSAO, June 8, 2021). This is surprising, since supporting seniors in community-based housing reduces the need for Alternative Level of Care (ALC) hospital beds and institutional placements (SSAO, October 17, 2022; Valluru et al., 2019). Compared with the cost of Ontario ALC beds ($842-$949/day/patient), paid home care costs only $45/day/person, far less than LTCI beds ($142/day) (Drummond et al., 2020). It is hence crucial not only to raise professionals' awareness of such options but to encourage professionals to lobby governments to fund their expansion.

Extensive domestic and medical in-home supports

Eventually, people with dementia will likely need more extensive daily support. However, this situation need not condemn them to abandoning their homes and communities. There are still in-home options that address most needs of people with dementia.

Community-based geriatric assessment. Planning for more extensive in-home supports should start with a community-based rather than a hospital-based geriatric assessment. Canadians with

[3]See www.toronto.ca/community-people/children-parenting/seniors-services/seniors-housing-services/supportive-housing-program/

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dementia are in fact six times likelier to be institutionalized if the initial assessment is done in hospital (CIHI, 2022) and disproportionately less likely to be referred to community services (Livingston et al., 2020). Hospital administrators, under pressure to control costs, in turn pressure case managers to quickly discharge patients no longer needing acute care. Many with dementia are automatically referred to LTCI without consideration of in-home services (Aaltonen et al., 2021), even though these patients could return home if the necessary community services were available (Forbes et al., 2008). Instead, under administrative pressure, discharge planners who have little time to get to know these patients or their communities apply the same intervention framework ad nauseum and are often unable to coordinate with the rest of the medical team (Preyde, Macaulay, & Dingwall, 2009). Instead, aware that community-services waiting lists are long, often unaware of all available options, and lacking time to research them, they ask families to choose LTCIs from a list (SSAO, April 21, 2021).

To facilitate senior patients' return home from the hospital, patients and their families need integrated continuing-care plans that address worries about daily needs. Hence, planning could start with community-based geriatric assessment, in coordination with the patients' family physicians, who know their situation well. In Ontario, Brock Community Health Centre offers a geriatric assessment program to which seniors can refer themselves or be referred by family or healthcare providers. The Centre's program comprises comprehensive in-clinic and in-home needs evaluation. Relevant community services are then coordinated by an interdisciplinary team along with seniors' primary-care providers (CELHIN, 2023). This approach not only facilitates in-home services, it promotes seniors' freedom of choice and ties into their existing care partner network. We wholeheartedly advocate for this approach to become the rule rather than the exception.

Paid home care and self-directed funding. Home care may be the most important route to preventing people with dementia's institutionalization (Zabalegui et al., 2014). It is far cheaper to initiate and operate than institutions (Drummond et al., 2020). Canadians, however, lack access to community services, given their underfunding and scarcity compared with socioeconomically similar countries (MacAdam, 2011). Because of this disadvantage, the proportion of Canadians over 65 remaining at home is far lower than seniors in Switzerland, Germany, Norway, Denmark, New Zealand, and the Netherlands (Drummond et al., 2020).

A pilot project in Connecticut exemplifies a paradigm shift in funding, where 156 unpaid care partners were funded to return their family members from LTCIs into their communities. Under Medicaid's Money Follows the Person (MFP) program, the project significantly increased care-partner satisfaction and strengthened community partnerships (Kristof et al., 2016). Furthermore, the MFP program directly funds seniors (SSAO, February 23, 2021). They and their family members choose where to spend the money: on institutions, home care, or other noninstitutional alternatives, whichever best suits their needs and values.

In Canada, a model for self-directed seniors'-care funding already exists. Younger people with physical disabilities can receive provincial funds to independently hire and manage their own personal attendants (Kelly, 2016). Wheelchair users lobbied for this funding as part of Canada's independent-living movement, beginning in the 1980s (Cranford, 2020). However, people with developmental or psychiatric disabilities cannot receive direct funding. Instead, their care is funded indirectly and managed by unpaid care partners or legal guardians (Kelly et al., 2020). Except for Saskatchewan, none of this direct or indirect funding specifically includes people with dementia. Further, as soon as disabled Canadians turn 65, they become ineligible for provincial disability income support and must apply for federal Old Age Security (OAS), the Guaranteed Income Supplement (GIS), and provincial senior-specific funding (e.g., New Brunswick's Long Term Care program [KI-19]). Even where direct funding has no age limit, as in Saskatchewan (Government of Saskatchewan, 2023), seniors are expected to hire and manage their own attendants. This expectation limits the program's usefulness for people with dementia (personal communication, Katherine Ottley, Canadian Association on Gerontology conference, October 26, 2023).

Reablement. Rehabilitation involves using physical, occupational, and speech therapy techniques to remedy impairments. In contrast, reablement (restorative care) aims to increase independence. Practitioners focus on building strength and confidence in abilities, promoting self-care, regaining skills, preventing hospital readmission, and, crucially, postponing institutionalization (Rostgaard et al., 2023; SSAO, November 21, 2022). Reablement is also particularly useful to dispel the assumption that people with dementia will only decline (Lévesque, 2022). Poulos et al. (2017) argue:

> The message for policy makers, practitioners, families, and persons with dementia needs to be "living well with dementia," with a focus on maintaining function for as long as possible, regaining lost function when there is the potential to do so, and adapting to lost function that cannot be regained. (p. 450)

Given the immense stigma surrounding dementia and cognitive decline, finding reliable, affordable reablement for people with dementia is challenging. Most dementia-oriented services ignore prospects for improving independence, considering people with dementia a homogenous and near-hopeless population (Keyes et al., 2016). Yet reablement holds significant promise, having been shown to reduce healthcare and support use, thus lowering costs (Aspinal et al., 2016). Encouraging seniors to regain some independence is more fruitful than helping unpaid care partners cope with their distress at watching seniors struggle (Poulos et al., 2017).

Healthcare cooperatives. With government-funded senior home care being insufficient, community-initiated alternatives have emerged. Healthcare cooperatives are one example. One type, worker cooperatives, are owned by personal support workers. A second type of healthcare cooperative is owned by its consumers, a group of seniors or families who want better home care. Each member contributes a certain amount per month to jointly hire a personal support worker (SSAO, December 5, 2022). With illness prevention and client responsibility as central tenets (Craddock & Vayid, 2004), healthcare cooperatives' services range from supporting activities of daily living to intensive medical assistance, thus narrowing the significant gap in community-based geriatric services (Craddock & Vayid, 2004).

Although Canadian healthcare cooperatives started in Saskatchewan in 1962, they are not yet the go-to option for aging in place (Craddock & Vayid, 2004). Nevertheless, their number appears to be growing nationally. Quebec has integrated healthcare cooperatives into its social economy as a relief valve for government-funded home-care services. The former are regarded more favorably than for-profit agencies, known to cut corners on services or underpay workers to maximize their profit (Craddock & Vayid, 2004). Although healthcare-cooperative services are not usually free, fees are kept reasonable with supplemental government funding.

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Public community-based-care insurance plans. National long-term-care insurance plans have been implemented in Japan, Germany, France, the Netherlands, and South Korea, among others. They cover not only institutional care but home and nursing care. Japan's plan, an international model of best practice, emphasizes community-based supports while facilitating familial care (Chen et al., 2020).

Long-term-care insurance plans can be financed by employer and employee contributions, income taxes, and pension deductions. These plans borrow from the self-directed-funding model, with one exception: they are federal, not provincial. Thus, they implement national policy standards, equalizing resources across the country. This option is not yet available to Canadians. Canada's overspending on institutional geriatric care and underspending on home care, compared with other OECD countries (Drummond et al., 2020), supports calls for abandoning this funding imbalance and switching to publicly funded insurance plans. When Réjean Hébert was Quebec's Minister of Health, he proposed such a plan. Although the project was not implemented, its design covered all "legal, administrative, funding, training and contractual" (Hébert, 2016, p. 45) conditions required for its application and thus could have become a model for Canada. We advocate such an initiative, as public community-based-care insurance plans show great promise for allowing seniors to choose where and how to receive care.

Short-stay care. Short-stay care allows family care partners who live with disabled adults to take breaks or vacations while care recipients occupy bedrooms in group homes, supported apartments, or LTCIs (CLT, 2022). Short-stay care can also provide regular respite when care partners feel burned out, have limited resources at home, or need more community support. Crucially, short-stay care can, together with other interventions, significantly reduce negative care experiences and delay the institutionalization of people with dementia (Etters et al., 2008).

More broadly, respite care frees up ALC beds (Drummond et al., 2020), allowing hospitals to admit more patients from emergency departments (Affleck et al., 2013). Although family care partners have been hesitant to request short-stay care and thus relinquish their care to strangers (Strang & Haughey, 1998), respite care can allow seniors to try out institutions without the trauma of forced transitions accompanied by the stripping of civic freedoms (Lévesque, 2022). Although we advocate community-based-care options, respite care can help seniors make more informed choices about institutional care before agreeing to move, should they prefer that option. Conversely, short-stay care can facilitate hospital-to-home transition, while seniors recover and in-home services are arranged.

Ottawa has a guest house for people with dementia, a seniors-village bungalow containing 12 private rooms with private baths, common living room, kitchen, dining area, and secure courtyard. The bungalow is dementia safe (e.g., all hallways lead to common rooms, floors are soft). Fees are low, and guests can participate in a day program and household tasks (Cleary, 2020).

Paying family care partners. When seniors need extensive healthcare and/or domestic services, care may become nearly impossible to juggle with full-time employment. Raising children, being poor, living far from the senior, and lacking community support make unpaid care impossible. The impossibility may threaten the person with dementia's safety and well-being. Accessing paid leave from employers and/or being paid to care are two ways to solve this problem. Either way, family care partners can better support their family members, instead of grieving their placement in institutions when no other options are available.

Some federal programs pay family care partners.[4] However, these programs are insufficient and/or incomplete. From employment insurance, care partners may receive 55 per cent of their earnings (up to $650 a week) for 15 weeks under the family-caregiver-for-adults benefit, or for 26 weeks under the compassionate-care benefit (Government of Canada, 2023a). Only family care partners of critically ill or near-death individuals are eligible, however, ignoring care needs before death approaches. This is especially true for family members of people with dementia who die of other causes.

Canada also offers the caregiver tax credit, where citizens can claim either $2,350 or $7,525 depending on their relationship to the cared-for person (Government of Canada, 2023b). If that person pays taxes, they can also reduce them through the disability tax credit (Carl, 2023). Although a step in the right direction, these tax credits are nonrefundable and therefore irrelevant to most low-income care partners who pay little to no income tax (Lévesque, 2022). At the federal level, Canada still lacks nonmeans-tested payments (not affected by personal savings or income) to care partners. England, in contrast, offers the Attendance Allowance, Personal Independent Payment, and Disability Living Allowance (Alzheimer's Society UK, 2024). Everyone thus equally benefits from these supports across the earning spectrum.

Nova Scotia and Newfoundland and Labrador are the only provinces that fund family care partners directly. The latter's Paid Family Caregiver Program funds 4–5 hours of personal assistance/day/eligible person, with additional funding for homemaking and respite care (SSAO, February 25, 2021). Nova Scotia pays care partners only $400 a month, which renders its policy largely ineffective (Carl, 2023). Notably, most provinces offer some form of funding for home adaptations to bolster independence and respite care. Although these programs cut some costs, they hardly replace employed care partners' full-time salaries. Most Canadians are hence forced to delegate family-member care to publicly funded strangers.

Out-of-home supports

When all options that enable the person with dementia to remain at home have been exhausted, if the person does not want to live alone, or if unpaid care is not sufficient, it is time to look for community-based housing that provides more supports.

Community-based supportive housing. Our rationale for replacing LTCIs with community-based alternatives echoes a movement from the 1960s to the 2000s called 'deinstitutionalization' that challenged the institutional model of care for younger disabled people (Kelly, 2016). An alternative, community-based supportive housing (CBSH) was built for people with developmental, psychiatric, and other disabilities while institutions closed – although not in all provinces/territories.

As is currently happening with LTCIs, calls to improve institutions preceded calls to replace them, but deinstitutionalization advocates quickly recognized that institutions were ineffective and dehumanizing (Panitch, 2008). The movement ultimately enabled younger disabled people to live in CBSH or their own homes with supports (Cranford, 2020). Similar twentieth-century

[4]Although federal benefits are standard across Canada, other benefits vary between provinces and territories. They should be researched by professionals familiar with the provinces/territories.

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movements closed other institutions, such as orphanages and Indigenous residential schools. Deinstitutionalization-history lessons apply to creating sustainable LTCI alternatives.

CBSH for people with developmental disabilities is generally owned and run by nonprofit organizations. The first CBSH developed was group homes. Unlike LTCIs, group homes are not modelled on hospitals (Oldfield, 2019) but on family homes. These existing houses, renovated perhaps with added ramps and bathrooms, visually integrate into neighbourhoods. Group homes house from 4–10 residents with 24-hour staff support. Most bedrooms are private, some shared with one other person, and are decorated to residents' tastes with their own belongings. Welcome to visit, family and friends do not have to sign in or wear badges as in institutions. Staff and residents may cook meals together, do laundry, and clean. Staff accompany residents on outings of residents' choosing, to medical appointments, help with personal care, and provide emotional support. More recently, supported apartment living was developed, where several people share an apartment and staff rotate among apartments.

CBSH is purposefully located in neighbourhoods housing people of varying age, close to schools, day cares, shopping, and community centres. This housing thus does not segregate people in large buildings because of their age and disability. Since CBSH is small, it can operate less bureaucratically than institutions. Institutional time[5] does not predominate, with more time for relational care (Oldfield, 2019), and it is easier for residents to engage with surrounding communities. Staff can prioritize residents' wishes through routines that follow their rhythms; in other words, residents' time (Oldfield, 2019). CBSH is an indispensable shift towards better quality of life and civic engagement for older adults with disabilities, including dementia, while also being cheaper to operate than LTCIs (Robison et al., 2011).

In their systematic review, Pywell et al. (2023) found that small-scale homelike seniors'-care settings (SSHS) consistently improved outcomes, compared with institutional settings. SSHS had better care quality, functional-decline rates, social stimulation, emotional well-being, quality of life, and lower restraint use than institutional settings. Some outcomes (e.g., fewer hospital admissions) lowered healthcare costs. Residents reported more freedom, privacy, and stronger relationships. Staff seemed more comfortable encouraging independence and felt more motivated to stay, lowering turnover. Pywell et al. (2023) concluded that SSHS achieves superior results across many areas without inflating costs. Crucially, CBSH is safer, both physically and psychologically. During the COVID-19 pandemic, seniors in LTCIs were 13 times more likely to die than their community-dwelling peers (Fisman et al., 2020). Under a social model of care, CBSH staff are expected to focus on building residents' existing strengths, while encouraging choice and independence (SSAO, March 31, 2021). Although in Canada, the CBSH model has been applied on a small scale to serve seniors, including those with dementia, it has been applied more widely in the United States, Sweden, Germany, and Japan (SSAO, March 31, 2021). CBSH is a very good option for seniors who do not want to live alone or with family, or who do not have unpaid care partners such as adult children to offer necessary supports.

Multigenerational housing. When seniors with dementia have immediate family to rely on, multigenerational housing can provide safety while they not only remain in the community but close to their families. Homes can be expanded into multigenerational dwellings in multiple ways. The first is accessory dwellings (also called granny flats and laneway homes). These are small, self-contained houses constructed in the backyards of family homes or replacing garages. Homeowners can build them for their parents or, when the homeowners are seniors, they can build and occupy the accessory dwellings while their children and grandchildren occupy the main house. When grandparents no longer need the accessory dwellings, they can be rented out for income. Second, homeowners with smaller lots can construct accessory units inside their houses (e.g., in-law suites in the basement or home extensions). Both parties have separate spaces with reliable supports nearby when needed; for example, childcare for parents, domestic and other support for grandparents, and companionship for all.

Third, suburban developers are constructing large multigenerational houses to serve immigrant families, in which senior parents customarily live with their children in a family model of care. These new houses incorporate parents' suites that, later, can be offered to extended family members or rented out for income. Hence, even if a multigenerational house is purchased to serve family members' needs, it remains a potentially revenue-generating investment.

Although increasingly common across Canada, retrofitting houses into multigenerational homes may face systemic barriers. Zoning bylaws meant to exclude multifamily housing may only allow single-family dwellings, with accessory buildings without a construction permit limited to a maximum of 100 sq. ft. Permits may require separate electrical hookups to the power grid for accessory dwellings, increasing their costs. However, many cities have changed planning regulations and zoning to allow these accessory dwellings (Benzie et al., 2020). Not only do they benefit seniors who wish to live with their families, but for cities wanting to increase density, these dwellings do so without visibly changing neighbourhoods and generating backlash from the surrounding homeowners.

Cohousing. Cohousing is a type of communal living in which single houses, apartments, or townhouse clusters are designed to facilitate activities among residents by, for example, sharing dining rooms and gardens. Individual units can be owned privately or by an organization and rented out. Buyers or renters agree to support each other socially and instrumentally and may also share operating and maintenance costs, and pool their resources (e.g., through bulk purchasing). This cost minimization and the collective approach are advantages of cohousing.

There are two potential drawbacks to cohousing: (a) conflicts may affect the community's operation and volunteer-task allocation (Benzie et al., 2020) and (b) because cohousing often requires residents to buy their units or contribute to a house purchase, it may not be affordable for low-income seniors (Poulin, 2022).

Another form of cohousing is where middle-aged people and/or seniors purchase a home together. They care for each other and, when they no longer can, jointly hire personal support workers (PSWs) and homemakers. Notably, cohousing communities are not informal. Prospective buyers must draw up and sign legal contracts regarding how they will jointly own the house, operate it, and share expenses. According to communal agreements, this form of cohousing can be managed by family or friends to accommodate physical and cognitive impairments that arise with aging (Lord, 2022). Overall, seniors' cohousing focuses on social and health-related support, with either accessible designs or budget allocations to retrofit units for accessibility that reduce the need for institutional care (Poulin, 2022).

Nonprofit housing cooperatives. These are apartment buildings or townhouse clusters collectively owned by all resident members.

[5]Oldfield (2019) explains, institutional time is the dominant force structuring daily life for LTCI staff and residents. Residents' time is how residents would prefer to structure their daily lives.

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Member volunteers democratically run each cooperative through boards of directors and committees, and large cooperatives often have paid staff to manage and maintain property. Rents remain affordable since they only increase with the cooperative's budget, which members must approve collectively; there is no profit (Harahan et al., 2006). Wheelchair-accessible units in some cooperatives house members who may receive attendant care. Senior members may receive home care.

Because housing cooperatives are more secure and affordable than private-market housing, members may stay for decades, their cooperatives becoming *de facto* NORCs. To facilitate aging in place, members can use cooperative funds to retrofit units, apply for grants as nonprofit organizations, and neighbours may become unpaid care partners (Harahan et al., 2006). Given cooperatives' collective structure, services arranged by individual members can be coordinated to improve service-delivery efficiency. Coordination can improve flexibility for care recipients, along with working conditions and job security for workers (Cranford, 2020).

Pocket neighbourhoods. These are small car-free neighbourhoods comprising 6 to 12 dwellings clustered around an open area. Entrances face each other, fostering interaction among neighbours. The dwellings may include bedrooms for paid caregivers (Benzie et al., 2020). Pocket neighbourhoods can minimize isolation, a strong predictor of declining health in old age (Freedman & Nicolle, 2020). However, there is little research on how well pocket neighbourhoods serve seniors with high or rapidly changing care needs (Benzie et al., 2020). At least, when people living with dementia live in small neighbourhoods well connected with community services, they are less likely to 'fall between the cracks' when their needs surpass available services. For seniors whose dementia progresses slowly, is well managed, and/or who are frequently visited by unpaid care partners, pocket neighbourhoods are an excellent option for maintaining meaningful community engagement.

Conclusion

The institutional model of dementia care – locked wards in long-term-care institutions – is not only rife with problems but unanimously repudiated as a last resort and unimaginable end of life (Lévesque, 2022). Segregating disabled people, including those with dementia, in institutions is against the UNCRPD, a treaty that Canada signed. Yet Canada's dementia care remains clouded by systemic ageism and ableism, with institutions as the default option irrespective of seniors' overwhelming preference for aging in place. Decades of deinstitutionalization enabled younger disabled people to live in the community with supports. Do seniors with dementia and other chronic conditions not deserve the same?

In this article, we contribute to dementia-care literature in multiple ways. We describe a plethora of more humane alternatives to institutional dementia care that exist, or could exist, in Canada. We present a roadmap for professionals to consider all relevant care options when helping clients with dementia and their families plan service trajectories that keep clients out of institutions. Our roadmap incorporates supported decision making, an underapplied approach in dementia care that empowers people to preserve their agency, rather than the substitute decision making that currently dominates the institutional landscape. Therefore, both our roadmap and descriptions of alternatives to institutions contribute to the growing practice of advanced care planning.

Given the strong evidence in support of community-based alternatives for dementia care presented above, we argue that politicians' continued funding of institutions and reluctance to fund noninstitutional alternatives – which are cheaper, safer, and have higher rates of satisfaction (Estabrooks et al., 2020) – is inexcusable. We hope that this article will be useful to professionals, their associations, and dementia advocates in lobbying governments to reallocate our tax dollars from funding institutions to expanding existing community-centred options and creating new ones. We also hope that this article contributes to a paradigm shift in how Canada serves its citizens with dementia. Spreading the word about noninstitutional alternatives to your colleagues, family, and friends will broaden their knowledge of options and promote change. Write your MP and your MPP, MLA, or MNA, and lobby them in person. Tell them to shift funding from institutional care to home care and community-based options.[6] Encourage your colleagues, family, and friends to lobby their local politicians, too. If you belong to a professional association, encourage executives to add the paradigm shift to the organization's advocacy agenda and lobby federal and provincial politicians. As we have shown throughout this article, paradigm shifts away from institutional care are possible.

Supplementary material. The supplementary material for this article, which contains references not in the References list, can be found at http://doi.org/10.1017/S0714980824000308.

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[6]Seniors for Social Action Ontario (www.seniorsactionontario.com) is doing this. Look for a similar organization in your province/territory.

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