Enabling the Future Provision of Long-Term Care in Canada

NATIONAL INSTITUTE ON AGEING

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Table of Contents

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About the National Institute on Ageing and the Future of Long-Term Care Series Sponsors

The National Institute on Ageing (NIA) is a public policy and research centre based at Ryerson University in Toronto. The NIA is dedicated to enhancing successful ageing across the life course. It is unique in its mandate to consider ageing issues from a broad range of perspectives, including those of financial, physical, psychological, and social well-being.

The NIA is focused on leading cross-disciplinary, evidence-based, and actionable research to provide a blueprint for better public policy and practices needed to address the multiple challenges and opportunities presented by Canada's ageing population. The NIA is committed to providing national leadership and public education to productively and collaboratively work with all levels of government, private and public sector partners, academic institutions, ageing-related organizations, and Canadians.

The NIA's 2019 Policy Series on the Future of Long-Term Care has been sponsored by and produced in collaboration with AdvantAge Ontario, the Canadian Medical Association (CMA), Essity, and Home Instead Senior Care.

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Since 1867, the **Canadian Medical Association** has been the national voice of Canada's medical profession. We work with physicians, residents and medical students on issues that matter to the profession and the health of Canadians. We advocate for policy and programs that drive meaningful change for physicians and their patients.

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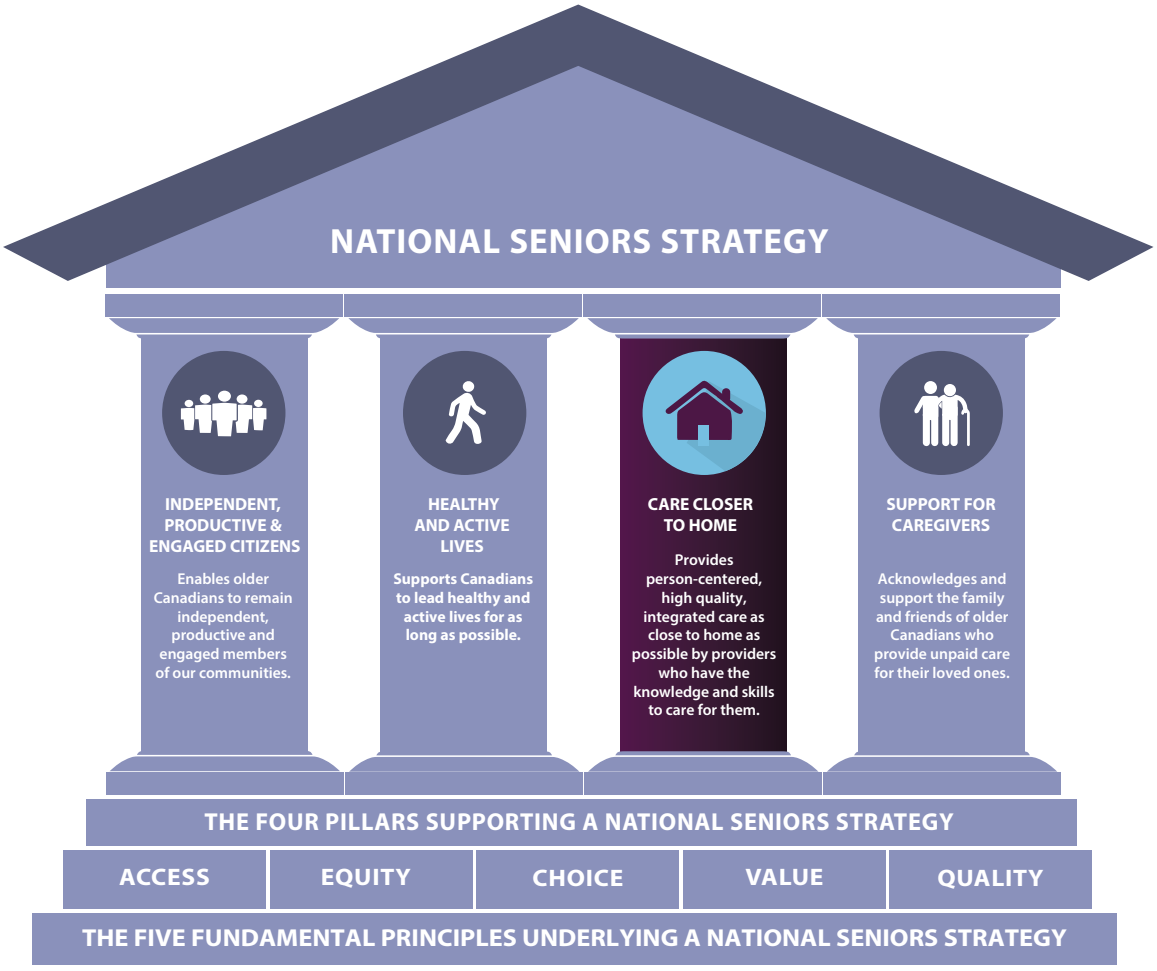
About the NIA's National Seniors Strategy

The NIA further serves as the academic home for the National Seniors Strategy (NSS), an evolving evidence-based policy document co-authored by a group of leading researchers, policy experts and stakeholder organizations from across Canada and first published in 2014. The NSS outlines four pillars that guide the NIA's work to advance knowledge and inform policies through evidence-based research around ageing in Canada: Independent, Productive and Engaged Citizens; Healthy and Active Lives; Care Closer to Home; and Support for Caregivers.



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Disclaimer: The NIA has developed this document to provide a summary of general information about the provision of long-term care in Canada, as well as to discuss emerging enablers to support the future of long-term care.

An Introduction to the NIA's 2019 Policy Series: The Future of Long-Term Care

Each year, the NIA identifies a key policy challenge to address through expert research, broad engagement, and actionable reports. This year, the NIA is launching a three-part policy series that examines the current system of home and community care and of care delivered for older Canadians in designated buildings, such as nursing homes.

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Governments are looking for the right mix of publicly desired, clinically appropriate, and cost-effective services delivered across a variety of settings and to a population with an increasing diversity of needs, abilities, and challenges. At the same time, there is a growing demand and necessity to provide more high-quality *long-term care* to Canadians within the confines of strained health care budgets and limited household means. This has become particularly challenging, as Canadians are now living longer with more complex

Defining *Long-Term Care*

The NIA defines *long-term care* as: A range of preventive and responsive care and supports, primarily for older adults, that may include assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) provided by either not-for-profit and for-profit providers, or unpaid caregivers in settings that are not location specific and thus include designated buildings, or in home and community-based settings.

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health, social, and functional issues than any previous generation.

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When Canada established its universal health care system in the 1960s, the average age of Canadians was only 27 years and life expectancy was less than 70 years. Today, Canadians can expect to live more than 80 years. Decision-makers of previous generations faced less pressure to comprehensively address how *long-term care* services should be provided or funded. When Medicare was founded across Canada, the population was young and growing; ensuring all Canadians had universal access to primary and hospital care was the priority. But Canada is very different today than it was 50 years ago and, while its citizens have matured, its health care system hasn't kept pace with their evolving needs.

The Future of Long-Term Care in Canada is Largely Uncharted Territory

It's always easier to be critical of the past and present than it is to optimistically envision the future and the path to get there. This NIA series will attempt to do both. And while the future is uncharted territory, challenges cannot be left to future generations of Canadians. The provision of health and social care, like all large, complex systems, requires constant evolution in response to changing circumstances and priorities. Therefore, the goal of this NIA policy series is to understand the present with an aim towards charting a clearer future for the provision of *long-term care* in Canada.

It is important that governments spend their tax revenues in the most effective and efficient ways to help ensure the future sustainability of systems, programs, and services, and to produce better outcomes for the ageing population. While government funding is crucial, better quality care is achievable by means other than just spending. Better, evidence-based

policy, targeted funding with clear accountability measures and aims, and political will to enact reforms can help achieve desired outcomes.

Governments have a central role to play in providing the right care and support, in the right place, at the right time and by the right provider. But Canadians of all ages also have the right and ability to understand how they can participate in determining the best ways for them to age with independence, dignity, and respect in the place of their choice. Canada's universal health care system may not be perfect, but its principles are a clear point of pride for many Canadians. Canadians expect government to provide the essential care they will need and are therefore surprised when faced with a *long-term care* system that is not fully funded by government. Instead, the provision of *long-term care* relies on a mix of public and private funding and varies in the way it is structured, organized, and delivered across every province and territory.

What is further becoming clear is that the need for *long-term care* will not be easily met by current levels of public funding. Canadians are justified in asking: 'What options do I have?,' 'What's publicly funded?,' 'What should I organize and pay for myself?,' 'How much will I need to save to meet my goals?,' 'How can I stay in my home if I only need a little help to do so?,' 'Where do I go if I can no longer manage on my own at home?,' and 'How can I best be supported and enabled as an unpaid caregiver to another person?'.

In this context, Canadians will need more clarity on how existing publicly and privately funded options can be leveraged and integrated to produce the type and level of care they will want and need. Canadians may also need governments to enable them to better help themselves. A number of countries have turned to government-enabled private or public mechanisms to pay for *long-term care*, some of which are surveyed in this report.

The NIA's Future of Long-Term Care Policy Series Reports

In the inaugural report of this series, Dr. Samir Sinha, the NIA's Director of Health Policy Research, and his team will explore the current provision of *long-term care* across Canada and place it within the global context of comparable countries that are also tackling significant demographic

transitions as they redevelop their systems of care. While Canada's current challenges will be highlighted, so too will evidence-informed opportunities and enablers of innovation in this growing and important area of care. Dr. Sinha's report will set the health policy stage for the rest of the series, which will work towards developing clear recommendations for government policy and decision-makers, care providers, and citizens to consider that can improve the approach to the future provision of *long-term care* within the fiscal reality all governments are facing.

In the second report, Dr. Bonnie-Jeanne Macdonald, the NIA's Director of Financial Security Research, Dr. Michael C. Wolfson, former assistant chief statistician at Statistics Canada, and Dr. John Hirdes, Professor at University of Waterloo and Ontario Home Care Research and Knowledge Exchange Chair, will investigate the projected future costs of providing home and community care, and care provided in designated buildings, such as nursing homes, if no action is taken to advance the status quo. In acknowledging that provincial and territorial budgets are currently stretched, the purpose of this report will be to project the real costs of providing home and community care and care in designated buildings over the next three decades. This report will build on existing research and literature, and use a large-scale population modelling tool to show projected costs and scenarios based on real-life data. This will allow policy and decision-makers and stakeholders to really understand for the first time what future care needs may actually truly cost for all of Canada. Where Dr. Sinha's report will set the stage for necessary health policy reforms, this second paper will set the stage for necessary fiscal reforms.

The third and final report of the series will then bring together experts in financial and health policy to present options and recommendations for a feasible and fiscally responsible set of policy scenarios, to enable high-quality care services for older adults.

The NIA will engage with a broad cross-section of experts, care providers, economists, government officials, and the public. The overall goal of this Policy Series will be to help government policy and decision makers, existing care providers, and members of the general public clearly understand the options available to meet the *long-term care* needs for Canada's ageing population.

Executive Summary

Canada is Currently Struggling to Meet the Needs of Its Ageing Population

Older Canadians overwhelmingly want to age with dignity and autonomy in their homes and communities with appropriate care and support for them and their families. Canada's provinces and territories, however, are struggling now more than ever to meet the rapidly growing needs of the ageing population. Over 430,000 adult Canadians were recently estimated to have unmet home care needs (Gilmour, 2018b), while over 40,000 Canadians are currently on wait lists for nursing homes due, in part, to a lack of available home and community-based care.

Governments around the world are looking for the right mix of publicly desired, clinically appropriate, and cost-effective services delivered across a variety of settings to a population with an increasing diversity of needs, abilities, and challenges. At the same time, there is a growing demand and necessity to provide more high-quality *long-term care* to Canadians within the confines of increasingly strained health care budgets and limited household means. This has become particularly challenging, as Canadians are now living longer with more complex health, social, and functional issues than any previous generation.

Over 430,000 adult Canadians were recently estimated to have unmet home care needs (Gilmour, 2018b), while over 40,000 Canadians are currently on wait lists for nursing homes due, in part, to a lack of available home and community-based care.

While government spending on the provision of *long-term care* is increasing across Canada, it has not kept pace with the spending of most other Organization for Economic Co-Operation and Development (OECD) nations. There is also

insufficient clarity across Canada on where the private and public provision of services begin and end and what amount and types of *long-term care* can and will be publicly-supported.

Meanwhile, older Canadians, their families and their caregivers still find it challenging to access the right care and supports when they need it, with a majority reporting that their families are not in a good position (financially or otherwise) to care for older family members if they were to need long-term care (Ipsos Public Affairs, 2015).

Canada Is Struggling to Define What Long-Term Care Is and Looks Like Across The Country

There is no commonly accepted definition of long-term care across Canada.

In fact, there are almost as many definitions as there are Canadian jurisdictions and health systems. The lack of definitional consistency is compounded by insufficient, imprecise, and inconsistent data, making it difficult to understand how much Canadians and their governments spend on the provision of *long-term care*, where and how care services are delivered, who is delivering it, or even how many Canadians are receiving or actually need it. In exploring this topic, the NIA chose not to simply adopt an existing international definition of long-term care. Rather, the NIA focused on recognizing the common elements across existing definitions (See Figure 1) that describe what *long-term care* constitutes, as well as where and how it is commonly being delivered and by whom.

Defining *Long-Term Care*

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Current Key Challenges in the Provision of Long-Term Care

Canadians struggle to understand what to expect from, and how to navigate, publicly-supported *long-term care* services, and how best to prepare for their own needs as they age. The current care that is available is not seen as offering the level of flexibility and choice that is needed to meet the needs of an increasingly diverse population. Both care providers and unpaid caregivers have unique needs that must be better recognized and addressed to ensure that Canada can continue to attract these individuals to meet the growing and evolving care needs of the ageing population.

The current delivery of *long-term care* across Canada also remains inadequate and challenging. Many Canadians report having unmet home care needs, others remain on wait lists for admission to nursing homes, and a costly imbalance of care provision across the system has resulted in thousands of Canadians on a daily basis waiting in expensive hospital settings as 'Alternate Level of Care' (ALC) designated patients often until their far less expensive long-term care needs can be met (Gibbard, 2017).

Finally, with no established federal standards for this type of care across Canada, there exists a patchwork of programs and variations in the availability of services, level of public funding, eligibility criteria, and out-of-pocket costs for clients and residents at the level of each province and territory. As many Canadians also choose to purchase additional care from private agencies, provinces such as Quebec have deliberately encouraged and further subsidized this practice as a way to help its citizens better meet their long-term care needs. What is clear is that no approach or jurisdiction in Canada has yet emerged as the best jurisdiction for the provision of *long-term care*.

A Sector Already Full of Innovative Responses

Despite the current challenges, providers and jurisdictions across Canada, and around the world, have been supporting innovation in the *long-term care* sector through the development, spread, and adaptation of models of care, support, and care

practices. The last few decades have seen a host of new innovative policies, models of care, and approaches being implemented in the provision of *long-term care* that have evolved based on regional priorities. In examining these care innovations in a more systematic way, the NIA has segmented Canada's older population into four categories across the *long-term care* continuum (See Figure 7).

Emerging Enablers and Opportunities

Finally, the NIA has identified four emerging enablers that could support the future provision of *long-term care* in Canada. Indeed, a sustainable and successful future will depend on us adopting a strategic approach that is grounded in:

1. **Enabling evidence-informed integrated person-centred systems of *long-term care*, accounting for the expressed needs and desires of Canadians.**

2. **Supporting system sustainability and stewardship through improved financing arrangements, a strong health care workforce, and enabling technologies.**

3. **Promoting the further adoption of standardized assessments and common metrics to ensure the provision of consistent and high-quality care no matter where Canadians need it.**

4. **Using policy to enable care by presenting governments with an evidence-informed path towards needed reforms.**

The NIA will use these potential enablers as the basis for its continued conversations around the future provision of *long-term care* in Canada in 2019 and beyond. Canadians should expect and deserve access to appropriate and affordable *long-term care* options that enable them to age with dignity, independence, and respect. Achieving this will require decisive action based on solid evidence, that enables innovation and begins an honest national conversation around what it will truly cost to provide better, more equitable and higher quality care for all Canadians.

Section 1: Contextualizing the Provision of Long-Term Care in Canada

Why Long-Term Care Matters

When Canada's postwar generation began turning 65 in 2011, growing numbers of policy-makers began to appreciate that the traditional approaches towards funding the provision of health and social care services across Canada were no longer sustainable. For example, in 2016 older adults comprised a sixth of Canada's population but accounted for approximately 45% of its provincial and territorial health expenditures (CIHI, 2017a).

Canada's ageing population and shifting demographic imperatives are now presenting a challenge for how care should be provided and funded in Canada. The Canada Health Act (CHA) was created in 1984 and specifically focuses on the provision of hospital and physician services and does not address the universal provision of *long-term care* or pharmacare.

While not enshrined in the CHA, each of Canada's provinces and territories have established ways of providing a level of nursing home, home, and community care and support services. While coverage levels and qualifying criteria vary significantly across provinces and territories, there is a growing recognition of the inherent value of these services to meet the *long-term care* needs of an ageing population effectively and sustainably.

The resulting demand for home and community care services is already unprecedented and is only expected to grow as the population ages. For older Canadians, the availability of services like nursing, physiotherapy, occupational therapy, home maintenance, and personal support (hygiene care, support with dressing and meal preparation and housekeeping) can mean the difference between being able to remain at home and having to seek care and support in a retirement or nursing home with the associated public and private expenses. While Canada is spending more on health, social, and community services than ever before, older Canadians, their

families and their caregivers still find it challenging to access the right care and supports, when and where they need it.

Canada's unprecedented demographic shift presents both challenges and opportunities. The majority of Canadians now see access to care in, or close to, their homes, and a robust home care system as their top national health care priorities. A 2015 national survey conducted by Ipsos Public Affairs for the Canadian Medical Association (CMA) found that 63% of respondents expressed concerns that their families were not in a good position (financially or otherwise) to care for older family members if they needed long term health care (Ipsos Public Affairs, 2015). When asked what they would prioritize to improve the care of older Canadians, 92% prioritized the availability of health care professionals trained to provide health care to older Canadians, 89% of respondents wanted to see the provision of more home and community care, and 88% wanted to see improved access to nursing homes (Ipsos Public Affairs, 2015).

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As Canadians want to age and receive care in the setting of their choice, as appropriate to their needs, they increasingly need and desire a robust *long-term care* sector. Governments and the private sector have taken note by significantly expanding their provision of a broad range of *long-term care* services over the past few decades.

Despite this increased focus, over 40,000 Canadians are currently on wait lists for nursing homes due, in part, to a lack of home and community-based care. In fact, in 2015/2016 over 430,000 adult Canadians were estimated to have unmet home care needs (Gilmour, 2018b). A major consequence of all of this has been the creation of a costly imbalance of care provision across the system, which has resulted in thousands of Canadians on a daily basis waiting in expensive hospital settings as 'ALC' designated patients often until their far less expensive long-term care needs can be met (Gibbard, 2017). Approximately 14% of hospital beds across Canada, or around 7,500 beds, are occupied by ALC-designated patients (CHSRF, 2011). In Nova Scotia, approximately 1/3 of hospital beds, are occupied by ALC-designated patients (Picard, 2019). In 2017, the federal government responded in part by beginning to transfer $600 million annually to the provinces and territories in addition to the Canada Health Transfer (CHT) agreement to specifically improve the provision of home and community-based care across the country (Department of Finance, 2017).

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The availability of the right care in the right place is not the only concern. Canadians are clearly concerned about the public and personal costs of care in older age. In its most recent 2019 national survey conducted for the CMA, Ipsos found that that 88% of respondents were worried about the growing health care costs due to the ageing population, with 58% reporting that they believed that many Canadians will delay their

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Health care quality and costs currently top the worries of Canadians, with 65% of respondents over 55 years of age reporting it as their greatest concern (Ipsos, 2019). It is no surprise that 66% of respondents over age 55 reported that they will vote for the party that they believe has the best plan for the future of health care (Ipsos, 2019).

Health care may be a complex system, but at its centre are the people who provide and receive the vital care that is needed. Providers of *long-term care* services in Canada are facing mounting challenges in finding and retaining qualified staff to support the growing and complex health and social care needs of an ageing population. As this report notes, much of that has to do with the systemic over-prioritization of the provision of primary and hospital-based care at the expense of those working in the *long-term care* sector. Front-line care providers across Canada's *long-term care* sector have generally been

underappreciated, overworked, and underpaid, despite being the teams and individuals who care for the most frail, vulnerable, and complex amongst us. It's clear that adequately supporting and recognizing the invaluable work these dedicated individuals provide in enabling older Canadians to age at home and in their communities will be crucial to the future successful provision of *long-term care* in Canada.

An increasing number of unpaid caregivers are also burning out from the challenge of helping their loved ones to age in the place of their choice. Canada's over 8 million unpaid caregivers – usually family or friends of other Canadians in need - provide far more than the $25 billion annually in care cost savings for the publicly funded health care systems they were estimated to be saving a decade ago (Hollander, Liu, & Chappell, 2009). But this support has come at a considerable cost to unpaid caregivers themselves. With approximately 35% of working Canadians balancing paid work with unpaid caregiving duties (Government of Canada, 2015a), these individuals are increasingly finding it a challenge to maintain a balance of work, life, and caregiving duties (NIA, 2018). Not only are all Canadian unpaid caregivers at an increased risk of burning out, but the added challenges being faced by unpaid caregivers who also work are now being identified as a significant potential threat to Canada's future economic productivity (NIA, 2018).

In Canada, the Ministry or Department of Health in each province and territory is responsible for the overall funding and provision of health and long-term care services, including the strategic direction, priorities, and supporting legislation and regulations (CHCA, 2013). Different approaches can result in a patchwork system of similar care types across Canada, but a virtue of Canada's federal model is that provinces can reform or create systems of care that address the regionalized and particular needs and challenges of each province and territory. Nevertheless, there is a clear opportunity to learn from the approaches taken by international jurisdictions facing similar issues.

A Spotlight on Denmark's Unique Approach to the Provision of Long-Term Care

Three decades ago, Denmark was facing similar demographic and fiscal imperatives that Canada is currently experiencing. Denmark took a seemingly radical approach at the time in prioritizing its future health care spending investments into their home and community care sector and in the development of more assisted living and supportive housing units (DIW Berlin, 2010).

Doing so allowed Denmark to not only contain its growing health care spending, but also allowed it to greatly reduce the overall demand for nursing home care and to deliver more care in the community where people wanted to receive it. Denmark, in fact, was able to avoid building any new nursing homes for close to 20 years, while closing thousands of hospital beds (DIW Berlin, 2010). The country also saw a 12% reduction in its overall long-term care expenditures to the population 80 years and over during the first decade of its new approach (Stuart & Weinrich, 2001).

In the 1990s, Denmark's municipalities, which were put in charge of providing long-term care services, became required by law to offer at least one preventive home visit per year by a community-based health care professional, such as a nurse, to those age 75 years and over (Vass et al., 2007; Pederson, 2014), on the premise that a proactive visit could prevent larger problems and lead to better care outcomes and lower costs.

More recently, Denmark has implemented a deliberate 'reablement' policy approach, enabling restorative care to become a key feature of any ongoing home and community-based care it provides. This well-evaluated approach not only benefits older persons and their families but has also been found to be effective in reducing the need for health care services, thereby reducing overall future per person costs of long-term care services (Tessier et al. 2016; Lewin et al., 2013).

While Denmark spends 2.5% of its GDP on publicly funded long-term care health services compared to an OECD average of 1.7%, its annual spending growth rate of 2.5% on long-term care services over the past decade was well below the annual OECD average growth rate of 4.6% (OECD, 2017).

Denmark's unique approach to the provision of long-term care has led it to currently spend 36% of its long-term care funding on care in designated buildings, such as nursing homes, while spending 64% on home and community-based care – a reversal of the OECD average spending of 65% of long-term care funding on care in settings like nursing homes and only 35% on home and community-based care (OECD, 2017).

What Does the NIA Mean By Long-Term Care?

The NIA's engagement with its stakeholders thus far on this topic has made it clear that *language* and *vocabulary* has come to matter a great deal when discussing all aspects of the provision of *long-term care* in Canada. This has especially become the case when more negative connotations have developed, fairly or unfairly, around the provision of certain types of *long-term care*, as well as those who provide and receive them. Some jurisdictions like Ontario have come to officially use the term long-term care to specifically describe its nursing home sector – even though this sector is increasingly using its assets to provide a broader range of short-term and home-based care services as well. This reality led British Columbian providers to now refer officially to their nursing homes as 'care homes' rather than 'long-term care homes'. In Manitoba, these settings have been commonly referred to as 'personal care homes'. For the purposes of this series, these care settings will be referred to as 'nursing homes' as it remains the most commonly understood descriptor of this form of long-term care.

The use of the term *long-term care* by the NIA, therefore, may seem at first somewhat confusing for Canadian audiences, as there is no single accepted and inclusive term used across all provinces and territories compared to other international jurisdictions. Most international definitions tend to use the term long-term care to encompass the provision of home, community, and nursing home care and supports.

While globally-focused organizations like the World Health Organization (WHO) and Organization for Economic Co-Operation and Development (OECD) have established their definitions of long-term care, neither has yet become the accepted definition of long-term care internationally – although there seems to be a greater convergence around how the term is being used inclusively internationally versus its more specific uses in Canada.

In the United States and around the world, the term long-term care has been traditionally used to refer to a

broad range of services including formalized home care, community support services, care in designated buildings (including nursing homes, retirement homes, assisted living facilities, supportive housing and co-housing models), and non-formalized care supports often provided by non-government funded care providers, including unpaid caregivers and volunteers. The NIA recognizes the struggle with trying to define *long-term care*. There are some people and organizations who believe that the existing global definitions are too broad. At the same time, there is no consensus on another term that is overarching and comprehensive enough to replace the existing international definitions of long-term care. But if the collective aim is to create a system that is based on evidence, best practices, and that responds to what Canadians want, there's a clear need to define and outline a systemic approach that recognizes the broader spectrum of care and support that older Canadians will need to age with dignity and respect in their places of choice.

Indeed, other terms such as 'assisted living' or 'continuing care' have different and specific meanings within the larger basket of *long-term care* services and may not be broad enough to encapsulate the current global understanding of what *long-term care* is. In order to be in line with a broader and well-established international dialogue that is taking place around the future provision of *long-term care*, the NIA consulted with a broad range of stakeholders for the development of this inaugural white paper by using the term *long-term care* to encapsulate the spectrum of care and support being delivered in designated buildings or in home-and community-based settings already being provided across Canada. Indeed, while it may still represent a less than ideal term in Canada due to the way it has been co-opted in certain Canadian jurisdictions, there is currently no alternative that is being readily accepted when seeking to discuss the future provision of care in designated buildings, like nursing or retirement homes, or in home-and community-based settings.

The NIA and its stakeholders in responding to the WHO, OECD, and United States National Institute on Aging (US-NIA) definitions did not adopt any of their specified definitions but rather recognized their common elements (See Figure 1) and agreed that the NIA's work around *long-term care* should focus on the provision of services that are not location specific and can thus be provided by not- and for-profit providers in designated buildings or in home and community-based settings. It encompasses different types of care including both preventive and responsive care that also includes assistance with ADLs and IADLs provided by either care providers or unpaid caregivers.

Other Definitional Challenges within the Field of Long-Term Care

Canadian stakeholders have also noted the struggle with the use of terms like 'residential care'. For Indigenous Peoples in Canada especially, it may too closely resemble the term 'residential schools' and thus serve as an inclusivity barrier to working and fully engaging with some populations. The term 'facility' is also quickly losing favour. Many feel it could have the unintended effect of de-personalizing or de-humanizing the provision of *long-term care* and negatively representing the designated building that inevitably needs to become one's home. It further risks misrepresenting the providers of care in 'facilities' who aim to provide high-quality, personalized care against negative stereotypes. Indeed, no matter where a person lives and receives ongoing *long-term care*, they are likely to be receiving care and supports in a place that has become their 'home'.

In a similar manner, the term 'institutional' is also losing favour. It reminds Canadians of philosophies and practices from earlier decades that promoted the institutionalization of people with severe mental health issues, to considerable negative effect. In recognizing this latter point, the NIA has decided to use the term 'designated buildings,' referring specifically to the types of *long-term care* that are provided in a designated building designed or organized to facilitate the provision of *long-term care* in congregate settings (including nursing homes, retirement homes, assisted living

facilities, supportive housing building models) as opposed to a private residence or community-based setting.

There is also no common way of referring to people receiving *long-term care*. Where people in hospitals are commonly referred to as 'patients', no such accepted term pertains to people receiving *long-term care*. In many cases, those receiving care or supports in their own homes have been called 'clients', although in some jurisdictions there have been pushes to call home-care clients 'patients'. The push-back against the latter term has focused on the concern that 'medicalizing' home care can be further disempowering to care recipients when, in many cases, an individual may only need help with bathing, housekeeping, or laundry, rather than more clinically-oriented care. Not everyone wants to be thought of as a 'patient', especially as home care is seen by many as a means to preserve one's independence and ability to age at home.

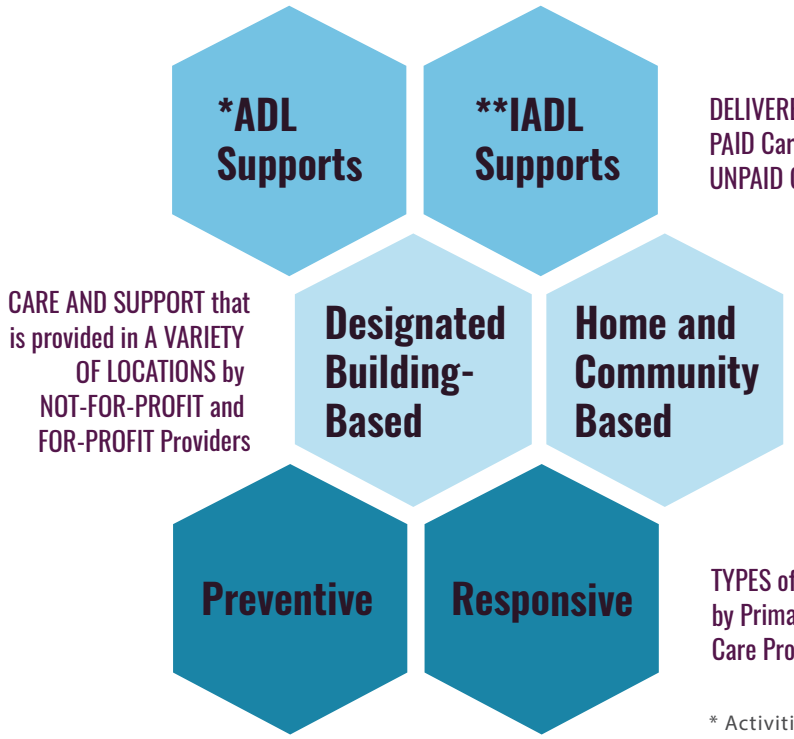
In designated buildings that have become a person's home, there has been some consideration of also using 'patient' instead of 'resident', which, again, has been seen as another way to undermine the personhood of these individuals. In response to these considerations, the NIA has decided to use the term 'client' and 'resident' specifically to refer to the individuals receiving *long-term care* within a private residence or a designated building designed or organized to facilitate the provision of *long-term care* services.

In keeping with current findings by Stall et al. (2019) the NIA will also use the terms 'unpaid caregiver' to represent individuals who provide care to another person primarily because a personal relationship exists and can include family, friends, and neighbours of care recipients. The term 'care provider' will be used to represent those who provide care because of a financial relationship which may include licensed or unlicensed care providers (Stall et al., 2019).

The NIA further recognizes that *long-term care* policies need to not only deliberately recognize the presence of non-government funded care providers, including unpaid caregivers, but also the role government-enabled supports can

play in the future delivery of *long-term care*, such as benefits for unpaid caregivers. The NIA also notes that the provision of *long-term care* is not necessarily restricted to meeting the needs of older adults. *Long-term care* has an important and specific role to play in the care and support of younger populations. For the purpose of this policy series, however, the focus will be on the provision of *long-term care* for older Canadians.

Figure 1: NIA Visual of the Components Inherent to the International Provision of Long-Term Care (LTC)



* Activities of Daily Living

** Instrumental Activities of Daily Living

Long-Term Care Definitions From Around the World

WHO Definition of Long-Term Care

"…the activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity." (WHO, 2015)

OECD Definition of Long-Term Care

"...a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL). This "personal care" component is frequently provided in combination with help with basic medical services such as "nursing care" (help with wound dressing, pain management, medication, health monitoring), as well as prevention, rehabilitation or services of palliative care. Long-term care services can also be combined with lower-level care related to "domestic help" or help with instrumental activities of daily living (IADL)." (Columbo et al., 2011).

United States National Institute on Aging (US-NIA) Definition of Long-Term Care

"…involves a variety of services designed to meet a person's health or personal care needs during a short or long period of time. These services help people live as independently and safely as possible when they can no longer perform everyday activities on their own. Long-term care is provided in different places by different caregivers, depending on a person's needs. Most long-term care is provided at home by unpaid family members and friends. It can also be given in a facility such as nursing home or in the community, for example, in an adult day care center." (National Institute on Aging, 2017)

A Look at the Current Provision of Long-Term Care in Canada - Categorizing the Types of Long-Term Care Being Provided in Canada

There is currently a wide variety of options available in the provision of *long-term care* across Canada. This includes: support for independent living or home and community care, or supportive housing, assisted living, or retirement homes; and nursing homes. Each serves populations with particular needs and challenges, but the differences among them are not always clear.

The Government of Canada (2010) currently defines **'Independent Living'** as involving older adults living by themselves and looking after themselves. Older adults may rely on family members and friends or neighbours to help them to live independently, or they may hire a care provider to come in and help with tasks or purchase services such as 'meals on wheels' to do so (Government of Canada, 2010). A key defining feature of what constitutes this definition of 'independent living' is that support services are not provided by the residence in which a person lives (Government of Canada, 2010).

The Government of Canada (2016a) currently defines **'Home and Community Care'** as care that is provided in home-based settings rather than in a hospital or nursing home, which allows individuals to remain independent in the community. This type of care can be provided by regulated health care providers (i.e. nurses, therapists), but also by non-regulated care providers such as personal support workers (PSWs) also known as health, continuing or simply 'care aides' (H-/C-/CAs) or nursing aides, volunteers, and unpaid caregivers (i.e. friends, family, and neighbours) (Government of Canada, 2016a). The Canadian Home Care Association (CHCA) (2016a) has promoted a more encompassing definition of **'Home and Community Care'** as an array of both health and support services provided in the home, retirement communities, group homes, or other settings to people with acute, chronic, palliative, or rehabilitative health care needs.

These services consist of assessments, therapeutic interventions, personal assistance ADLs and IADLs and unpaid caregiver respite and support (CHCA, 2016a). Overall, this type of care is recognized as an 'extended health service' and is thus not designated as an insured service under the CHA (CHCA, 2013). This has resulted in each province and territory developing their own legislation and accompanying policies and regulations to govern the provision of home and community care.

'Supportive housing, assisted living, or retirement homes' describe a different type of living arrangement in a specific location.

Highlights from the Landmark 2017 CIHI Report 'Seniors in Transition – Exploring Pathways Across the Care Continuum' (CIHI, 2017b)

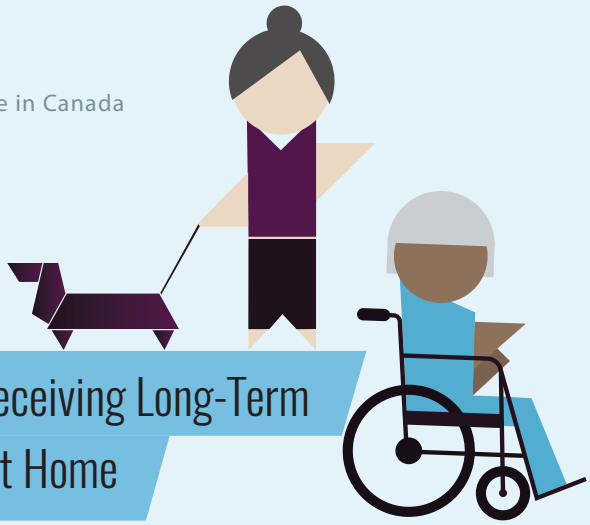
Canadian Institute for Health Information (CIHI) researchers have noted that compared to Canadians who are independent, greater reliance on physical assistance (i.e. personal care, toileting, mobility, and eating) increases one's likelihood of entering a nursing home environment. However, they further noted that 22% of older Canadians who were entering nursing home environments may have been able to receive care at home with appropriate home care and community-based supports.

Specific Factors that Currently Lead Canadians to Nursing Home Settings:

- 6.4 times more likely: If they were initially assessed in hospital
- 3.3 times more likely: If they need extensive personal hygiene or toileting assistance
- 3.2 times more likely: If they have moderate cognitive impairment (and 1.7 times more likely if there's a history of wandering)
- 2 times more likely: Older adults who lived alone (or without a primary caregiver in the home)

The defining feature of this type of housing is that the support services are included in a care package delivered in a designated building (Government of Canada, 2010). These services vary but can include meals, assistance with bathing, or access to an on-call nurse and/or non-regulated care provider (Government of Canada, 2010). These types of housing options can be owned and operated privately, while others are owned and operated by not-for-profit organizations, including faith-based groups. Some are government-owned and operated by local municipalities (Government of Canada, 2010).

The Government of Canada (2004) defines **'Long-term Care Homes'** as a designated building-based place for individuals to live and receive 24/7 supervised care but also a range of professional health and personal care services, and supports with activities such as the provision of meals, laundry, and housekeeping. As this type of care is not insured under the CHA, each province and territory develops its own legislation and accompanying policies and regulations to govern the provision of nursing home care in their jurisdiction. As is also the case with 'Home and Community Care,' this province and territory directed approach has led to a considerable lack of consistency across the country in the level or types of care that are being offered, how care can be accessed, funded and measured, and how providers are governed, operated, and staffed (Government of Canada, 2004).



A Spotlight on Canadians Receiving Long-Term Care in Nursing Homes and at Home

The population being served by Canadian nursing homes has become increasingly complex over the past decade. In 2015-2016, 87% of residents living in nursing homes had some type of cognitive impairment while 69% specifically had dementia, 50% had behavioural challenges, while 31% experienced depression (CIHI, 2016). Overall 82% required extensive assistance with their care or were dependent for all of their ADL care (CIHI, 2016).

Despite the growing complex care needs of nursing home residents, the quality of care being received within Canadian nursing homes has continued to improve in a number of key areas. The use of restraints to manage the care of residents with significant behavioural challenges, for example, decreased between 2013-2014 and 2017-2018, from 9.6% to 5.7%, respectively (CIHI, 2019a). Complete restraint use data is provided by Alberta, British Columbia, Newfoundland and Labrador, Saskatchewan, Yukon, and Ontario (CIHI, 2019a). As of 2017-2018, restraint use varies from a low of 4.5% in Ontario to a high of 14.2% in Yukon (CIHI, 2019a). The trends in restraint use have varied significantly in some jurisdictions. For example, Yukon's rate decreased from 18.2% in 2013-2014 to 13% in 2014-2015, but then increased again to 19.1% in 2016-2017 and then decreased again to 14.2% in 2017-2018 (CIHI, 2019a). Newfoundland and Labrador also had increases from 2014-2015 to 2016-2017, before decreasing again to 12.1% in 2017-2018 (CIHI, 2019a). Alberta, Ontario, Saskatchewan, and British Columbia continued their trend of a continued decrease in restraint use between 2013-2014 and 2017-2018 (CIHI, 2019a).

Similarly, the potentially inappropriate use of anti-psychotics in Canadian nursing homes has also decreased between 2013-2014 and 2017-2018, from 30.0% to 21.2% respectively (CIHI, 2019b). This indicator determines how many nursing home residents are taking antipsychotics drugs without having a diagnosis of psychosis (CIHI, 2019b). Data on the potentially

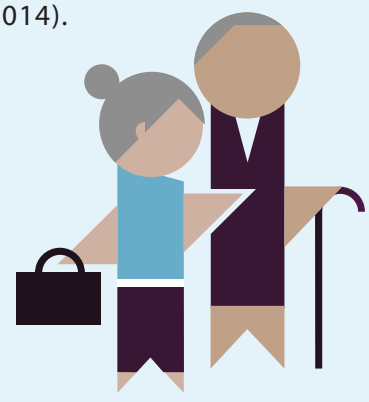
inappropriate use of anti-psychotics are provided by Alberta, British Columbia, Ontario, and Yukon, and from some homes in Newfoundland and Labrador and Saskatchewan. As of 2017-2018, the potentially inappropriate use of anti-psychotics ranges from a low of 17.1% in Alberta to a high of 35.4% in Newfoundland and Labrador (CIHI, 2019b). British Columbia, Alberta, and Ontario have seen a consistent decrease in their rate between 2013-2014 and 2017-2018 (CIHI, 2019b). Saskatchewan's rate decreased from 2014-2015 to 2016-2017 and then remained stable at 26.9% from 2016-2017 to 2017-2018 (CIHI, 2019b). Newfoundland and Labrador's rate remained relatively stable until 2016-2017 and then decreased from 37.8% to 35.4% (CIHI, 2019b). Yukon's rate has seen a slight increase from 2013-2014 to 2017-2018 from 27.4% to 27.9% (CIHI, 2019b).

Canadians Receiving Home Care

The Commonwealth Fund's 2017 International Health Policy Survey of Seniors found that Canadians who are receiving publicly funded home care services have higher needs compared to those who are not receiving home care services:

- 59% are over age 75
- 43% describe their health as fair or poor
- 53% have 3 or more chronic health conditions
- 59% are taking 5 or more medications
- 46% live alone
- 54% of home care recipients started receiving their home care services after a hospital visit (CIHI, 2018a)

Another study that specifically examined the provision of publicly funded home care across Ontario and Winnipeg found that over 90% of recipients required full assistance with their IADLs, while 35% had ADL impairments; approximately 50% had some level of cognitive impairment; and 54% had daily pain that could be severe (Mofina & Guthrie, 2014).



The Funding and Delivery of Long-Term Care in Canada

The way *long-term care* is financed in Canada is complicated and varies by jurisdiction. The CHA is Canada's federal health care insurance legislation and defines the federal principles that govern the Canadian health care insurance system (Health Canada, 2019). The CHA encompasses 'extended health care services,' which includes aspects of long-term care provided in designated buildings (nursing home, intermediate care) and the health aspects of home care and ambulatory care services (Health Canada, 2019).

The CHA sets out criteria and conditions the provinces and territories must fulfill in order to receive funding under the CHT (Health Canada, 2019). However, with changes to how 'extended health care services' were re-categorized in 1977, their resulting future provision was never subsequently regulated as strictly as those that are defined as 'essential' or 'core insured services' under the CHA are (See Box on page 33).

Limited Data Make it Difficult to Accurately Estimate Long-Term Care Expenditures Across Canada

There are significant differences in estimates around the share of long-term care funding in Canada for nursing home-based care versus home and community-based care (Grignon & Spencer, 2018). To address this, both CIHI and the OECD have developed their own estimation methods to identify and quantify long-term care expenditures in Canada, who pays for it (i.e. public or private), and how the funding is actually used. Each method, however, has its weaknesses as they are based on a number of inferences (Grignon & Spencer, 2018). Grignon & Spencer (2018) have adapted both the OECD and CIHI data sources to generate a third method to create what they call a 'preferred estimate.'

Using Grignon and Spencer's (2018) method, Dr. Michael Wolfson, former assistant chief statistician at Statistics Canada, estimated that in 2018, $33 billion was spent on *long-term care* in Canada (or 13% of the $253 billion that was spent overall on health care) (CIHI, 2019c).

Of the $33 billion, approximately $27 billion or 80-82% was spent on nursing home care and approximately $20 billion (75%) of these nursing home care costs was publicly-financed, while the remaining $7 billion (25%) was paid for privately through various co-payment mechanisms.

Approximately $6 billion (of the $33 billion) was therefore spent on home and community based care (which does not include 'home supports' such as meals on wheels, transportation, and other non-health components). Of this $6 billion, $4 billion was publicly-financed, while $2 billion was paid for privately.

Table 1: Visualization of Canadian Long-Term Care Spending Estimates for 2018 (Based on Grignon & Spencer (2018) Methods)

Category	Nursing Home Care	Home and Community-Based Care	Long-Term Care
Public Spending	$20 B	$4 B	$24 B
Private Spending	$7 B	$2 B	$9 B
Total Spending	$27 B	$6 B	$33 B

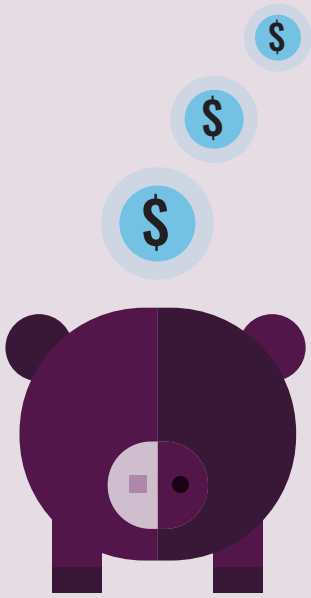
A Brief History of *Long-Term Care* Funding in Canada

- In 1977, federal funding supporting insured health care services was replaced by a block fund transfer, known as the EPF Act *(Federal-Provincial Fiscal Arrangements and Established Programs Financing Act)* which also included a new transfer for the 'Extended Health Care Services Program' (e.g. nursing home care or health aspects of home care). This portion of the EPF transfer was made on a virtually unconditional basis, meaning it was not linked to specific program delivery criteria (Health Canada, 2019).

- In 1995, the federal government restructured the Act to be called the *Federal-Provincial Arrangements Act*, with provisions for a Canada Health and Social Transfer (CHST) (Health Canada, 2019).

- In 2004, the CHST was restructured into two new transfers, the CHT and the Canada Social Transfer (CST) with the CHT supporting the federal government's commitment to maintain criteria and conditions of the *Canada Health Act* and the CST supporting post-secondary education, social assistance, and social services (Health Canada, 2019).

- In Budget 2017, the federal government provided provinces and territories with $11 billion in new funding over ten years. In addition to the CHT $6 billion was specifically provided to improve access to home and community care and $5 billion for mental health services (Department of Finance, 2017).



Long-Term Care Administration and Service Delivery Models Vary Significantly Across Canada

In most provinces and territories, the Ministry or Department of Health is responsible for: health and care system planning, setting strategic policy directions and priorities; legislation and regulations (including determining the eligibility for access, service allocation, as well as client user fees for home and nursing home care); standards and guidelines; monitoring, accountability, and compliance; and, the funding of services (CHCA, 2013). One exception is New Brunswick, where the responsibility is shared between the Department of Health and the Department of Social Development (CHCA, 2013).

There are significant variations in the way the administration/service delivery of *long-term care* is structured across the country. Nursing home care is publicly financed and regulated but can be delivered by either government, not-for-profit, or for-profit providers. For example, while these ratios vary across the country, approximately 44% of publicly financed Canadian nursing home care is provided by for-profit entities, 29% by not-for-profit entities, and 27% by local or provincial/territorial governments (CIHI, 2014). Nevertheless, the way nursing home care is structured and delivered is largely consistent across Canada, although eligibility and co-payment criteria vary.

When it comes to the delivery of home and community-based care, most Canadian jurisdictions deliver and procure professional services such as nursing, therapies, and social work, through public sector employees and personal support and homemaking through contracts with non-governmental private for-profit and not-for-profit providers (CHCA, 2013). Earlier this year, British Columbia announced that it was taking control of the employee contracts of publicly-financed but privately-delivered home support services to bring the care providers delivering these services back under direct control of its health authorities (Zussman, 2019). Its primary justification was that it would offer a better way to integrate services offered by the health authorities through their own teams of care providers (Zussman, 2019).

In 2013, Alberta announced that home and community care services that were being delivered by 72 agencies would be replaced by 13 organizations, with anticipated savings of $18 million per year (Komarnicki, 2013). The majority of organizations that won the contracts to deliver home and community-based care ended up being private for-profit providers based in Ontario (Global News, 2013). A subsequent report that was commissioned to review this process found that it was done fairly and thus the changes would remain (Alberta Health Services, 2013).

In Ontario, since 2007, 14 Local Health Integration Networks (LHINs) have been responsible for planning, funding, and integrating a variety of locally-determined non-governmental not-for-profit or for-profit providers to provide the full range of home and community care services, including for nursing, therapies, personal support and homemaking services, as well as supplies and equipment (CHCA, 2013; Auditor General of Ontario, 2015). It was recently announced, however, that the LHINs will be gradually phased out over the coming years to create a series of more flexibly financed and delivered care systems to be known as Ontario Health Teams (OHTs) (MOHLTC, 2019).

Quebec remains an exception in Canada with its creation of a hybrid funding system to support the local provision of home and community-based care and supports. Currently, Quebec has 22 integrated health and social services centres (CISSS/CIUSSS) responsible for coordinating all forms of care being provided in their regions and overseen by the Ministere de la Santé et des Services Sociaux (MSSS) (Gouvernement du Quebec, 2019a). These centres further ensure the coordination of long-term care services provided by all partners in the network including local centres that provide home and community-based care (CLSC) and nursing home care (CHSLD) (Gouvernement du Quebec, 2015). At least 343,000 adults of all ages in Quebec are currently receiving publicly funded home care services (Hendry, 2018). While 80% of publicly-funded home care was delivered by CLSC home care staff in 2012, in order to save costs, now over one-third of it is being provided by contracted home-care workers (Hendry, 2018).

Quebec also deliberately encourages and subsidizes the acquisition of private home care and personal support services both through its *Financial Assistance Program for Domestic Help Services* and its refundable *Tax Credit for Home-Support Services* for those over age 70 years of age (Gouvernement du Quebec, 2019b; Revenu Quebec, 2018a).

In 2017, the Quebec Ombudsman reviewed the provision of home care and support services and found that while it has been estimated that at least 15% of people over 65 require home care services, only 8.6% were actually receiving any (Le Protecteur Du Citoyen, 2017). In 2018, the Quebec Ombudsman noted several issues including: a decrease in the number of service hours being allocated to people with lower needs; caps on the number of service hours being allocated or new exclusion requirements being introduced; and, in half of the centres, a lack of compliance with the Ministry's Instruction concerning free domestic assistance for people under the low-income threshold (Le Protecteur Du Citoyen, 2018). Due to these findings, the Government of Quebec announced an extra $100 million in 2018 to provide more home support services (Le Protecteur Du Citoyen, 2018).

A Spotlight on Quebec's Unique Funding Mechanisms to Support the Local Provision of Home and Community-based Care and Supports

In 2003, the Government of Quebec introduced its *Chez Soi: Le Premier Choix* home support policy that allows people who need only domestic help, such as house and yard work, laundry, shopping, errands, or meal preparation, to be referred to a local social economy enterprise recognized by the Ministry to provide these services (Le Protecteur Du Citoyen, 2018).

For low-income individuals with incomes of less than $17,520 (singles) and $26,686 (couples) respectively, the services were offered free of charge (Gouvernement du Quebec, 2019b). People with slightly higher incomes (singles above $17,520 up to $41,520, couples from $26,687 up to $50,686) were required to pay privately, however they were eligible for a discount (currently $4 off the hourly rate) through the *Financial Assistance Program for Domestic Help Services* (Gouvernement du Quebec, 2019b). Through this program, the recipient pays only the difference between the rate charged and the reduction they receive (Gouvernement du Quebec, 2019b).

Quebec also offers a refundable *Tax Credit for Home-Support Services for Seniors* (older adults over the age of 70) for home-support services equal to 35% of support expenses up to a designated maximum (Revenu Quebec, 2018a). The annual maximum on eligible expenses is $19,500 for a person who is considered independent (maximum credit $6,825) and $25,500 (maximum credit $8,925) for a person who is considered dependent on others (Revenu Quebec, 2018a).

For individuals with incomes over $57,400, the tax credit is reduced by 3% of the difference between their annual income and the threshold of $57,400, unless they are considered dependent on others, in which case no reduction is applied. Services under this tax credit include: housekeeping services (such as dusting, vacuuming, washing floors, etc.); laundry services; grounds keeping or maintenance work outside the home; personal care services (help with dressing and personal hygiene); meal services (help eating and drinking or preparing meals); nursing services, companion sitting services; person-centred remote monitoring services; and, services using a personal GPS locator (Revenu Quebec, 2018a).

It is not certain if people are more likely to benefit from the more flexible care allocation and financing approaches that Quebec has pursued or by the way care is being resourced and allocated in other provinces.

Comparing What Canada Spends on Long-Term Care with other OECD Nations

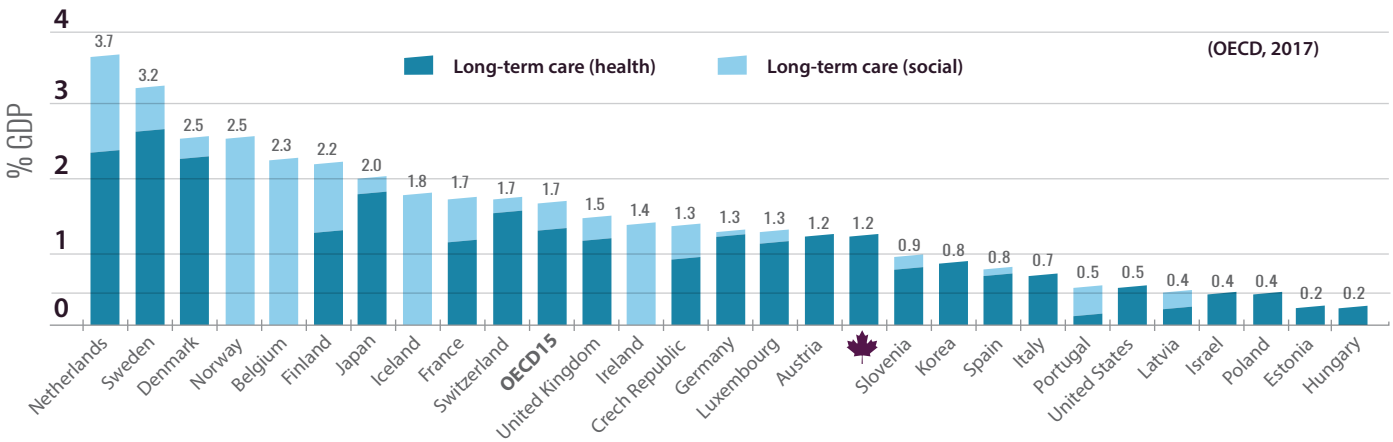
The OECD reports that in 2016-2017 Canada spent 11% of its public-sector health expenditures on long-term care and this area represented 14% of its total health expenditures (OECD, 2019).

Canada spends comparatively less on the provision of publicly-funded long-term care compared with other developed countries.

Figure 2 shows that Canada spends 1.2% of its Gross Domestic Product (GDP) on publicly-funded long-term care health services, compared to an OECD average of 1.7% (on long-term care services), which is well below countries like Denmark that spend 2.5% of their GDP on long-term care services (OECD, 2017).

Canada spends comparatively less on the provision of publicly-funded long-term care when compared with other developed countries.

Figure 2: Long-Term Care Expenditure (health and social components) by Government and Compulsory Insurance Schemes, as a Share of GDP, 2015 (or nearest year) Across OECD Nations

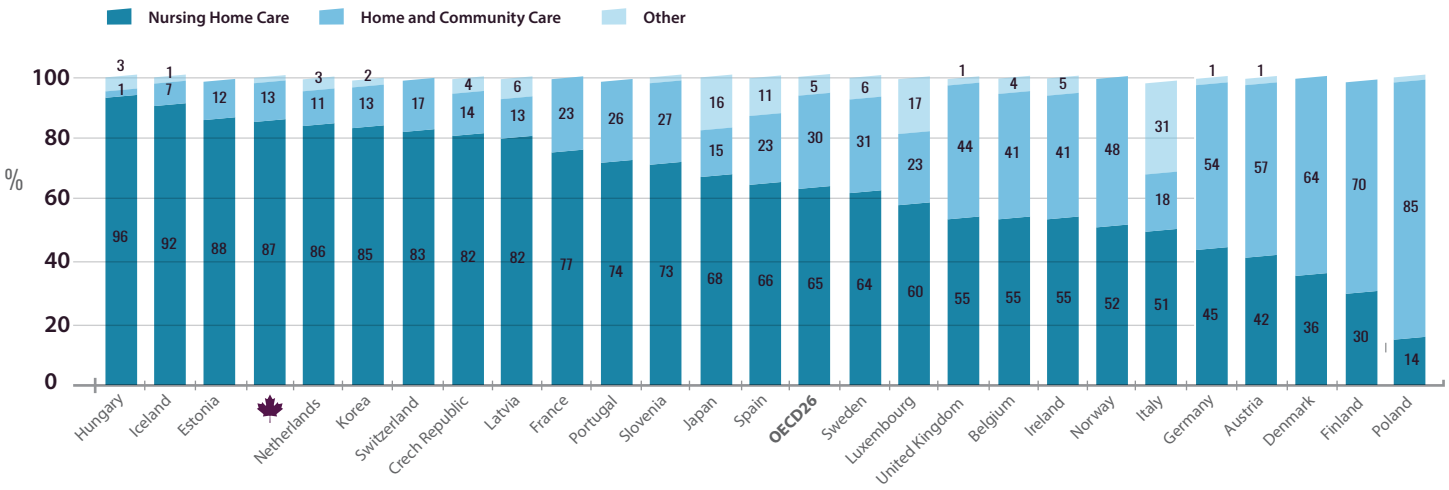


Note: The OECD average only includes the 15 countries that report health and social LTC. Source: OECD Health Statistics 2017.

The OECD also notes that not only do the amounts being invested in the provision of long-term care services vary internationally, but the proportions on where it is invested also vary significantly. For example, Figure 3 shows that, on average, OECD countries spend 65% of their long-term care spending on care in designated buildings like nursing homes and only 35% on home and community-based care (OECD, 2017). In comparison, Canada spends at one extreme of its OECD comparators in spending 87% of its long-term care dollars on care in designated buildings and only 13% on home and community-based care (OECD, 2017). At the other extreme, countries like Denmark spend 36% of their long-term care spending on care in designated buildings while spending 64% on home and community-based care (OECD, 2017).

Canada spends at one extreme of its OECD comparators in spending 87% of its long-term care dollars on care in designated buildings and only 13% on home and community-based care (OECD, 2017).

Figure 3: Government and Compulsory Insurance Spending on LTC (health) by Mode of Provision, 2015 (or nearest year) Across OECD Nations



Note: "Other" includes LTC day cases and outpatient LTC. Source: OECD Health Statistics 2017.

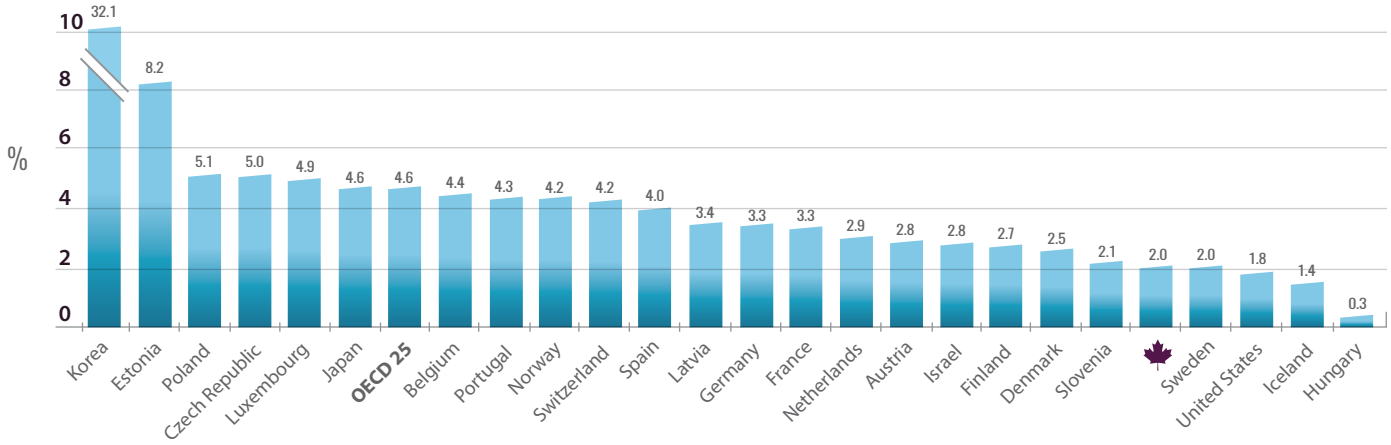
(Adapted from OECD, 2017)

Canada's spending growth rate on long-term care was significantly behind other developed countries during the period of 2005-2015. The average reported annual OECD spending growth rate on long-term care services was 4.6% as displayed in Figure 4. Over the same period, Canada had one of the lowest overall annual spending growth rates in long-term care at 2% - at or just below the rate of inflation (OECD, 2017).

Canada's spending growth rate on long-term care was significantly behind other developed countries during the period of 2005-2015 (OECD, 2017).

Figure 4: Annual Growth Rate in Expenditure on LTC (health and social) by Government and Compulsory Insurance Schemes, in Real Terms, 2005-2015 (or nearest year) Across OECD Nations

(OECD, 2017)



How Many Older Canadians Are Actually Receiving Long-Term Care Services?

There is no clear consensus on the number of older Canadians who are actively receiving care or services across the *long-term care* continuum, neither is there a consensus on the proportion of Canadians receiving care in various settings. Nevertheless, NIA researchers have tried to utilize a variety of sources to attempt to piece together a current picture of for whom, how many, and where *long-term care* is being delivered in Canada.

There is no clear consensus on the number of older Canadians who are actively receiving care or services across the long-term care continuum, nor is there a consensus on the proportion of Canadians receiving care in various settings.

Based on the estimates in Table 2, the number of Canadians over age 65 receiving any type of *long-term care* range from 763,735 to 1,256,575, which represents approximately 13% to 21.2% of Canadians over 65 years of age.[6] According to Canada's 2016 Census, the equivalent of 2.8% of Canadians over the age of 65 have reported unmet home care needs (Gilmour, 2018b; Statistics Canada, 2016b).

Table 2: Variable Existing Estimates of Canadians Over 65 Receiving Long-Term Care

Care Provided to Canadians over Age 65	OECD (Data from 2016)(OECD, 2019)	Statistics Canada – Census 2016	CHCA (Data from 2011)
Designated Building-Based Long-Term Care	252, 235[1]	402, 575[2] (Statistics Canada, 2016a)	N/A
Home and Community-Based Long-Term Care	514,800[3]	511,500[4]	854,000 (CHCA, 2013)
Those with Unmet Needs	N/A	167,100[5]	N/A

[1] The OECD uses the 2016 Census – they include in their definition: nursing homes; facilities that are a mix of both a nursing home and a residence for senior citizens, and residential care facilities such as group homes for persons with disabilities and addictions.

[2] This calculation includes: nursing homes, residences for senior citizens, and facilities that are a mix of both a nursing home and a residence for senior citizens.

[3] The OECD uses data collected from the CCHS Annual Component.

[4] This is based on data collected from the CCHS Annual Component.

[5] This is based on data collected from the Canadian Community Health Survey Annual Component.

[6] Based on the population of 65 years and over in the 2016 Census, which was 5,935,630 (Statistics Canada, 2016b).

While a more current number of publicly-funded *long-term care* recipients has not been produced, it is understood that even the recent OECD numbers may also be significantly underestimating the actual number of Canadians receiving this sort of care.

A Spotlight on the Provision of Paid Home Care Services to Canadian Households

- 52% of Canadians reported that their home care services were funded solely by public sources
- 27% of Canadians reported that their home care services were paid for solely out-of-pocket
- 7% of Canadians reported that their home care services were solely covered by insurance coverage
- 8% of Canadians reported that their home care services were paid at least in part by government and/or insurance coverage

(Gilmour, 2018a)

Canadians with private insurance that covered all or part of long-term care costs were less likely to have unmet needs (Gilmour, 2018b).

- 2/3 or 63.4% of those Canadians who reported having unmet needs attempted to find additional help. Of these:
  - 43% looked to government home care programs
  - 7.8% to private agencies
  - 6.6% to unpaid caregivers such as friends, family, and neighbours
  - 3.3% to voluntary organizations to provide additional home care supports (Gilmour, 2018b)

A Spotlight on Ontario's Approach to Long-Term Care: Swimming Against Canada's Dominant Policy Current?

With growing public investment in the *long-term care* sector across Canada, it is important to understand the different approaches each province and territory has in the provision of care and on growth in spending. The latest OECD data show that across Canada, 87% of public investment in long-term care goes to nursing home-based care versus 13% on home and community-based care (OECD, 2017).

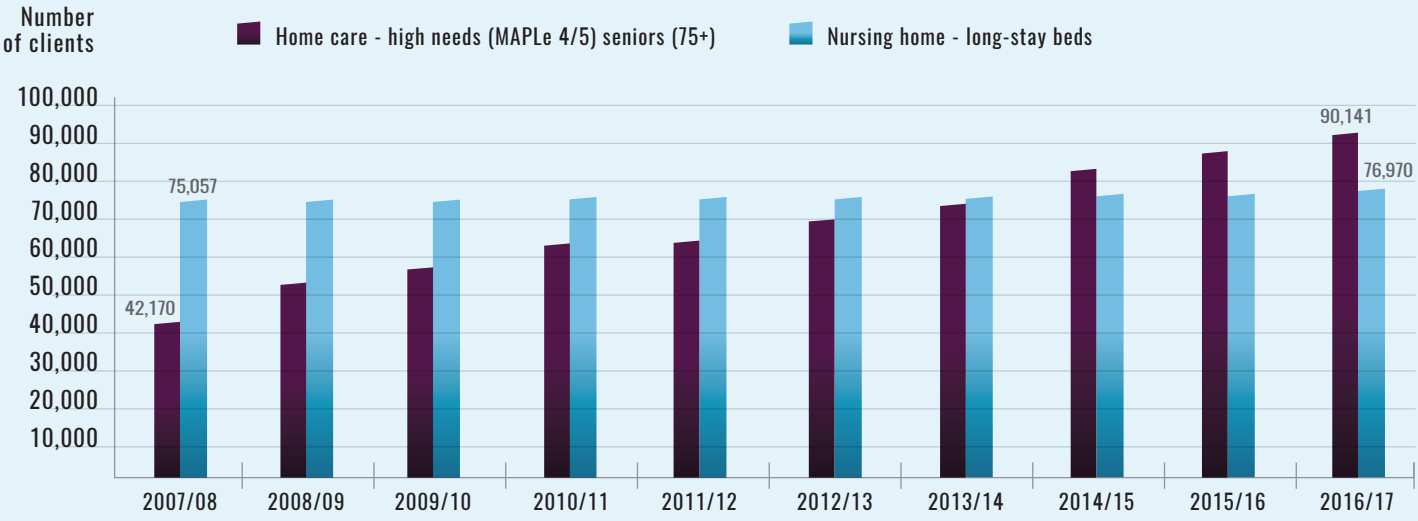
Ontario stands out as one jurisdiction that has deliberately flipped its ratio of spending in favour of delivering more home and community-based care over nursing home-based long-term care. In 2010-11, Ontario spent 6% on the provision of home and community care and 7.7% on nursing home care, as percentages of its total $44.77 billion health expenditure (Ministry of Finance, 2012). Currently, home and community care spending in Ontario accounts for 10% of the province's $61.3 billion in total health expenditures while spending on nursing home care had shrunk to 7% (Ontario, 2018).

Ontario stands out as one jurisdiction that has deliberately flipped its ratio of spending in favour of delivering more home and community-based care over nursing home-based long-term care.

In 2012, Ontario developed Canada's first comprehensive Seniors Strategy (Sinha, 2012) that emphasized the importance of both expanding its long-term care investments and growing its home and community care sector. In 2012, the Government of Ontario began a deliberate policy of expanding its home and community care budget by at least

4% annually, compared to capping its nursing home expenditures at 2% annually. This deliberate policy to increase its spending on home and community care allowed it to more than double what it spent on home and community care as a proportion of its overall total health expenditures. Spending on home care grew from $2.7 billion (6.0% of total health spending) to $6.1 billion (10% of total health spending) between 2010-11 and 2018-19. In comparison, the Ontario government oversaw a more muted growth in its spending on nursing home care as a proportion of its overall health care budget, growing from $3.4 billion (7.7%) to $4.3 billion (7%) between 2010-11 and 2018-19. Between 2007-08 and 2016-17, Ontario's number of nursing home beds serving high-needs Ontarians 75 years of age and older has remained steady between 75,057 and 76,970. At the same time, the number of high-needs Ontarians 75 years of age and older who received intensive care at home rather than in a nursing home more than doubled, from 42,170 to 90,141 during the same period as is illustrated in Figure 5 (MOHLTC, 2018).

Figure 5: High-Needs Older Ontarians (75+) Cared for with In-Home Care versus existing LTC Capacity between 2007-08 to 2016-17



*The number of LTC long-stay beds shown are for april of every FY shown, from monthly LTCH System Reports

(Adapted from MOHLTC, 2018)

During the same period, the per capita supply of, demand for, and rate of placement into nursing homes for Ontarians 75 years of age and older significantly declined with the greater availability of publicly funded nursing home care alternatives.

Health Quality Ontario (HQO) (2019) recently reported that 44% of its publicly supported home care clients with an unpaid caregiver in 2015/2016 reported experiencing distress, anger, or depression, compared to 33% in 2013/2014 and 15.6% in 2009/2010 (HQO, 2016).

The MOHLTC (2018) shows that a day of care for a high-needs client costs the government approximately $95 for home care, $177 for nursing home care, and $730 for 'ALC-level hospital care (See Appendix A for glossary).

The greater supply of home care is still not meeting the current needs of Ontarians and their caregivers. With the types of clients being supported with publicly funded home care becoming collectively more cognitively impaired, more functionally disabled, and sicker, the corresponding levels of their caregivers reporting experiencing distress, anger, or depression related to their role and/or were unable to continue their caregiving activities has risen as well (HQO, 2019). Health Quality Ontario (HQO) (2019) recently reported that 44% of its publicly supported home care clients with an unpaid caregiver in 2015/2016 reported these concerns compared to 33% in 2013/2014 and 15.6% in 2009/2010 (HQO, 2016). This perhaps explains that despite its significant investments in strengthening its home and community care sector, there remains a growing demand for publicly funded long-term care services in Ontario.

With the wait list for nursing homes growing to 34,834 in February 2019 (OLTCA, 2019a) from 19,700 in 2012 (Sinha, 2012), the recent election in Ontario saw all three major political parties commit to building 30,000 new nursing home beds over the next decade to try to meet the province's growing need for capacity in the broader *long-term care* sector.

Understanding the New Federal Prioritization of Home and Community-Based Care

The federal, provincial, and territorial governments across Canada know that Canadians increasingly want to age at home and in their communities. Mounting fiscal pressures have led provincial and territorial governments to emphasize providing more care at home rather than in more expensive care settings like nursing homes. The Canadian Association for Long-Term Care (CALTC) notes that an average day of 'ALC-designated' care in a hospital continues to cost multiples of what delivering equivalent care in a nursing home or at home with home and community care (CALTC, 2018), which ends up tying up thousands of expensively resourced hospital beds daily across Canada. In this context, the federal, provincial, and territorial governments agreed to make home care a key focus of the 2017 federal budget. In 2017, the federal government designated $6 billion over 10 years for provincial and territorial governments to invest in the provision of more home and community care (Department of Finance Canada, 2017).

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To help monitor the impact of this landmark investment, the Federal, Provincial, and Territorial (FPT) health ministers endorsed the creation of a set of indicators for measuring access to home and community care recommended by CIHI that will be publicly reported on an annual basis beginning in 2019-2020 (CIHI, 2018b).

With accompanying investments being made in the provision of publicly funded *long-term care* across Canada, measuring and analyzing its impact and outcomes will facilitate better access to home and community care. Further improvements in the quality of *long-term care* services for Canadians will come with the broader dissemination of established and innovative best practices and technologies.

Understanding the ALC Situation across Canada

One criticism of the current investments being made in the expansion of home and community-based care across Canada is that the focus seems to be on offering support to hospitals to manage their ALC-designated patients (see Appendix A for Glossary), instead of prioritizing keeping clients with complex or high levels of need at home or in their communities in the first place.

An ALC designation is given to a person who is occupying a bed in a designated building but who no longer requires the intensity of resources or services typically provided in that setting (CIHI, 2017b). ALC designations capture people who are waiting to return home or to another setting to receive rehabilitative or *long-term care*. But ALC designation most often applies to those individuals being transitioned from acute care to nursing home care settings (CIHI, 2012). It is estimated that on any given day, approximately 7,500 patients with ALC designations account for 14% of the total number of hospitalized Canadians (CHSRF, 2011).

Introducing the CIHI Recommended Indicators for Access to Home and Community Care

CIHI welcomed the FPT health ministers' endorsement of a set of indicators that will be used to measure pan-Canadian progress towards improving access to home and community care. These new health indicators include measures related to (CIHI, 2018b):

- Wait times for Home Care and Referral to other Services
- Hospital Stay Extended [in ALC Days] Until Home Care Services or Supports Ready
- Home Care Services Helped the Recipient to Stay at Home (Self-Reported)
- Caregiver Distress Levels
- (In)appropriate Move to Long-Term Care
- Death at Home/Not in Hospital (To Be Defined)

CIHI reported on the first of these indicators recently (2019d), Hospital Stay Extended [in ALC Days] Until Home Care Services or Supports Ready, which measures the median number of days patients remain in hospital when no longer requiring it, until home care services or supports are ready.

While it was found that more than 90% of hospital patients across Canada can access home care promptly, 1 in 12 are currently having their hospital stay extended until those services or supports are ready (CIHI, 2019d). A typical patient most likely to have an extended stay in hospital until these services are available was sent home after 7 extra days or less in hospital, but 1 in 10 waited longer, extending their stay by 39 extra days or more in hospital (CIHI, 2019d).

Wait times varied from a low of 3 and 4 days in Manitoba and Nunavut respectively to as high as 18 and 24 days in Prince Edward Island and the Northwest Territories respectively. Furthermore, 50% of these patients are 82 years of age and older, 60% are women, and 23% have dementia (CIHI, 2019d). Quebec could not provide any equivalent data that could allow comparison (CIHI, 2019d).

Older adults waiting for nursing home care are more likely (90%) to be designated ALC than those who are waiting for home care services (57%) (CIHI, 2017b). However, those who were waiting for home care spent longer in ALC (median wait of 34 days) than those who were waiting for nursing home care (median of 28 days) (CIHI, 2017b).

There are provincial/territorial variations across these measures. In Saskatchewan, for example, an ALC-designated patient had a median wait time for home care of 16 days and 14 days for nursing home care. In British Columbia, the median wait was 34 days for home care and 32 days for nursing home care (CIHI, 2017b).

By providing care in a timely fashion to older adults at home, their communities, or nursing home settings instead of within hospitals, it has been estimated that $2.3 billion in hospital-based ALC spending could be saved annually (Simpson et al., 2015), which is equivalent to more than a third of the total the federal government provided to provinces and territories through transfers to improve access to and quality of home care.

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Moving Towards Standardized Assessment and Care Planning for the Provision of Long-Term Care Services Across Canada

In general, older Canadians who require any form of *long-term care* will require an initial assessment to identify their current needs and types of services for which they may be eligible (CIHI, 2017b). Increasingly, older Canadians might receive a standardized interRAI assessment, which is an assessment instrument that has been developed by the InterRAI Collaborative, a global network of clinicians and scientists who volunteer their time and are committed to improving the health care for older, frail, or disabled people (CIHI, 2017b). This group's work has been particularly relevant to frail older adults, often characterized as those living with chronic illnesses and/or disabilities, whose care often necessitates the use of a variety of clinical and support services requiring multiple assessments (Sinha, 2012). The suite of assessment tools is available for free as long as the health, social, and community care providers using them agree to share the anonymized data they collect when assessing patients and clients (Sinha, 2012). CIHI serves as the repository for all interRAI data collected in Canada (Sinha, 2012). Currently, over 3 million Canadians have been assessed, with over 12 million InterRAI Care Assessments.

A Spotlight on interRAI Care Assessments (Sinha, 2012)

The InterRAI Minimum Data Set (MDS) is made up of a core set of approximately 70 assessment criteria that are important across all care settings and are required to perform a comprehensive assessment. The criteria have the same definitions, observation time frames, and scoring methods. Examples include: cognitive skills, ADLs, and health symptoms. Items that are specific to a particular population or setting can be added to this core set of criteria.

The identification of certain criteria indicate the presence or absence of problems. In order to provide a sense of the severity of a problem there are validated scales that are used. These scales can also be used to monitor changes over time. For example, there is a pain scale that is used to determine the severity of a pain problem. Some tools are built with screeners, which are used to identify a problem that is not easily detected by a single observation (i.e. delirium) or can be used to determine the likelihood of a future adverse event.

As seen in Figure 6, an interRAI assessment system allows clinical observations to be translated into problems, scales, screeners, clinical assessment protocols, and quality indicators.

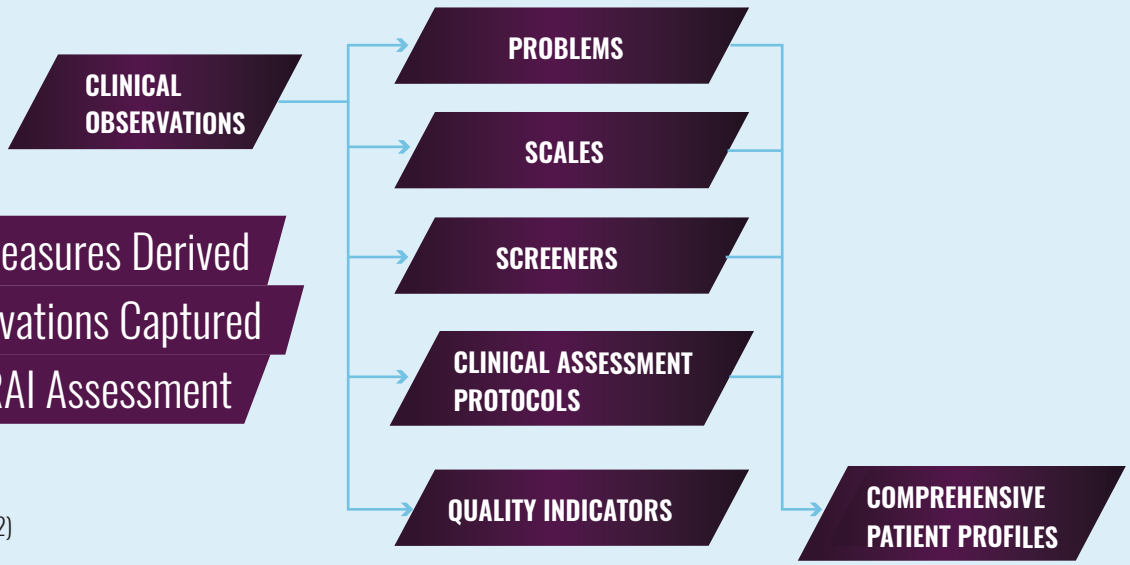

Figure 6: Measures Derived from Observations Captured in an interRAI Assessment

(Adapted from Sinha, 2012)

Clinical Assessment Protocols (CAPs) are written materials that are designed to consider major issues that may be triggered by the initial assessment. The CAPs provide those responsible for care planning with prevention and treatment options. They also determine whether there is a need for further evaluation or treatment that will be needed, based on established guidelines and protocols. This allows for the development of evidence-based and individualized care plans. Quality indicators are designed to look for areas of suboptimal care or for opportunities for improvement.

InterRAI tools are now used across Canada and around the world in a variety of long-term care settings. Those who receive home-based or community-based care are often assessed using one of the following interRAI assessments: Resident Assessment Instrument – Contact Assessment (InterRAI-CA), Community Health Assessment (InterRAI-CHA), Home Care (InterRAI-HC), or Palliative Care (InterRAI-PC). Those who require nursing home care are assessed using the InterRAI Resident Assessment Instrument – Minimum Data Set (RAI-MDS 2.0), while New Brunswick (CIHI, 2019e) and Nova Scotia are currently moving to adopt the new InterRAI Long-Term Care Facilities Assessment (InterRAI-LTCF) (Nova Scotia, 2018). As more experience is gained in their application across the world, and as further research is conducted, the interRAI suite of assessments are continuously upgraded and shared for free.

The CALTC notes that all publicly funded nursing homes in Alberta, New Brunswick, Ontario, and Prince Edward Island report their InterRAI data to CIHI (CALTC, 2017). A portion of nursing homes in British Columbia, Manitoba, Newfoundland and Labrador, Nova Scotia, and Saskatchewan further report their data, but there are no nursing homes in Quebec reporting this type of data (CALTC, 2017).

The Method for Assigning Priority Level (MAPLe) Algorithm is increasingly being used to prioritize individuals for access to a wide range of long-term care services and levels of care appropriate for their needs. The MAPLe algorithm is based on 14 indicators that are collected in

the interRAI tools. A level from 1 (low) to 5 (very high) is assigned for each client that is assessed. It is based on items such as ADLs, cognitive functioning, falls, and risk of institutionalization. This has been a useful algorithm to help care providers better understand the types of clients they are serving, the types of care that would best meet their needs, and the priorities.

In Section 3, the interRAI DIVERT Scale is also highlighted as a validated case-finding tool to detect future risk of emergency department use among home care clients (Costa et al., 2015).

Section 2: Current Challenges in the Provision of Long-Term Care

Over the past decade, several reports have helped to articulate the growing challenges faced by many in the provision of *long-term care* across Canada. The NIA's engagement with national experts and other stakeholders identified four broad categories of challenges that will need to be addressed in order to advance the future provision of *long-term care* in Canada. These include acknowledging:

1. **Challenges faced by older Canadians and their unpaid caregivers in receiving care**

2. **Challenges faced by care providers and unpaid caregivers in delivering care**

3. **Challenges in the organization and delivery of care**

4. **Challenges to the public and private financing of care**

1. Challenges Faced By Older Canadians and their Unpaid Caregivers in Receiving Care

Older Canadians and their unpaid caregivers consistently report being dissatisfied with how *long-term care* services are resourced, organized, and delivered. In addition to hearing the frustration around the lack of care that some face, many older Canadians and their unpaid caregivers note that they are not even sure what options are available, what the associated costs are, if it is publicly funded, how to access it, and how to ensure it can be more person-centred, flexible, and responsive to their own needs.

Understanding What is Available and How to Navigate It

The NIA and others have heard repeatedly through consultation that there is a lack of public awareness and understanding about *long-term care* options, potential financing requirements, and obligations. For many, an admission to a care setting like a nursing home is considered

the default rather than one of multiple options on a continuum from low to high intensity *long-term care* and services that can be offered in a variety of settings.

Equally concerning is that there is a lack of awareness amongst primary care and hospital care providers on both what the continuum of *long-term care* consists of and how best to connect older adults and their unpaid caregivers to the right care, in the right place, at the right time. Indeed long-standing reports, such as the Romanow (Romanow, 2002) and Kirby Reports (Kirby, 2003), have reported that clients, caregivers, and many health and social care providers do not know which services are publicly funded, under which conditions, and the associated assessment process for determining eligibility. Not enough has changed since these reports were released almost two decades ago. A more recent report noted that there is "a strong need for a clearly defined publicly-funded 'basket of services' that recognizes that non-clinical supports such as homemaking, meal preparation, supportive housing, transportation and respite are often essential to supporting an individual at home" (Donner et al., 2015).

The Care that is Available Doesn't Always Provide Flexibility and Choice

In trying to support older adults with much more complex health and social care needs to live independently and age in the community, the models of *long-term care* will need to be more responsive, enable greater choice, and engage meaningfully with older adults and their caregivers as partners in care. Indeed, several stakeholders from across Canada noted an ongoing gap between what people want and need from *long-term care* systems and what is actually offered and delivered. The less Canada's system recognizes the existing diversity of functional, social, financial, ethno-cultural, or even behavioural needs, the less able it will be to deliver the appropriate care that will truly empower Canadians to age in place with dignity and respect.

Care Recipients and Providers Have Diverse Needs and Views

The growing diversity of Canada's population is creating a new series of challenges in the provision of *long-term care*. Older *long-term care* recipients are finding it increasingly challenging to receive culturally

appropriate and safe care. Many care providers also come from increasingly diverse backgrounds that can further create challenges in appreciating the diverse needs and views of care recipients and care providers, especially when caring for individuals with dementia.

A diversity of needs and a diversity in providers exists, but matching the two isn't always easy. The NIA's National Seniors Strategy has raised the importance of recognizing and acting on the needs of older Canadians from different ethno-cultural groups, as well as those from lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities (Sinha et al., 2016).

The provision of food, for example, is important when considering culturally appropriate care, with a need to accommodate cultural tastes and dishes in care homes (Daly, 2016). Additionally, access to laundry facilities can help make a home more culturally appropriate (Armstrong, 2019). For example, in Vancouver, a daughter of a resident in a nursing home expressed that in her culture it was important for the child to care for their parents and being able to do laundry in the nursing home setting when they visited was one way to express their love and care (Armstrong, 2016).

Resident-to-Resident Abuse and Violence is a Growing Challenge

Dementia and other mental health issues can contribute significantly to the occurrence of resident-to-resident violence in designated buildings providing *long-term care*. These factors should not be used as an excuse for inaction by care providers and authorities, who may assume that these incidences are acceptable consequences of diagnoses (McDonald et al., 2015). A scoping review in 2015 found that the total number of resident-to-resident abuse cases in 2011 across Canada was 6,455, representing 28% of all reported abuse cases in nursing homes (McDonald et al., 2015). The most prevalent types of resident-to-resident abuse were physical abuse, physical and verbal abuse, sexual abuse, and then verbal abuse (McDonald et al., 2015). In 2015, an 84-year-old woman nursing home resident died in a British Columbia nursing home ten days after being pushed by another resident with dementia (Office of the

Seniors Advocate, 2016a). Her death was one of nine that has been related to resident-to-resident aggression in nursing homes since 2012 (Office of the Seniors Advocate, 2016a).

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In 2015/2016, there were 418 reported incidents of resident-to-resident abuse across British Columbia (Office of the Seniors Advocate, 2016b). In Ontario, there were 27 known resident-on-resident homicides in nursing homes over a five-year period, according to the Ontario Coroner (Ontario Health Coalition, 2019).

While action is required to reduce resident-to-resident abuse and other forms of abuse in care settings like nursing and retirement homes (McDonald et al., 2015), it's a complex issue to manage, when the behaviours that underlay the abusive actions may not have been appreciated by the abuser and can be hard to investigate and prevent with traditional approaches. More effort will be needed to prevent as much as possible this form of abuse.

2. Challenges Faced by Care Providers and Unpaid Caregivers in Delivering Care

There are significant provider capacity challenges in delivering *long-term care* in Canada – and this includes both care providers and unpaid caregivers. High-quality care for older Canadians requires the capacity to provide such care.

It has become more challenging to attract and retain individuals in careers caring for older Canadians with increasingly complex care needs (CALTC, 2018). At the same time, 98% of older adults age 65 and

over who receive publicly funded home-based long-term care services note that they had one or more unpaid caregivers also involved in their overall care (CIHI, 2010).

The growing care and financial burdens being placed on family members, friends, and neighbours acting as unpaid caregivers should not be underestimated, as it could likely threaten the ongoing availability of persons willing to serve in such roles.

Challenges for Unpaid Caregivers

When considering the overall needs of the *long-term care* workforce, it is important to note that this should also include considerations for unpaid caregivers. Unpaid caregivers do not usually receive training or support to take on these roles (WHO, 2015). Indeed, the WHO noted that it is unlikely that relying on the availability of unpaid caregivers will be sustainable in countries like

Defining an Unpaid 'Caregiver'

The NIA has adopted the Change Foundation's definition of caregivers as "the people – family, friends, neighbours – who provide critical and ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability of end of life circumstances." (The Change Foundation, 2016).

The NIA also pairs the term 'caregiver' with 'unpaid' as Stall et al. (2019) helped to determine that this pairing of words is preferred by those providing unpaid care. Stall et al. (2019) further noted that the term 'informal' caregiver should be avoided as many unpaid caregivers may find this term insulting and invalidating. While 'family caregiver' or 'family/friend caregiver' are also preferred terms, 'unpaid caregiver' provides more inclusive terminology as it recognizes unpaid caregivers beyond those who are only family and friends (Stall et al., 2019).

When referring to a caregiver who is paid for their services, the NIA uses the term 'care provider'.

In 2012, an estimated 8.1 million Canadians aged 15 and over had provided unpaid care to a chronically ill, disabled, or ageing family member or friend in the previous year (Sinha, 2013).

Canada as people continue to live longer and eventually farther apart from their families, have fewer children, and more women enter the paid workforce (WHO, 2015).

In 2012, an estimated 8.1 million Canadians aged 15 and over had provided unpaid care to a chronically ill, disabled, or ageing family member or friend in the previous year (Sinha, 2013). Providing unpaid care includes activities such as driving someone to an appointment, preparing meals, assistance with bathing and dressing, or administering a treatment (Sinha, 2013). The majority of unpaid caregivers (89%) report providing care for at least one year or longer, with 50% providing care for four years or longer (Sinha, 2013).

There are approximately 6.1 million Canadians, or 35% of employed Canadians, who are working and balancing unpaid caregiving duties at the same time (Government of Canada, 2015a). In 2012, an estimated 54% of Canadian unpaid caregivers were female (Sinha, 2013). Women were also more likely to spend 20 hours or more per week providing care, while men on average spent less than one hour per week providing care (Sinha, 2013). In 2012, almost 30% of Canadian unpaid caregivers were also characterized as being members of the 'sandwich generation' often women between the ages of 35 and 44 who are caring for an older adult and raising a child under the age of 18 (Sinha, 2013).

Dementia increases the complexity of *long-term care* provision. Given that the number of people living with dementia will increase with an ageing population, more recognition and support for unpaid caregivers will be needed. Unpaid caregivers of older adults with dementia were found to provide more hours of care

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and experience higher levels of distress than those who are providing care to adults without dementia (CIHI, 2018c). Additionally, 45% of those providing unpaid care for someone living with dementia experienced distress while 26% of other unpaid caregivers reported experiencing distress (CIHI, 2018c).

The NIA and others have previously highlighted some of the issues facing Canada's unpaid caregivers, including: the fact that their role often remains inadequately recognized; there are limited financial supports for unpaid caregivers, especially working unpaid caregivers; the health care system is difficult for unpaid caregivers to navigate because of a lack of integration between service providers; there are significant financial, emotional, and, physical costs associated with caregiving; and there is a lack of information or formal training for unpaid caregivers (NIA, 2018).

45% of those providing unpaid care for someone living with dementia experienced distress while 26% of other unpaid caregivers reported experiencing distress (CIHI, 2018c).

Challenges for Care Providers

The *long-term care* workforce in Canada is made up of hundreds of thousands of dedicated professional and non-professional care providers including: registered nurses (RNs); registered or licensed practical nurses (RPNs, LPNs); nurse practitioners (NPs); health care aides (HCAs), care aides or attendants (CAs), or personal support workers (PSWs); therapists including physiotherapists (PTs), occupational therapists (OTs), and Speech Language Pathologists (SLPs); registered pharmacists (RPhs); registered dieticians (RDs); and other workers such as housekeepers and food services staff working in designated buildings providing care, such as nursing or retirement homes.

HCAs or PSWs are the care providers most often providing long-term care across all settings, and they often assist with the provision of personal hygiene and care such as bathing, dressing, toileting, mobilization, and meal time support (Barken & Armstrong, 2018). These types of care providers may be delegated to perform more complex medical tasks under the supervision of nurses, therapists, or other professional care providers (Barken & Armstrong, 2018). The work of HCAs and PSWs involve a wide range of skills to provide this level of care. Given the growing and recognized medical complexity of those requiring long-term care, HCAs and PSWs must be able to respond to and appropriately manage the behaviours of those living with dementia, perform more complex medical tasks when necessary, and account for cross-cultural issues that may be necessary to provide appropriate care to individuals from differing backgrounds (Barken & Armstrong, 2018).

Two types of nurses are the next most common types of front-line *long-term care* providers: LPNs (also known as RPNs) and RNs (Barken & Armstrong, 2018). Nurses in long-term care settings are often responsible for assessing residents and clients, delivering physical and psychological care, providing care management, and overseeing the administration of medications (Barken & Armstrong, 2018).

Documentation also accounts for much of a nurse's time (Barken & Armstrong, 2018).

Despite the number and variety of roles available for professionals in long-term care settings, there is low public awareness of the existing career opportunities (BCCPA, 2018a). Societal ageism further evokes stigma and a lack of prestige in working with older adults (BCCPA, 2018a). Far lower wages for those working in this sector compared to pay in other sectors also makes it hard to recruit and retain excellent long-term care providers (BCCPA, 2018a).

Chronic understaffing, stress, burnout, and less than ideal working conditions add barriers to recruitment and retention (McGilton et al., 2013; BCCPA, 2018a). The Ontario Personal Support Workers Association (OPSWA) found that an astounding 79% of the more than 13,400 PSW respondents to a 2018 survey reported being unhappy with their profession (Laucius, 2018).

Of those who reported being unhappy, almost 40% reported it was due to staffing issues (i.e. being short staffed), 26% said it was due to inadequate pay, just under 25% reported it was due to unsafe work environment, and 11% reported unsatisfactory working hours (Laucius, 2018). The survey also noted that approximately 33% of its responding PSWs had left the field, with two-thirds reporting their departure was due to burnout, 21% for inadequate pay, and 5% to injury (Laucius, 2018). Other studies from Ontario have found similar associations between supportive supervision and intent to turnover amongst PSWs providing care in nursing or care homes, and these studies have also emphasized the importance of supportive supervision for PSWs providing care (Bethell et al., 2017).

The Ontario Personal Support Workers Association (OPSWA) found that an astounding 79% of the more than 13,400 PSW respondents to a 2018 survey reported being unhappy with their profession (Laucius, 2018).

One study compared the results of a Health Care Aide (HCA) survey over time with representation from British Columbia, Alberta, and Manitoba, and found there were no improvements in scores, and that there was an observed worsening in scores around work-life and individual attributes, including care aide health, burnout, and job satisfaction (Chamberlain et al., 2019). It was further noted that there exists a historic perception that their work is domestic, unskilled, and of lesser importance (Chamberlain et al., 2019). This perception is counterproductive to factors that may be able to improve their working conditions and in turn the quality of care received by those they care for (Chamberlain et al., 2019).

In Ontario, 80% of nursing home administrators reported having difficulty filling shifts, which can impact their ability to meet regulatory requirements (OLTCA, 2019b). They reported that of the positions to be filled, PSW/HCA positions were the most difficult to fill, followed by RN positions (OLTCA, 2019b).

A 2017 survey of nurses working in home care and nursing homes found that approximately 90% of those surveyed reported that the acuity of the needs of their clients had increased, with 63% of home care nurses and 70% of nursing home nurses saying it has increased 'a lot' when compared to three years earlier (The Vector Poll, 2017). Choiniere & Lowndes (2018) noted that it was common to see only one or two RNs responsible for the care of an entire nursing home, and despite the growing intensity of care needs, staffing levels have remained minimal and more reliant on casual and part-time nurses and other care providers.

Indeed, many have highlighted that while the clients have changed greatly over the last decade, and now represent more highly complex individuals with equally complex care needs, funding formulas have not evolved to ensure the right levels of care can be provided to maintain the health, well-being, and safety of nursing home clients (RNAO, 2019).

A 2017 Canadian Federation of Nurses Unions (CFNU) survey found that excessive overtime has been a significant issue for home care nurses across Canada, with 63% saying they worked overtime at least once per week or almost every week, even when they

would have preferred not to (The Vector Poll, 2017).

Choiniere & Lowndes (2018) similarly concluded from their study that short-staffed working conditions and heavy workloads caused significant tension in the workplace, leading to exhaustion and staff burnout. Indeed, studies have found that nursing staff in nursing homes have identified excessive regulations, underfunding of the system leading to difficulty obtaining resources, non-supportive management, and external or personal factors as some of the factors that have influenced their intention to leave the workplace (McGilton et al., 2013). This was particularly highlighted in a 2017 CFNU survey, in which 55% of the nurses surveyed reported having a lack of time to do their job well (The Vector Poll, 2017).

Similarly, an Ontario sample of home care nurses found that age, income stability, patient variety, quality of care, satisfaction with salary and benefits, meaningfulness of work, work-life balance, relationships with their supervisors, and continuity of patient care all influenced their intent to remain employed (Tourangeau et al., 2017).

55% of the nurses surveyed reported having a lack of time to do their job well (The Vector Poll, 2017).

Nurses in Manitoba have identified their number one complaint as being chronic understaffing, which leads to an inability to spend adequate time with residents, delays in care, and rushing many aspects of care which is not ideal when providing care (Manitoba Nurses Union, 2018).

Finally, care providers have been increasingly facing violence from some clients with dementia (Manitoba Nurses Union, 2018). In nursing homes, workplace violence due to resident-to-staff abuse and violence continues to rise.

In Manitoba, 58% of nurses in nursing homes reported that they have experienced physical violence, 51% reported experiencing bullying or aggressive behaviour from residents and/or their families, and 51% reported receiving unwanted sexual attention from residents and/or residents' families (Manitoba Nurses Union, 2018).

3. Challenges in the Organization and Delivery of Care

The way *long-term care* services are organized across Canada remains less than ideal for older Canadians, their caregivers, and their care providers. Good information is typically hard to find, there is a lack of transparency on available care and setting options, and delivery of care is fragmented across multiple, often disconnected, systems of care.

In 2015/16, 433,000 Canadians were reported to have unmet home care needs (Gilmour, 2018b). Women, older individuals, and those living alone were more likely to have unmet needs than others (Gilmour, 2018b). The most frequently reported barrier to accessing long-term care amongst Canadians has primarily been the availability of services (Gilmour, 2018b). Other barriers included language, not knowing where to go to get care, the cost of care, or not being found eligible (Gilmour, 2018b). Indeed, the 2012 Ontario Caregivers Survey found that 38% of respondents reported being unfamiliar with which long-term care services were locally available (Sinha, 2012).

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For those who require *long-term care* services, wait lists have become an issue. The rapid growth of nursing home wait lists is evident. In Ontario, for example, the number of Ontarians approved and waiting for a nursing home bed grew by 45% from 2015 to 2018 (OLTCA, 2019b). By February 2019, 34,834 Ontarians were on a wait list for nursing home care, with an average placement time of 161 days (OLTCA, 2019a). In British Columbia, 1,379 people were waiting for a nursing home bed in March 2018, an increase of 7% over the previous year (Office of the Seniors Advocate, 2018).

On this wait list, 240 people were waiting in hospital (Office of the Seniors Advocate, 2018). Increases in wait lists often also reflect changes to other parts of the system that are not sufficiently alleviating the demand for nursing home care.

The 2012 Ontario Caregivers Survey found that 38% of respondents reported being unfamiliar with which long-term care services were locally available (Sinha, 2012).

Reducing nursing home capacity within a population where it is not matched by a corresponding expansion of home and community-based care funding and capacity often results in longer wait lists and drives hospital-based ALC rates (Jansen, 2011).

Individuals in need of care, their families, and care providers from across Canada have all reported being pressured to choose less than ideal care options in the interests of alleviating ALC pressures that are seen as the main drivers behind capacity issues being described as 'hallway medicine' or even 'code gridlock.'

In the United Kingdom, those individuals with ALC-designations have further acquired the more negative name of 'bed-blocker', a particularly troubling and pejorative term because it appears to affix the blame for the health system's capacity issues on the mostly older patients who are in need of long-term care in a system that cannot meet existing demands.

The Ontario Long-Term Care Innovation Expert Panel noted that "lack of integrated systems, poor coordination of admissions to long term care and overly complex rules related to eligibility and choice are resulting in bottlenecks, duplication, longer wait times and negative resident and family experience" (Long Term Care Innovation Expert Panel, 2012).

'First available bed' policies that have been enacted in some parts of Canada are meant to maximize nursing home bed capacity. But these policies start to appear cruel when the 'first available bed' is located outside of one's own community and far away from family (Canadian Health Coalition, 2018). In Newfoundland and Labrador, for example, an older woman was placed over 200km away from her home, making it very difficult for her family to visit her (Lord, 2017).

Another concern with 'first available bed' policies is that they can create situations of spousal separation (Mancini, 2019). Sometimes, these policies do not account for spouses living together.

Beyond the obvious emotional toll, prolonged spousal separations can be financially stressful, as the partner who remains at home may find it difficult to afford both the living expenses of the partner's nursing home care costs and their own costs associated with remaining at home (Family Caregivers BC, 2012). The burden of regulations within nursing home settings can also inadvertently reinforce a 'culture of compliance' which can divert time from clinical care towards performing regulated tasks and mandatory documentation (Long Term Care Innovation Expert Panel, 2012). Nurses in these settings have noted that regulations sometimes placed constraints on their creative thinking and professional judgement and led to a greater level of inflexibility in responding to the individual needs and care preferences of their residents (McGilton et al., 2013).

It has been found that excessive documentation burden often left little time to develop relationships with nursing home residents (McGilton et al., 2013). Some care providers further noted that they rarely left the workplace feeling accomplished or proud of their work, which resulted in burnout, frustration, and dissatisfaction with the work itself (McGilton et al., 2013). The limited use of integrated health records is another continuous challenge to the delivery of care; shared and effective information systems, can improve communication, coordination, and make transitions smoother, with fewer errors (Home Care Ontario, 2016). In Ontario, for example, care assessment, planning, and resource

allocation is often determined using mobile or web-based software, with limited integration between other systems of information technology (i.e. primary care or hospital). This results in greater siloing of care providers, which in turn leads to the further fragmentation of care for care recipients (Home Care Ontario, 2016).

Increasingly across Canada it is becoming recognized that the health systems themselves that provinces and territories have uniquely funded and developed to provide a range of *long-term care* services play an important role in influencing care outcomes. Indeed, system-based considerations, such as the organization and distribution of care and resources, appear to be the dominant factors in determining care and access to services. As a result, patient and system outcomes - rather than diagnostic and clinical factors or patient desires - come to dominate.

A recent study reinforced this: substantial inter-provincial variations in hospital admissions for patients receiving publicly-funded home care services or living in nursing homes appear to exist between Alberta, British Columbia, and Ontario (Hebert et al., 2019). In Ontario, for example, nursing home residents were found to have more than twice the odds of being transferred to a hospital, independent of all other factors including their underlying severity of illness, compared with those in Alberta and BC (Hebert et al., 2019).

In Ontario, for example, nursing home residents were found to have more than twice the odds of being transferred to a hospital, independent of all other factors including their underlying severity of illness, compared with those in Alberta and BC (Hebert et al., 2019).

In contrast, people receiving publicly-funded home care services in Alberta and BC were less likely to be admitted to nursing homes than those in Ontario, but they were more likely to be admitted to hospital regardless of their underlying severity of illness and other factors (Hebert et al, 2019).

4. Challenges to the Public and Private Financing of Care

For *long-term care* providers and recipients, the fact that this type of care is only recognized as an 'extended health service' and not a core, insured service under the CHA has resulted in each province and territory developing its own legislation and accompanying policies and regulations to govern the provision and financing of *long-term care* services. While core insured hospital and physician services have required a more uniform approach to funding and service provision amongst provinces and territories, the approach towards *long-term care* has been anything but.

All jurisdictions across Canada are facing similar challenges around quality, access, efficiency, financial sustainability, political will, and the ability of each government to pay for its *long-term care* services. With no established federal standards for this type of care across Canada, there exists a patchwork of programs and variations in the availability of services, level of public funding, eligibility criteria, and out-of-pocket costs for clients and residents (Jansen, 2011). While all provinces and territories regulate and subsidize nursing home fees, the eligibility criteria and means-testing methods employed vary widely (Jansen, 2011).

Some Canadians choose to purchase additional care from private providers and, in some provinces like Quebec, it has become a deliberately encouraged and subsidized practice through two distinct programs. Its *Financial Assistance Program for Domestic Help Services*, introduced in 2003, provides a reduction of the hourly rate charged for domestic help services that are offered by a ministry-recognized social economy enterprise (Gouvernement du Quebec, 2019b). In addition, Quebec offers a refundable *Tax Credit for Home-Support Services for Seniors*

equal to 35% of the expenses, up to a designated maximum, for home care and support services for those over age 70 (Revenu Quebec, 2018a). It is not certain if people are more likely to benefit from the more flexible care allocation and financing approaches that Quebec has pursued or from the way care is more traditionally provided and allocated in other provinces.

Demographic pressures and unmet needs point to an issue of sustainability for *long-term care* funding in Canada, which includes both publicly and privately funded care. Even if more funding were available, stakeholders have noted that some of the current ways *long-term care* services are financed do not incentivize the provision of the best possible care.

The provision of publicly-funded home care across Canada is increasingly being funded based on the tasks that are required to be performed rather than around outcome achievement. Within nursing home settings, the Registered Nurses Association of Ontario (RNAO) (2019) further notes that funding is not currently fully reflective of the varying functional and clinical needs of their residents.

For example, if a resident is incontinent, funding is provided for the care and the supplies required to manage the incontinence but not to support the staff hours required to implement prompted toileting at regular intervals to reduce the frequency of incontinence in the first place (RNAO, 2019), thereby improving outcomes for clients.

The RNAO (2019) highlights a "disincentive to improve patient outcomes" because, as problems are prevented or resolved, resident acuity decreases and funding in future years is decreased. This is because funding is based on 'case-mix index' which clusters residents into groups reflecting their relative costs of services and supports that individual residents are likely to use (RNAO, 2019). The RNAO also notes that the funding provided for assisting those living with dementia does not cover how time-consuming the interventions required for appropriately managing aggressive behaviours can be (RNAO, 2019). In 2010, Alberta Health Services began implementing patient care-based funding (PCBF) for

nursing home care providers (Crump, Repin, & Sutherland, 2015). It does not define the amount of provincial spending, but it instead caps spending and allocates the budget between nursing home care providers based on their residents (Crump et al., 2015). There is a flat rate paid to providers based on the number of beds operated to cover the cost of administration, compliance, and oversight (Crump et al., 2015).

There is also a variable portion where payment is made based on the needs of residents and the number of days a bed is occupied (Crump et al., 2015).

The majority of this payment is for staff to meet the needs of residents, and residents with greater needs are associated with increased funding amounts (Crump et al., 2015). Lastly, there is a small component that is the pay-for-performance aspects, whereby there is additional funding if the nursing home providers meet defined targets associated with quality (Crump et al., 2015). Alberta's system is a data-driven approach to funding based on care needs that are assessed and measured using the interRAI Resident Assessment Instrument – Minimum Data Set (RAI-MDS) 2.0 (Crump et al., 2015). The strengths of this model include a more open way of funding nursing home care providers that provides a clearer connection between care needs and resources provision (Crump et al., 2015). However, a number of these providers have struggled with understanding how the funding is allocated (Crump et al., 2015).

Furthermore, a noted weakness of this approach is that the case-mix index is based on average wage rates, which is problematic as having structurally higher wage rates disadvantages a number of care providers (Crump et al., 2015). Current nursing home care funding models can also appear to disincentivize efforts to improve patient outcomes where problems are prevented or resolved, since funding depends upon the acuity of the care recipient. As acuity decreases, the funding originally provided to deliver care decreases as well (RNAO, 2019). Indeed, the unintended and negative consequences of quality improvement efforts that can occur

is that care provider organizations can be financially penalized for positive outcomes (RNAO, 2019).

Care providers are not incentivized to reduce emergency department visits or hospitalizations, and they do not have financial incentives to do more at the community level to keep clients and residents away from hospitals and to better strengthen transitions of care. Therefore, a better alignment of funding and incentives may help produce better *long-term care* system outcomes.

Section 3: Opportunities for the Future Delivery of Long-Term Care

The last few decades have seen a host of new approaches and models become established around the provision of *long-term care* which have evolved based on jurisdictional priorities and societal demand. Indeed, there has been a growing emphasis on promoting more person-centred, flexible *long-term care* models that prioritize well-being, prevention, engagement, and choice. While the policy of de-emphasizing care provided in designated buildings has been motivated by evolving societal care preferences to enable the provision of care closer to home and the need to create a more sustainable health system, it is clear that the right incentives can drive the right change.

This section highlights emerging and leading evidence-informed models of care, support, and care practices that the NIA and its stakeholders from across Canada have identified. Each innovative model of care, support, or care practice that is presented could either be introduced into the Canadian context - or if already present - could be spread across Canadian jurisdictions in an effort to shape an enhanced future for the provision of *long-term care*.

To help contextualize the identified innovations in a more systematic way, each has been positioned within a conceptual framework based on four distinct ways to categorize Canada's heterogeneous older populations who will likely benefit from these innovations across the *long-term care* continuum as their needs and circumstances evolve (Sinha, 2012). This framework is agnostic of age but focuses more on the combinations of issues and needs that, with increasing complexity, can significantly impact a person's ability to live independently in the place of their choice:

- **Healthy older adults with minimal care issues and needs**

- **Older adults with moderately complex care issues living at home in the community**

- **Older adults with complex care issues and needs living in the community with intensive supports**

- **Older adults with complex care issues and needs living in designated buildings**

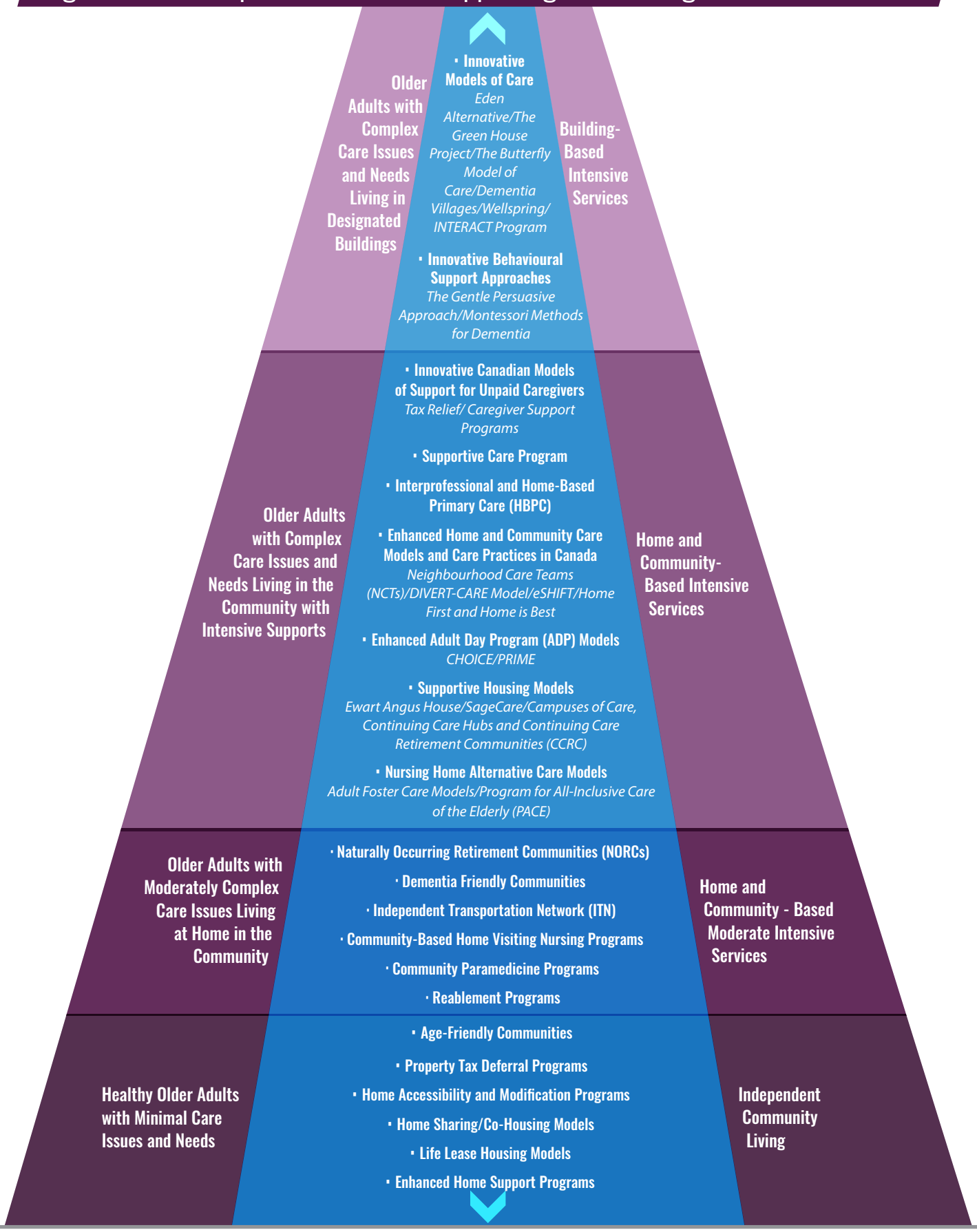
Figure 7 presents a pyramid shaped diagram envisioning the conceptual framework where each of its four levels correspond to an increasingly smaller and complex characteristic sample of the population. Each of the four categories lists a series of identified evidence-informed models of care, support, and care practices that would likely be well positioned to serve older adults, demonstrating a corresponding level of need.

It should be acknowledged that the needs of older adults are dynamic and can change in either direction along the continuum of care which is represented by the central arrow in the diagram.

The highlighted models of care, support, and care practices presented are meant to increase in intensity to meet the needs of older adults. Individuals may benefit from none, some, or many of these innovations at the same time and in varying ways depending on their own unique set of individual needs, resources, and preferences.

In an ideal model, all older Canadians, their families, and unpaid caregivers, will be empowered and engaged partners in their care with access to a local team of care providers who could provide timely and coordinated access to primary, speciality, and *long-term care* enabled by standardized assessment and care planning instruments.

Figure 7: A Conceptual Framework Supporting Future Long-Term Care Provision



Healthy Older Adults with Minimal Care Issues and Needs

The majority of older Canadians can look forward to living healthy and active lives for much of the extended life expectancy that Canadians have gained over the last fifty years. Indeed, for those who are able to make it to 65 years of age, it is generally expected that they will have an average of 20 years ahead of them, with the majority being in relatively good health. As a result, many older Canadians are living active lives largely unhindered by chronic health issues. Their memory and cognitive abilities remain in good shape, and they can get around easily by themselves and take care of their own personal care needs. They are unlikely to require or receive any home care or community support services, and they remain highly motivated to age-in-place in their homes and communities. In addition to being in mentally and physically good shape, they are likely to be active in their communities, have the support of a strong social network, and may actually be supporting others as volunteers or unpaid caregivers. Indeed, in Toronto for example, older adults were found to have higher social capital than people in their 20s, as shown in a recent Toronto Foundation report supported by the NIA (Toronto Foundation & Environics Institute, 2018). The innovations highlighted in this section are primarily ones that enable 'healthy ageing' and reflect a growing preference older Canadians have to remain independent and to 'age-in-place' for as long as possible.

Age-Friendly Communities

In 2006, the WHO launched its *Global Age-Friendly Cities (AFC)* Project to promote a more thoughtful approach to community development focused on the health and well-being of people of all ages and across the life course (Government of Canada, 2016b). AFCs have deliberate policies, services, and structures related to the physical and social environments that are designed to help older adults live, age, and remain involved safely in the community (Government of Canada, 2016b).

Through its work, the WHO has identified eight domains of community life that influence the quality of life and health of older persons and, indeed,

people of all ages: respect and social inclusion; social participation; communication and information; civic participation and employment; outdoor spaces and buildings; transportation; housing; and community support and health services (WHO, 2007). The adoption of these eight domains into the design and development of communities can support the needed transformation of communities into age-friendly ones.

The WHO's Global Network for Age-friendly Cities and Communities has over 800 member cities and communities across 41 countries, including 80 across Canada alone (WHO, 2019).

The WHO's Global Network for Age-friendly Cities and Communities has over 800 member cities and communities across 41 countries, including 80 across Canada alone (WHO, 2019). Amongst communities that have taken part in age-friendly community development activities at various levels, many have learned to assess their level of 'age-friendliness,' how to integrate an ageing perspective into urban planning efforts, and how to create age-friendly environments that consider not only the design of physical features but also infrastructure, policies, and service provision.

Property Tax Deferral Programs

With most older homeowners living on fixed income sources that may not be keeping up with property tax increases and the cost of living, many provinces and municipalities across Canada have established programs to allow them to put-off paying their property taxes or tax increases until they are more financially able or until they sell their homes (National Association of Federal Retirees, n.d.).

Provinces like Alberta and British Columbia offer older homeowners low-interest home equity loans which then allow the provincial government to pay the homeowner's property taxes to the municipality (National Association of Federal Retirees, n.d.).

The homeowner can repay the loan at any time (National Association of Federal Retirees, n.d.). In Ontario, low-income older adults and those with disabilities who are also homeowners can get a partial deferral of provincial land and education tax (Ministry of Finance, 2016). Many Ontario municipalities also offer their own corresponding property tax deferral programs. Indeed, many municipalities across Canada offer low-income older adults full or partial property tax deferral programs (National Association of Federal Retirees, n.d.).

Home Accessibility and Modification Programs

The Federal Government's Budget 2015 introduced a non-refundable *Home Accessibility Tax Credit (HATC)* that applies to expenses of up to $10,000 per year, that results in a maximum credit of $1,500 for expenses incurred for work performed or goods purchased towards a renovation of a dwelling that allows an individual to gain access to or be functional within the dwelling and reduce their overall risk of harm. Individuals aged 65 years or older, or those holding a valid disability tax certificate, as well as those supporting others who directly qualify are entitled to claim this tax credit (Government of Canada, 2015b).

At the provincial level, some provinces have also established programs for lower income older adults and those living with disabilities to renovate dwellings to increase their accessibility. Both Nova Scotia and PEI have well-developed ranges of grant programs to enable low-income older adults to age-in-place. Nova Scotia's *Senior Citizens' Assistance Program* provides grants of up to $6,500 to carry out necessary health-and-safety-related home repairs; the province's *Home Adaptation for Seniors' Independence* helps older adults pay for home adaptations with one-time forgivable grants of up to $3,500 (Province of Nova Scotia, 2019). Lastly, Nova Scotia's *Parent Apartment Program* provides low-interest loans to make additions or renovations to an existing single detached dwelling to create affordable housing accommodation for older family members (Province of Nova Scotia, 2019). The PEI *Home Renovation Program* provides low-income older

adults with up to a maximum of $6,000 for eligible renovations to the structure, heating, plumbing, or electrical systems of their home in order to improve safety (Government of PEI, 2019a).

Home Sharing/Co-Housing Models

HomeSharing is a unique living arrangement that occurs where two or more people who are typically not related choose to reside together in the same residence under a mutually beneficial arrangement (BAFSC, 2015). A typical *HomeShare* arrangement provides each person with their own private space and some shared common areas, however the landlord typically offers their tenant a subsidized rent in exchange for a certain agreed upon number of hours of weekly support activities, such as household maintenance and help with groceries. *HomeShare* Programs have been established in Alberta, Newfoundland and Labrador, Quebec, and Ontario (BAFSC, 2015). They have been profiled as ways that allow landlords to age-in-place while tenants gain access to a more affordable housing arrangement that can help further combat social isolation.

The Ryerson City Building Institute (2019) has defined *Co-housing* as "an intentional, self-built community wherein residents maintain private dwellings centered around communal spaces and services tailored to meet their own specific needs." In this communal housing arrangement, residents own their housing unit but share common areas, which allows for mutual support, shared resources, and workloads which can include a caregiver, a cook, and a driver (Halton Region, n.d.). Examples exist across the country such as *Harbourside Co-Housing* in British Columbia and *Solterra Co-Housing* (Ryerson CBI, 2019). Please see the box entitled Introducing the *Golden Girls Act* on page 136 for more information about legislative steps that are being considered in Ontario to enable more co-housing living arrangements.

Life Lease Housing Models

The *life lease housing model* represents a combination between rental and ownership. In this model, the property is not owned but instead residents own an 'interest' in the property in exchange for a lump sum up-front payment, with monthly maintenance fees and property tax payments (Ministry of Municipal

Affairs and Housing [MAH], 2014). The life lease interest gives people the right to live in a unit rather than owning it. When people want to leave, the life lease 'interest' is then sold to a new resident (MAH, 2014). Life lease projects in Canada started in the 1970s and 1980s and there are now more than 300 across the country (MAH, 2014). Life lease buyers are typically older adults who are looking to downsize and reduce home maintenance responsibilities and gain access to social and recreational programs and a sense of community (i.e. religious or cultural) (MAH, 2014). Typically, a basic level of maintenance services are offered to life-lease holders such as yard maintenance, but some sponsors choose to offer a wider range of services like laundry, housekeeping, meals, and support services (bathing, transportation, and medication reminders) (MAH, 2014). This option is desirable as it may be more affordable than other housing options as is owned and is exempt from land transfer taxes (MAH, 2014).

Enhanced Home Support Programs

The Veterans Independence Program (VIP) was launched in 1981 by the Service Delivery Branch of Veterans Affairs Canada (VAC) (CHCA, 2013). It provides veterans and other eligible clients with funding for services such as grounds maintenance, housekeeping, home adaptation, transportation, meal delivery services, personal care, and professional health and support services (VAC, 2019). The program does not replace other federal, provincial or municipal programs, it has been designed to complement existing programs when necessary to best meet the needs of its clients and better enable veterans to remain in their own homes and communities for as long as possible (CHCA, 2013). In 2008, *SMILE* or the *Seniors Managing Independent Life Easily Program* was created in Ontario's South East LHIN as an enhanced home and community support program managed by VON with community partners (VON, 2018).

SMILE enables low-income adults who are 75 years of age or older, require assistance with multiple household tasks, have unmet needs, and are at risk of losing their independence due to increasing frailty, to select the types of community support services that will allow them to remain in their own home for as long as possible (VON, 2018). As of 2015, *SMILE* served more than 2,000 clients with a budget of $6.4 million annually (BOC Research and Evaluation Group & SHS Consulting, 2015). Overall, clients and caregivers report being satisfied with the program that offers flexibility and choice around the provision of their services, and they report that it helps them remain at home (BOC Research and Evaluation Group & SHS Consulting, 2015). It was also found to positively impact their overall health, social connectedness, psychological well-being, and comfort and safety at home (BOC Research and Evaluation Group & SHS Consulting, 2015).

In PEI, the *Seniors Independence Initiative* provides financial assistance to lower income older adults for practical services that allow them to remain in their own homes and communities (Government of Prince Edward Island, 2019b). Services that are eligible include light housekeeping, general home and property maintenance, snow removal, meal preparation, among others (Government of Prince Edward Island, 2019b). Low income older adults must apply and then they are contacted by a staff member and an assessment will be done to determine the level of individual and household need (Government of PEI, 2019b). Those older adults who are approved to receive funds can directly choose service providers (with the exception of immediate family members) or they can choose to select from a list of approved businesses (The Guardian, 2017).

Older Adults with Moderately Complex Care Issues Living at Home in the Community

Even as older Canadians acquire chronic health issues, many with good primary care can live in relatively good health and independence. Most of the older adults in this category are living with at least one chronic health issue, but their overall health care remains relatively stable. For the most part, their memory and cognitive abilities are good, and they can still get around their communities and manage many of their basic care needs, but are likely to benefit from some forms of regular assistance. They may be receiving home and community support services. They are still likely to be active in their communities and have a good social network. They may rely on their friends, families, or neighbours to provide some additional unpaid support to enable ageing-in-place.

The innovations highlighted in this section are primarily ones that enable 'healthy ageing' through more structured models of care, support, and care practices that continue to enable 'ageing-in-place' through the continued promotion of independent living in their homes and their communities for as long as possible.

Naturally Occurring Retirement Communities (NORCs)

The term *NORC* is meant to describe "any geographically defined community in which at least 40 percent of the population is 60 or older and lives in their own homes" (Piturro, 2012). NORCs exist in various locations including apartments, condominiums and single-family homes within a block or neighbourhood (Masotti et al., 2006). NORCs are usually self-organized arrangements within an active community with a large number of physically and socially active older adults that encourage participation and sometimes lead the creation of communal supports and services (Masotti et al., 2006).

An example of a successful NORC development within Canada is called OASIS. Based in Kingston, Ontario, OASIS has 60 older adults living in an apartment building where their

needs are identified and managed (Simmons, 2018). Shared programming includes catered and communal meals three times a week, social activities, exercise programs, an on-site personal support worker, and a participatory decision-making model to support their activities (Simmons, 2018).

There are many more examples of NORCs in the United States. Those who are most likely to use NORC services are frailer, typically older, women, less educated, and more isolated (Cohen-Mansfield, Dakheel-Ali, & Frank, 2010). At the same time, those who used the services were more likely to participate in leisure activities (Cohen-Mansfield et al., 2010). Many report being very satisfied with the recreation, social work services, health services, and transportation services provided (Cohen-Mansfield et al., 2010). Indeed, participants agreed that it made them feel more a part of the community, it improved their social life, and they would recommend it to others (Cohen-Mansfield et al., 2010).

Dementia-Friendly Communities

A Dementia Friendly Community is one "where people living with dementia are understood, respected and supported" and people living there are aware of and better understand dementia (Alzheimer Society of ON, 2019). British Columbia, Saskatchewan, and Ontario have all been supporting the development of these communities through various initiatives.

In 2016, the Alzheimer Society of British Columbia published a *Dementia-Friendly Communities Toolkit* to support communities that plan to become more inclusive, respectful, and understanding of individuals living with dementia (Alzheimer Society of BC, 2016).

In Ontario, the *Blue Umbrella Programme* was developed to encourage organizations and businesses to pursue training around dementia awareness and support (Garner, 2018). Upon completing training that is led by the Alzheimer Society and a person living with dementia, a blue umbrella window decal is awarded so that attendees can show customers that they are supportive and welcoming to community members living with dementia (Garner, 2018). In the last few years, thousands of Ontarians have received this training (Garner, 2018).

Independent Transportation Network (ITN)

ITN is the only non-profit transportation network for older adults in the United States (ITN America, 2018). There are currently ITN affiliates in 14 communities across 13 states, from Maine to Florida to California serving a population of individuals who need transportation, but can no longer drive (ITN America, 2018). ITN affiliates all operate as non-profit social enterprises. After a few years of operation, ITN affiliates are modeled to be able to be self-sufficient enterprises. As of May 2018, ITN had provided over 1 million rides and had approximately 4,866 active members and 751 volunteers (ITN America, 2018).

ITN members can request a ride for any reason including doctor visits, shopping trips, other appointments, and social activities (ITN America, 2018). ITN drivers are carefully vetted to ensure safety, and they can either be serving as volunteers or paid individuals (ITN America, 2018). In fact, many ITN drivers are people who are retired themselves, but are building up ride 'credits' for their future needs (ITN America, 2018). When people drive others, they are able to store 'credits' in their own Personal Transportation Accounts, which they can use later when they are unable to drive themselves (ITN America, 2018). Similarly, those new members who donate their cars to their ITN affiliates are rewarded with a commensurate amount of ride 'credits' in their own Personal Transportation Accounts (ITN America, 2018). This innovative model also allows members to pre-purchase their own ride 'credits' as well as for friends and families to also pre-purchase ride 'credits' for them as well (ITNBluegrass, n.d.). The cost of a ride is pre-determined based on distance and how far in advance it is booked which better allows an ITN affiliate to pre-determine the number of drivers it may need on a given day. Overall, this unique model allows for no actual money to change hands during the course of a ride (ITN America, 2018). Those who use the service will receive a statement once a month with specific details about the rides they have taken (ITNBluegrass, n.d.).

Community-Based Home Visiting Nursing Programs

In 1998, Denmark established a care model where a community-based nurse or other professional offers an annual preventive home visit for those 75 years of age and older (Pederson, 2014), on the premise that a proactive visit can prevent larger problems and lead to better outcomes.

In 2004, *Community Matrons* became a new clinical role in England for experienced, skilled nurses who use case management techniques with individuals with high-cost and high-needs patients (Department of Health, 2005). This program is based around similar models aimed at improving chronic disease management in the community from the United States, such as Guided Care, EverCare, and Pfizer (Singh & Ham, 2006). While the clinical effectiveness of these models has been mixed, Community Matrons have been found to have a beneficial effect on the perceptions of patients around their care, psycho-social support, access to services, and advocacy (Williams et al., 2011).

In 2006, the first *Buurtzorg* nurse-led home care team was created in the Netherlands, and it has since grown to 900 teams and 10,000 nurses providing care for 90,000 clients a year across the country (Sheldon, 2017). In this exclusive nursing model, a team of approximately 10 nurses work as self-governing teams within a neighbourhood. They provide many types of care including medical and support services (i.e. help washing and feeding), which is normally done by less expensive and less qualified care providers (Sheldon, 2017). On average each team provides care for 50 clients, from a catchment of 15,000 people (Sheldon, 2017). Nurses offer much input in their initial assessment of clients' needs before they withdraw slowly to encourage independence (Sheldon, 2017).

The Buurtzorg team develops as much independence among its clients as possible as they support the creation of links with other services, volunteers, and family members who can offer solutions to enable ongoing independence (Sheldon, 2017). It has been found that Buurtzorg is preferred by patients, staff appreciate the independence and responsibility, and high quality of care can be

provided at lower cost (Sheldon, 2017). No large-scale comparative research of clinical outcomes, however, is yet available (Sheldon, 2017). A version of the Buurtzorg model is currently being trialled in central Toronto, Ontario (AMS, 2019).

Community Paramedicine Programs

Increasingly, paramedics are being recognized as uniquely positioned to be engaged in more non-traditional roles to support the health care needs of vulnerable older adults at increased risk of negative outcomes (Sinha, 2012).

Community paramedicine has been defined as "a model of care whereby paramedics apply their training and skills in non-traditional community-based environments outside of the usual emergency response/transport model. The community paramedic practices in an expanded role; working in non-traditional roles using existing skills" (IRCP, 2019). In some rural and remote parts of Canada, paramedics have been used to reduce emergency calls and emergency department visits by providing home visits (Ruest, Stitchman, & Day, 2012).

In some models, paramedics who were responding to 911 calls were allowed to refer their patients to home and community care services (Verma et al., 2018). This was in an attempt to prevent future emergency calls and emergency department visits (Verma et al., 2018). These programs have been shown to improve care for adults living in the community and to reduce the unnecessary use of ambulance and hospital-based services (Ruest et al., 2012; Verma et al., 2018). There now exist community paramedicine programs in Alberta, British Columbia, Nova Scotia, Ontario, and Saskatchewan (IHE, 2017).

Reablement Programs

There is an increasing demand for rehabilitation for older people to help better manage both acute and gradual declines in function. Traditionally, individuals needing more intensive rehabilitation could only receive it in hospitals or other similar settings. Over the past few decades, community-based rehabilitation options like day hospitals, and in-home and community-based therapy options including exercise and falls

prevention programs are being developed and are demonstrating their ability to improve outcomes.

Furthermore, the provision of traditional home care services for those with functional limitations is increasingly encouraging a reablement approach that encourages service users to develop the confidence and skills to once again complete their functional tasks independently and continue to live at home.

Indeed, among frail older people with chronic illness, it is possible to improve independence and health status through restorative approaches to care that help people re-learn or develop new skills that help them adapt to their condition by learning or re-learning the skills needed to function in everyday life. These approaches not only benefit older persons and their families, but have also been found to be effective in appropriately reducing the need for healthcare services and reducing the cost of long-term services (Tessier et al. 2016; Lewin et al., 2013).

Indeed, one major cost-effective analysis from Australia showed the median cumulative cost of all home care services, in a group that received reablement services, was approximately half that of a matched usual home care group at three months, and less than one-third the cost at nearly five years (Lewin et al., 2013).

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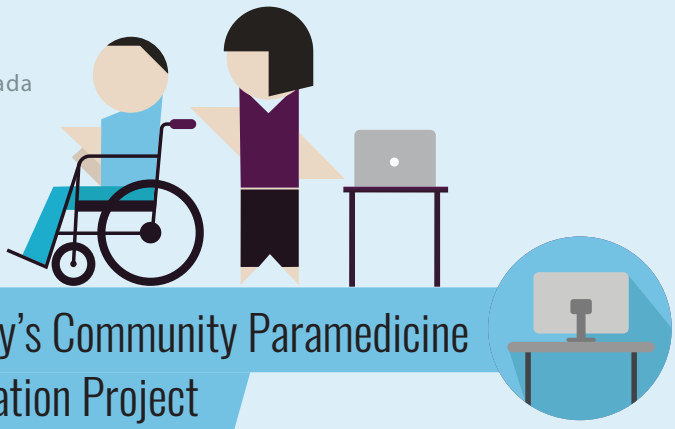
Core Characteristics of Reablement Programs

STRUCTURE	Interdisciplinary team of varying composition
	Training and ongoing support for team members
PROCESS	Free services for 6-12 weeks
	Programs accessible to everybody, but some prioritize those leaving the hospital
	Generic interventions (not requiring a high degree of professional specialization) offered by non-professionals
	Evaluation of users by professionals via structured and comprehensive assessment
	Goal-oriented plan developed with users and their caregivers
	Treatment plan reviewed regularly
	Weekly team meeting
OUTCOME	Improved ADL, IADL and HRQoL and less service utilization

ADL = activity of daily living; **IADL** = instrumental activity of daily living; **HRQoL** = health-related quality of life

(Tessier et al., 2016)



A Spotlight on Canada Health Infoway's Community Paramedicine Remote Patient Monitoring Demonstration Project

Canada Health Infoway recently sponsored a three-year Community Paramedicine Remote Patient Monitoring demonstration project in Ontario to see if enabling community paramedics to provide digital health monitoring supports to promote better patient self-management over a six-month period or longer could keep patients with chronic illnesses safe at home and out of the hospital (Brohman et al., 2018).

The program provided interested patients with a combination of bluetooth-enabled devices based on their specific health conditions such as a weigh scale, blood pressure or heart rate monitor, glucometer, and a transmitting device that could send their biometric data to local community paramedics to facilitate real-time monitoring that could engage and the patient's primary care providers when needed to better support and facilitate their care (Brohman et al., 2018).

Data available on 1,109 enrolled patients working with 14 paramedic services generated 368,510 biometric readings and over 28,000 alerts (Brohman et al., 2018). These were responded to by their assigned paramedics who provided over 3,200 patient coaching sessions (Brohman et al., 2018).

The program's formal evaluation demonstrated that it achieved a 26% reduction in 911 calls, a 32% reduction in hospital admissions, and a 35-41% reduction in hospital readmissions (Brohman et al., 2018). These generated an estimated $7,279 per patient per year in cost avoidance for the health care system versus the $1,134 per patient investment cost to deliver the intervention (Brohman et al., 2018).

Older Adults with Complex Care Issues and Needs Living in the Community with Intensive Supports

Most of the older adults in this category likely have three or more chronic health issues and functional limitations that significantly impact their ability to live independently in their communities. They have a greater likelihood of living with memory or cognitive limitations that can also impact their ability to get around by themselves and take care of their basic care needs. They are also more likely to need assistance with their ADLs. Their overall health is therefore likely to be characterized as complex. They are likely to be living at home, in a retirement residence, or a supportive housing environment, and are dependent on a variety of home care and community support services and looking to friends, families, or neighbours to provide unpaid care and supports. They are also likely to interact frequently with various health, social, and community care providers at the same time. They are at significant risk of complications that occur when communication between their providers is not handled well, especially during care transitions that raise care coordination and medication management issues. They are less likely to be as active in their communities than those in the previous categories, and their health issues may significantly limit their abilities to maintain a good social network.

The innovations highlighted in this section are structured models of care, supports, and care practices that continue to enable 'ageing-in-place' in the homes and communities of older adults for as long as possible with more intensive and structured supports.

Innovative Canadian Models of Support for Unpaid Caregivers

The NIA's 2018 report, *Why Canada Needs to Better Care for its Working Caregivers,* highlighted a number of emerging models of programmatic and financial supports available for unpaid caregivers across Canada.

Although there are differences across the country, on average an unpaid caregiver spends approximately 17-19 hours on caregiving per week

(CIHI, 2018c; Health Council of Canada, 2012). Approximately 10% of caregivers provide more than 30 hours of care per week (Sinha, 2013).

Unpaid caregivers often step into their roles not being provided with the appropriate training to do the tasks that are expected of them, including providing medical care, navigating health and social care systems, and acting as substitute decision makers (The National Academies of Sciences, Engineering, & Medicine, 2016).

In Canada, 26% of caregivers caring for older adults reported experiencing distress (CIHI, 2018c). This reality is even more prevalent among those caring for people with dementia, with 45% of them reportedly experiencing distress (CIHI, 2018c). Among the many reasons why caregiver distress is concerning and important to address is that it can quickly lead to the premature nursing home admission of care recipients.

As Stall (2019) states, "most Canadian caregivers do not have access to caregiver-specific education and supports despite evidence that these can improve their well-being and that of the care recipient." There is a growing recognition of the importance that coaching and skills development can play in helping caregivers feel more empowered in understanding and managing their roles and around how to best support those they provide care and support for. It has been found that there are benefits to caregiver interventions that involve education, skills training, and counselling (The National Academies of Sciences, Engineering, & Medicine, 2016).

Tax Relief

Tax credits are often underutilized, even though they are one of the most common forms of financial support for unpaid caregivers (Sinha, 2013). Very few eligible unpaid caregivers are receiving tax credits (Sinha, 2013; Turcotte, 2013) because they remain unaware of what financial assistance is available to them (Sinha et al., 2016).

Federal and provincial tax credits are generally limited to unpaid caregivers who are related to the care recipient, however Manitoba should be noted for its Caregivers Recognition Act that deliberately recognizes that non-relative caregivers are one of the fastest growing groups of caregivers in Canada and offers support to any

person who is an unpaid caregiver (Sinha et al., 2016).

All federal, and most provincial, caregiver tax credits and EI benefits are either non-refundable or linked to an employment history (Sinha et al., 2016). As a result, unpaid caregivers must have a high enough income to claim against the tax credit in order to receive it as a deduction (Sinha et al., 2016). Quebec (Revenu Quebec, 2018b) and Manitoba (Government of Manitoba, n.d.), however, stand out as exceptions in deliberately making their tax credits refundable and not based on the caregiver earning a sufficient income.

Many of the existing financial supports do not deliberately support low-income unpaid caregivers (Stall, 2019). Nova Scotia is an outlier among Canadian provinces in providing support for low-income caregivers caring for low-income older adults (Stall, 2019) who have a high level of disability or impairment, which puts them at a high risk of being admitted to a nursing home (Province of Nova Scotia, 2019).

Through its *Nova Scotia Caregiver Benefit Program*, if both the caregiver and care recipient qualify, the caregiver receives $400 per month. This program has significantly reduced the premature admission to nursing homes and reduced caregiver distress levels among both care recipients and their caregivers in Nova Scotia (Warner, Poss, & McDougall, 2015).

Through its Nova Scotia Caregiver Benefit Program, if both the caregiver and care recipient qualify, the caregiver receives $400 per month. This initiative has demonstrated its ability to significantly reduce the premature admission to nursing homes and reduced caregiver distress levels (Warner, Poss, & McDougall, 2015).

A Spotlight on Mount Sinai Hospital's Reitman Centre's Caregiver Support Programs

The Reitman Centre at Mount Sinai Hospital in Toronto, over the past decade, has been creating academically grounded programs that can provide caregivers with training, support, and skills required to support people living with dementia (NIA, 2018).

Their 8-week CARERS (Coaching, Advocacy, Respite, Education, Relationship, and Simulation) Program includes group psychotherapy, problem-solving techniques, and experiential learning through use of simulated patients for caregivers, while providing respite with an arts-based group for care recipients (Chiu, Wesson, & Sadavoy, 2013). Participants show improved caregiving competence, ability to cope with stress, and mental well-being (Chiu et al., 2013).

This program was endorsed by the Alzheimer Society of Ontario, which received funding through the Government of Ontario's Dementia Strategy to make this program accessible to caregivers in-person or online across Ontario.

More recently, TEACH (Training, Education, and Assistance for Caregiving at Home) was developed and launched as an in-person or online interactive group, offering a condensed program of practical communication and coping skills training to those caring for a family member or friend living with dementia. It also provides an online tele-mindfulness meditation group on managing stress and coping with challenging emotions for those caring for a family member or friend living with dementia that has shown a positive impact (Enhancing Care for Ontario Care Partners Program, 2019).

To make the knowledge it provides to caregivers of people living with dementia through its programming more accessible, the Reitman Centre, with funding through the Government of Canada's Social Development Partnership Program, also launched its own smartphone application called the 'Dementia Advisor' that helps caregivers improve their communication and problem solving skills, builds resilience, and reduces stress through chat-based role playing. The scenarios simulate a real-life situation that takes only minutes to complete and cover a range of topics including: dealing with refusal, managing difficult behaviours, dealing with family tension, managing work-life demands, and accessing and managing services (Mount Sinai Hospital, 2019).

Supportive Care Program

In Nova Scotia, the Supportive Care Program was established to uniquely support individuals living with cognitive impairments. Under this program an individual may be provided with $500/month for Home Support Services (including personal care, respite, meal preparation, and household chores) while low-income Supportive Care recipients may also receive a reimbursement for snow removal services of up to $495/year (Province of Nova Scotia, 2017).

To be eligible, the person must be a Nova Scotia resident with a valid health card, have significant memory loss or memory problems that affect their daily functioning and must have a substitute decision maker (Province of Nova Scotia, 2017). Additionally, Nova Scotia's Continuing Care Program must find that the person needs a minimum of 25 hours/month of care support. Once approved, the money is directly deposited into the individual's bank account and all receipts for services must be submitted to the Nova Scotia Health Authority (Province of Nova Scotia, 2017). Finally, individuals do not have to report this funding as income on their income tax returns because it is considered payment for medical expenses (attendant/respite services) by the Canada Revenue Agency (Province of Nova Scotia, 2017).

Interprofessional and Home-Based Primary Care (HBPC)

While access to primary care is essential to ageing well, different types of older adults will require different types of primary care. Those with only a handful of chronic issues can still be well-served by office-based primary care physicians or nurse practitioners working alone.

People with multiple chronic health issues including Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF), and often inter-related social issues would benefit from more interprofessional team-based approaches to care provided through Primary Care Networks, Community Health Centres, and other team-based models of care that have been evolving across Canada.

Additional access to care issues are being faced by a growing subset of the older population, such as those who become housebound for a combination of social, functional, and cognitive reasons. It is estimated that there are at least 100,000 older homebound Canadians (Stall et al. 2013a). For these individuals, home–based primary care has become a necessity and not a convenience, although it is not consistently available across Canada.

Ironically, at the same time as the need for it is growing, the number of physicians across Canada providing house calls has been steadily decreasing (Stall et al., 2013b). The resulting access-to-care gap has meant that these patients tend to wait until their care deteriorates resulting in a 911 call, ED visit, and hospitalization (Stall et al., 2014).

There is sufficient evidence to show the value of HBPC for frail older adults. A landmark systematic review by Stall et al. (2014) demonstrated that this type of care resulted in substantial reductions in emergency department visits, hospitalizations, hospital bed days of care, long-term care admissions, and/or long-term care bed days of care. It also demonstrated that for HBPC care models to be most effective, they should adhere to three common design principles: 1) the primary care provider leads an interprofessional care team and is the primary visitor to the patient, 2) the program holds regular interprofessional care meetings, and 3) the program provides

after-hours support (Stall et al., 2014). Smith-Carrier et al. has led several analyses of HBPC models that exist in Ontario, demonstrating significantly positive outcomes from the perspectives of patients, caregivers, and care providers in these models (Smith-Carrier et al., 2012; Smith-Carrier et al., 2015; Smith-Carrier et al., 2017).

The House Calls Program in Toronto has become a Canadian HBPC exemplar that has been able to demonstrate a 29% reduction in expected unscheduled readmissions at three months after an index-hospitalization and a 67% die-at-home rate for its homebound patients (Sinha, 2012).

Furthermore, the United States *Independence at Home (IAH)* Demonstration Project that worked with 14 Individual HBPC Interprofessional Primary Care Practices, serving over 10,000 homebound patients between 2012 to 2017, demonstrated itself to be a cost-effective model of care, mainly on its ability to reduce expensive nursing home care utilization and costs (Mathematic Policy Research, 2019).

Enhanced Home and Community Care Models and Care Practices in Canada

Neighbourhood Care Teams (NCTs)

A new project based in Toronto focuses on implementing a more integrated system of home care delivery designed to better meet the diverse needs of people living in high-density urban neighbourhoods (Toronto Central LHIN, 2014). Within any health region in Ontario, there can be multiple home and community care coordinators and service provider organizations delivering a variety of the same home and community care services to a variety of older clients living in the same neighbourhood including large buildings where they live.

A significant reorganization has taken place that sees home and community care coordinators assigned to one neighbourhood, or even one building, working with only one or two providers of home and community care services. This has allowed better alignment and efficiency amongst the front-line providers who can now better work as members of an integrated team that know each other and their clients, their unpaid

caregivers, and their local neighbourhoods better. A future evaluation of this innovative approach is planned.

DIVERT-CARE Model

Costa et al. (2015), using Canadian InterRAI Home Care Assessment Data, developed and validated a case-finding tool to detect future risk of emergency department use among home care clients known as the *Detection of Indicators and Vulnerabilities of Emergency Room Trips (DIVERT)* Scale that has been endorsed by HQO. It can be used in real-time when an InterRAI-HC assessment is routinely performed in most Canadian provinces and territories, many of which have implemented its use in some way (Costa et al., 2015).

Further work has supported the creation of a scalable chronic disease management model known as *DIVERT-CARE (Collaboration, Action, Research, and Evaluation)* (Schumacher et al., 2018). The combined use of the DIVERT Scale with the *DIVERT-CARE* chronic disease management model has since been the focus of a non-randomized pragmatic cluster trial in southern Ontario. The pilot trial included 100 home care clients in three sub-regions. Emergency department use was reduced by just over 20% in the 7-month follow-up period (Costa et al., 2017).

The *DIVERT* team is now conducting a Canadian tri-research council-funded, full-scale cluster randomized trial in British Columbia (Island Health), Ontario (Hamilton Niagara Haldimand Brant Local Health Integration Network), and Newfoundland and Labrador (Western Health) (Big Data & Geriatrics Models of Care, 2018). This implementation trial is testing the real-world effectiveness of the DIVERT-CARE chronic disease management model in home care practice and is the largest of its kind conducted to date.

The eShift Alternative Professional Home Care Provider Staffing Model

The eShift staffing model was launched in 2010 in Ontario's South West LHIN as a unique way to address the shortage of home care nurses available to provide more intensive home and community care for clients with complex care needs (South West LHIN, 2014). This model

provides PSWs, also known as HCAs and CCAs in other jurisdictions, with specialized training and technology tools that allow them to provide clients with better end-of-life, palliative care at home (South West LHIN, 2014). This model allows several PSWs to transmit important real time information to a remotely designated nurse who monitors the information being submitted and can intervene if there is a concern about changes to the condition of the palliative client (South West LHIN, 2014). It has been found that the eShift model has supported more patients to die in their place of choice, reduced caregiver stress and burden, and resulted in shorter hospital stays and lower readmission rates for the complex end-of-life clients being served through this model (VON, 2017).

Home First and Home is Best

Home First was initiated in 2008 by the Mississauga Halton LHIN and quickly spread across Ontario and other parts of Canada (Queen's Printer for Ontario, 2014). In being seen as a 'philosophy' rather than a specific program or project, this approach seeks to ensure that every effort will be made to ensure adequate home and community care resources will be leveraged whenever possible to enable persons who are admitted to a hospital to return home (Queen's Printer for Ontario, 2014).

This approach has been implemented differently based on local needs and circumstances, but virtually all have focused on frail older populations at risk of losing their independence and being admitted to a nursing home (Sinha, 2012). This approach properly assesses the needs of older adults so that only those who require nursing home care are applying for it, with the ultimate goal of reducing both the demand and wait lists for nursing homes (Sinha, 2012). At Halton Healthcare Services, the number of ALC to nursing home patients within the hospital dropped from 87 in September 2008 to 30 in June 2009 (CHCA, 2010). The acute percentage of ALC-designated patients in hospital also dropped from 28% to 3-5% (CHCA, 2010).

In British Columbia, *Home is Best* has been the adaptation of Ontario's *Home First* approach. Home is Best includes proactive discharge

planning, expanded community support services, increased access to home care services, telephone outreach, and overall care coordination by a health care team working with their primary care provider (CHCA, 2016b). Those with less complex issues are contacted by a 'surveillance nurse' who can intervene to avoid further deterioration. This approach has reduced the time it takes to admit a client to community support services, decreased the overall number of ALC patients, decreased hospital stays, and reduced emergency department visits (CHCA, 2016b).

Enhanced Adult Day Program (ADP) Models

There is mounting evidence that *Adult Day Programs (ADPs)* can deliver positive health, social, psychological, and behavioural benefits both for the people receiving care and for their caregivers (Ellen et al., 2017).

A recent study from British Columbia found that older adults who attended day programs had decreased rates of ED visits, hospitalizations, and fewer overall hospital days (Kelly, 2017).

Traditional day programs sometimes are unable to cater to individuals with more complex medical needs such as the need to be administered insulin during the day. In Ontario, there has been a move to create more enhanced ADPs in each region to better respond to the needs of frail, at-risk seniors with cognitive impairment, behavioural issues, and complex chronic medical conditions that can be better addressed with the addition of a skilled professional care provider like a nurse (West Neighbourhood House, n.d.). Other provinces like Alberta and Manitoba have further developed enhanced ADP models, in Edmonton and Winnipeg in particular.

Comprehensive Home Option of Integrated Care for the Elderly (CHOICE)

Similar to the *Program for All-Inclusive Care of the Elderly (PACE)* model in the United States (see later in this section), Edmonton, Alberta's *CHOICE Program* model was designed to help older adults live independently in the community for as long as possible (Alberta Health Services [AHS], n.d.). It provides clients with access to a day centre one to five days a week where they can be further supported

by an interdisciplinary team that provides medical, psychological, social, and support services. Unpaid caregivers are further supported by the program, which provides them with respite on the days their care recipients are at the day centre (AHS, n.d.).

CHOICE fees are currently $125.76/month (AHS, n.d.). One evaluation of the model found that *CHOICE* decreased falls and reduced the number of emergency room visits, hospital admissions, and hospital lengths of stay among clients (Samuel et al., 2015, as cited by The Good Samaritan Society, 2019).

Program of Integrated Managed-care of the Elderly (PRIME)

Similar to *CHOICE*, Winnipeg, Manitoba's *PRIME* Program offers an enhanced primary health care model supported by an interprofessional team that has its clients visit a day centre at one of two locations for one to five times per week, they can take part in a wide range of activities including medical care, social programs, exercise, and counselling (Winnipeg Regional Health Authority, n.d.).

Established in 2009, the program serves older adults 65 years of age and older who have chronic medical conditions and psychosocial care needs. It offers them after-hours nursing support and further aims to prevent emergency room visits (Winnipeg Regional Health Authority, n.d.). The program charges clients an income-based monthly fee for services that are excluded from provincial health coverage (Winnipeg Regional Health Authority, n.d.). While a promising model, it's unclear if this one has been achieving the same impact as the *CHOICE* or *US PACE* Programs.

Supportive Housing Models

A growing array of publicly and privately available supportive housing and assisted living options are being created to provide older adults the opportunity to maintain their independence in their communities despite having higher functional care needs including when living with dementia (Sinha, 2012). What is common with this type of service is that it is provided in a building that houses at least five or more older adults with care providers such as PSW/HCAs available 24 hours a day to provide

assistance with an individual's personal care needs. Older adults with higher incomes usually can afford privately run retirement home or assisted living options that may be available in their communities. Many older adults choose retirement home living for many different reasons. The accommodations and lifestyles that they offer can meet a number of different needs and preferences (Sinha, 2012). Lower income older adults, however, often need to rely on the publicly funded available options that typically can be delivered at a quarter of the cost that care in a nursing home would cost to deliver (Sinha, 2012). Some exemplar models are further profiled below.

Ewart Angus House: An Intensive Supportive Housing Option for Older Adults Living with Dementia

Since 1999, the *Ewart Angus House* has been part of the continuum of care offered by SPRINT Senior Care (SPRINT Senior Care, n.d.). Ewart Angus Homes Inc. is a private not-for-profit organization that owns the Ewart Angus Home building and has partnered with SPRINT Senior Care to provide care to older adults living with dementia (SPRINT Senior Care, n.d.). This home is an option for people with dementia who can no longer be cared for at home but are not at the stage of their illness that requires them to live in a nursing home environment (SPRINT Senior Care, n.d.). *Ewart Angus*, therefore, offers a safe, home-like environment for 20 people living with dementia who need personal support and supervision from a team of specially-trained PSWs/HCAs (SPRINT Senior Care, n.d.). Meaningful, practical activities are used to help residents remain as involved as possible and maintain their sense of independence (SPRINT Senior Care, n.d.). Residents have their own en-suite bedrooms and live in clusters of five individuals around a common area and kitchen (SPRINT Senior Care, n.d.). They are encouraged to bring their own personal furnishings to personalize their bedroom and to move freely around the home, which is a monitored and secured environment (SPRINT Senior Care, n.d.). Their care providers deliver around-the-clock support with medications and personal care and programs seven days a week, such as exercise classes and arts and crafts (SPRINT Senior Care, n.d.).

SageCare: A Specialized Private Retirement Home Option for Older Adults Living with Dementia

The SageCare Retirement Home was established in 2000 as a private care home option for people living with dementia (SageCare, 2018). The home is meant to provide a creative alternative to a nursing home setting in a place that feels like home, encourages community, and supports each resident as a unique individual (SageCare, 2018). All of its care providers receive special dementia training. Each new resident is assessed by an interdisciplinary team, and a personalized environment is created for their specific behaviours (SageCare, 2018). This home is seen as an exemplar in the provision of privately financed dementia care. It is now planning to replicate and offer its model of care in more communities across the Greater Toronto Area and beyond.

Campuses of Care, Continuing Care Hubs and Continuing Care Retirement Communities (CCRC)

Increasingly across Canada, the Campus of Care Communities are being developed. These are groups of residences or buildings in which more than one level of housing and care is provided. They often consist of a combination of supportive housing, assisted living, and/or retirement and nursing home care (Kary, 2015).

A Campus of Care is meant to allow people to age in one place even as their care needs change (Kary, 2015). There exists no public financing model to create a complete Campus of Care and thus the creation of these require a mix of financing options, good timing, and creative thinking. This is especially the case when different publicly financed options come with their own regulatory frameworks that make the seamless delivery of continuing care sometimes hard to deliver. Nevertheless, in Ontario, preliminary reported benefits of this concept include: improved ability of older adults to maintain well-being, independence, and social capital; reduced social isolation; a continuum of care which allows for better ageing-in-place; economies of scale; improved care coordination and respite; and educational placements and opportunities in the care of older adults (Morton-Chang, 2018).

In parts of Canada, *Continuing Care Hub Models* are being established by using a nursing home as the centre for the delivery of a wide range of services for older adults. These services can include the provision of primary care, chronic disease management, rehabilitation, oral care, foot care, adult day/night programs, meals on wheels, and caregiver supports. This model leverages existing physical spaces and long-term care programs to centralize and integrate care and expertise (Long Term Care Innovation Expert Panel, 2012). It is particularly well-suited for smaller communities or rural and northern areas where a small hospital and/or nursing home is the only care available (Long Term Care Innovation Expert Panel, 2012).

The British Columbia Care Providers Association defines four key features of Continuing Care Hubs: integration of health professionals and family in the care of older adults; new roles for care providers; new funding models (outcome-based funding); and, expanded role and co-location of services (Kary, 2015).

A Continuing Care Retirement Community (CCRC) offers multiple levels of care and living arrangements in one location, supporting an older person to 'age in place' as their care needs change over time (Erickson Living, 2018). For example, a resident could start in independent living, where they can manage their own daily living activities, and then transfer to a nursing home setting when they need more support (Erickson Living, 2018).

A popular model of care established in the United States, CCRCs offer independent living, assisted living, inpatient rehabilitation, and nursing home living environments in a stand-alone community that houses hundreds to thousands of older adults (Erickson Living, 2018). These communities also provide primary care as well as a full spectrum of home health care services on site that are often delivered by the CCRC itself. What has made this model work in many parts of the United States is that CCRCs are enabled to use existing funding mechanisms to become providers of a variety of care services themselves and even in some cases offer their home Medicare Advantage Health Insurance Programs to help cover and fund the full spectrum of care they are making available to their members who live in these communities.

Nursing Home Alternative Care Models

Adult Foster Care Models

In the United States, adult foster care models are becoming an increasingly popular alternative care approach to support older adults who are eligible to move into an assisted living or nursing home environment. This approach allows adults to live with their care providers in home-like settings in their communities where usually no more than four or five residents are receiving care (Sinha, 2012).

Similar to providing foster care for children, foster care for older adults involves paying a person or a family to house and oversee the basic care needs of an older person. Their needs are typically non-medical in nature and involve assistance with the ADLs and ongoing supervision (Paying for Senior Care, 2018). This could be beneficial for older adults who do not require the professional aspects of a nursing home setting but who may not have anyone to help them with their personal care needs, need more supervision than they are able to afford, or live in substandard housing (Sinha, 2012). Adult foster care is a more affordable option as it is approximately half the cost of a nursing home and less expensive than assisted living (Paying for Senior Care, 2018).

In Canada, Ontario's Niagara Region had established a small elder foster care program for financially marginalized, medically stable older adults with limited social supports who were at risk of a premature nursing home placement (Sinha, 2012). There are no legislative barriers to for this model to regain a foothold in Canada (Sinha, 2012).

Program for All-Inclusive Care of the Elderly (PACE)

There were 122 organizations across 31 US states operating *PACE Programs* (NPA, 2019). This model of care, first developed in San Francisco's Chinatown, provides an alternative to nursing home care for older adults designated as needing this level of care (NPA, 2019). This model's alternative services allow

them to remain living in their own home or in assisted living environments. An interdisciplinary team that includes among others a dietician, driver, physiotherapist, nurse, and a social worker provides care through an adult day health centre. It is supplemented with in-home or referral services as needed (Centers for Medicare & Medicaid Services, n.d.).

This well-researched model of care has demonstrated its ability to significantly reduce future nursing home placement. PACE clients at the time of an eventual nursing home admission were more cognitively impaired, more likely to be severely cognitively impaired, and more likely to have overall functional impairment (Segelman et al., 2017). Those in the program receive more flexible and tailored supports, which enable them to remain in the community longer, despite living with higher levels of cognitive and overall impairment (Segelman et al., 2017). It was also found that rates of hospitalization, readmission, and potentially avoidable hospitalizations are lower in PACE populations than other comparable populations (Segelman et al., 2014).

Older Adults with Complex Care Issues and Needs Living in Designated Buildings

Most of the older adults in this category likely have multiple chronic health issues. Their overall health is likely characterized as complex and, if not managed well, could require frequent urgent visits to local EDs and hospitals. These adults are more likely to have cognitive impairment and mood issues, and they likely need significant assistance and support from others to get around and to help them manage their personal care needs. They are also likely to be living in a designated building. They are at significant risk of complications that occur when communication between their providers is not handled well, especially during care transitions that raise care coordination and medication management issues. They are unlikely to be as active in their communities as those in the previous categories, and their complex health issues may severely limit their abilities to stay connected with others.

The innovations highlighted in this section are structured models of care, support, and care practices that continue to enable 'ageing-in-place' in nursing home care environments with the most intensive and structured supports.

Innovative Models of Care

Eden Alternative

This nursing home model was first developed in the early 1990s in New York State in an attempt to change the way nursing homes are run (Eden Alternative, 2014). The *Eden Alternative* represented a significant shift towards person-directed values and practices that put the resident first (Eden Alternative, 2014). The development and implementation of this model is meant to impact the physical environment, organizational structure, and psycho-social interactions within the home (Eden Alternative, 2014). This model promotes heavy family involvement and includes animals, plants, and children to combat loneliness, helplessness, and boredom (Rosher & Robinson, 2005). It provides residents with choice about when to bathe, wake up, and eat (Rosher &

Robinson, 2005). *The Eden Alternative* has been found to improve residents' psychological well-being including reduced rates of depression, loneliness, helplessness, and boredom (Li & Porock, 2014). It has also been found to increase visits of family members and an improvement in the families' perceptions of respect given to older adults by the staff (Rosher & Robinson, 2005).

The Green House Project

The Green House Project was developed out of the Eden Alternative in the early 2000s (Brune, 2011; The Green House Project, 2019), its core values that include providing a more meaningful life for residents, empowered staff, and a real home-like environment (The Green House Project, 2019).

Green House homes are home to 10-12 individuals who each have a private room and an attached bath, but share a central living space that has a kitchen, dining area, and living area (Cohen et al., 2016). This model mandates that the care is provided to the residents by a consistent and empowered team of care providers who are responsible for their personal, clinical, and home care activities (Cohen et al., 2016).

Care in this model is also intended to be person-centered so that older adults are able to dictate their schedule, their activities, and their meals (Cohen et al., 2016).

Green House homes were also found to have fewer bedbound or catheterized residents or those presenting with pressure ulcers, and fewer 30-day readmissions than average for nursing home residents (Afendulis et al., 2016).

Those living in Green House homes have more choice around their own room furnishing, meal times, and they report experiencing more spontaneous and naturally occurring activities (Cohen et al., 2016). Green

House care providers were also found to spend more time with their residents as they not only take care of resident needs but they also do tasks like laundry, meal preparation, and light housework (Brown et al., 2015). Green House homes were also found to have fewer bedbound or catheterized residents or those presenting with pressure ulcers, and fewer 30-day readmissions than average for nursing home residents (Afendulis et al., 2016).

The Butterfly Model of Care

The *Butterfly Model of Care* was founded over two decades ago and has been adopted by more than 30 care homes across the United Kingdom, Ireland, Canada, and Australia (Dementia Care Matters, 2018; Welsh, 2018). This model is based on the belief that, for people who are living with dementia, feelings matter the most to them (BCCPA, 2018b). In order to become a *Butterfly Home*, a nursing home must undergo a one-year culture change program known as the *Butterfly Project* (BCCPA, 2018b). The transformation requires strong and supportive leadership and is based on developing emotional intelligence as the primary competency that care providers are trained to develop (BCCPA, 2018b). Peel Region in Ontario recently reported that after implementing the Butterfly Model, it saw a reduction in staff sick days, fewer resident falls, a decrease in antipsychotic use, and higher levels of social engagement (Welsh, 2018).

Dementia Villages

The first known Dementia Village, *Hogeway,* was established in the Netherlands in 2007. It is a village of approximately 150 residents, where approximately six to eight people share a house and are classified according to their shared interests and backgrounds (Sagan, 2015). Each household has at least one care provider to help with the household tasks. It is secure, but residents are free to roam around and are encouraged to help with tasks like grocery shopping or cooking (Sagan, 2015). The key feature of a dementia village is that it creates conditions for the residents that are familiar and allows them to remain active in daily life as much as possible.

Canada's first Dementia Village will open in 2019 in Langley, British

Columbia, and it will be comprised of six cottage-style homes and a community centre serving 70 people living with dementia (CANBRIT, 2019). Other publicly-funded villages are being planned in Vancouver and the Comox Valley in the coming years (Gangdev, 2019).

Wellspring

Wellspring is a group of 11 not-for-profit nursing homes in Wisconsin that seek to improve care by empowering their front-line staff with training in the nationally recognized best practices and skills that are needed to best do their job and take a more proactive approach to resident care (Stone et al., 2002). A Commonwealth Fund-supported study found that *Wellspring* nursing homes have lower rates of staff turnover, improved performance on annual inspections, and generally lower costs than other nursing homes (Stone et al., 2002).

Interventions to Reduce Acute Care Transfers (INTERACT) Program

INTERACT is a quality improvement program being adopted by nursing homes throughout the United States (Ouslander et al., 2014). INTERACT is now a quality improvement program used to manage changes in a nursing home residents' condition (Ouslander et al., 2014). This can reduce hospitalizations for changes that can be managed in the nursing home (Ouslander et al., 2014). INTERACT is based on five fundamental strategies: principles of quality improvement; early identification and evaluation of changes in condition; management of common changes in condition; improved advance care planning; and improved communication and documentation (Ouslander et al., 2014).

In 2011, INTERACT was found to reduce hospitalization rates by 17%, with those who were more engaged seeing a greater reduction than those who were less engaged (Ouslander et al., 2011). The average cost of the implementation was about $7,700 per nursing home and the projected Medicare program savings were approximately $125,000 annually (Ouslander et al., 2011). A more recent study found that INTERACT was associated with an 11.2% reduction in all-cause hospitalizations and an 18.9% relative reduction in potentially avoidable hospitalizations (Huckfeldt et al., 2018).

Innovative Behavioural Support Approaches

The Gentle Persuasive Approach

The Gentle Persuasive Approaches (GPA) program was established over a decade ago and has trained more than 300,000 Canadians (Young, 2018). GPA is a one-day dementia care education workshop. It includes four modules that focus on person-centred care principles, brain changes common in dementia and delirium, communication and interpersonal strategies, and staff-specific self-protective skills and techniques (Hung, Son, & Hung, 2018).

In this model, care providers are trained to spot potential signs of agitation and are encouraged to stop and think about the potential cause of the responsive behaviour (Young, 2018). In one study, hospital staff were trained, and found it was that participants felt the knowledge they gained during the workshop helped them understand the difficulties patients with dementia experienced in the hospital (Hung et al., 2018). Time constraints and short staffing, however, have made it hard to implement the program (Hung et al., 2018).

Montessori Methods for Dementia

This approach includes applying the Montessori method of educating children to activities for those living with dementia (Malone & Camp, 2007). For example, the activities require task breakdown, manipulating materials, external cuing, and matching tasks (Lee, Camp, & Malone, 2007). It has been demonstrated that Montessori educational principles could be adapted and used as an approach to providing dementia care (Malone & Camp, 2007). Its implementation requires that staff understand the purpose of these methods and know how to and have the time to put them into practice (Ducak, Denton, & Elliot, 2018).

One study that matched nursing home residents living with dementia with preschool children from an on-site child care center found that using Montessori-based activities for their interactions led to higher levels of positive engagement and lower levels of negative engagement among those living with dementia (Lee et al., 2007).

Section 4: Emerging Enablers and Opportunities to Support the Future Provision of Long-Term Care

Demand for *long-term care* services will continue to grow with the ageing population. The full spectrum of services will be required to address the wide range of needs and desires of Canadians, but there's little doubt that, if they have the option and ability, Canadians will want to age in place or in their own communities for as long as possible.

Indeed, a 2013 survey done by Ipsos Reid for the Royal Bank of Canada (RBC) reported that 91% of Canadians, both retired and non-retired, found it appealing to stay in a home of their own choice (not necessarily their current home) and be close to family and friends (Ipsos, 2013). The same survey found that 88% of retired older adults reported wanting to stay in their current home and pay for home care as needed (Ipsos, 2013). It also found 56% reported a preference for living in a retirement residence where care could be provided (Ipsos, 2013). Given the findings of this report, it's clear that there is a need to move from our current disconnected and patch-work approach in the provision of *long-term care* towards a system that better responds to Canadians' needs and desires in a sustainable, high-quality manner.

The WHO (2015) acknowledged the variations in long-term care systems across the globe. In Canada's case, there are some core general principles that should apply to all provincial and territorial systems.

The WHO (2015) contends that all long-term care systems:

- Must be affordable and accessible;
- Must uphold the human rights of care-dependent older adults;
- Should enhance older people's intrinsic capacities;
- Should be person-centred;
- Should treat the workforce (both paid and unpaid) fairly and give it the social status and recognition it deserves; and,
- Must have their national governments take responsibility for the stewardship of long-term care systems.

The CHCA also recently developed its 'Harmonized Principles for Home

Care' that include patient-and family-centred care; accessible care; accountable care; evidence-informed care; integrated care; and sustainable care (CHCA, 2016a).

The NIA agrees with the WHO and CHCA principles and proposes additional key enablers that could help foster the comprehensive and positive change that is needed across Canada's *long-term care* systems. Indeed, a sustainable and successful future will depend on us adopting a strategic approach that is grounded the following principles.

1. **Enabling evidence-informed integrated person-centred systems of *long-term care*, accounting for the expressed needs and desires of Canadians.**

2. **Supporting system sustainability and stewardship through improved financing arrangements, a strong health care workforce, and enabling technologies.**

3. **Promoting the further adoption of standardized assessments and common metrics to ensure the provision of consistent and high-quality care no matter where Canadians need it.**

4. **Using policy to enable care by presenting governments with an evidence-informed path towards needed reforms.**

1. Enabling Evidence-Informed Integrated Person-Centred Systems of *Long-Term Care,* Accounting for the Expressed Needs and Desires of Canadians

Meeting the future *long-term care* needs of older Canadians presents an opportunity to re-think our collective approach to meeting the growing and varied needs of an ageing population. This is especially the case as the number of Canadians living with multiple chronic health conditions, including dementia, increases (McMaster Health Forum, 2014). A 2017 Commonwealth Fund survey found that Canadians receiving publicly-funded home care services have higher needs, with 59% being over age 75, 43% describing their health as fair or poor, 53% having three or more chronic conditions, 59% being on five or more medications, and 46% living alone (CIHI, 2018a).

A 2017 Commonwealth Fund survey found that Canadians receiving publicly-funded home care services have higher needs, with 59% being over age 75, 43% describing their health as fair or poor, 53% having three or more chronic conditions, 59% being on five or more medications, and 46% living alone (CIHI, 2018a).

There will be a growing need for care models that are more flexible, adaptable, coordinated, integrated, and inclusive of the needs and preferences of older adults and their unpaid caregivers. For example, the concept of 'ageing in place' may have different meanings for different people. Indeed, for some, it may mean staying in their own home, while for others it may mean moving to a safer or adapted home where care can be obtained (WHO, 2015). Ideally, the focus should always remain on the older adult and what is right for them (WHO, 2015).

It has become well-established that unpaid caregivers provide the majority of the *long-term care* older adults are receiving in Canada. The 2017 Commonwealth Fund survey also found that 59% of Canadians receiving help with ADLs reported receiving it solely from family members or friends (CIHI, 2018a). It is important to not only recognize the contributions of unpaid caregivers as part of an older person's care team, but also to acknowledge that there are limits to what they are able and should be expected to do (Columbo et al., 2011). Similar to those for whom they provide care, unpaid caregivers should be provided with individualized supports, training, and respite as needed and not be financially penalized for the significant contributions they make. Ensuring that the *long-term care*

The 2017 Commonwealth Fund survey also found that of those Canadians receiving help with ADLs, 59% reported receiving it solely from family members or friends (CIHI, 2018a).

system prioritizes the preferences and needs of its clients, residents, and their unpaid caregivers will be an essential enabler in developing an integrated system that delivers the best possible outcomes.

In 2016, it was found that while 403,810 or 2.9% of Canadian households are multi-generational, meaning that they include at least three generations of the same family living together, which represented the fastest growing type of living arrangement in Canada, with a growth rate of almost 38% from 2001 to 2016 (Statistics Canada, 2017). Indigenous and immigrant families are more likely than others to be living in multi-generational households and to have grandparents and grandchildren living in the same home (Battams, 2017; Statistics Canada, 2017). Some families are choosing this living arrangement

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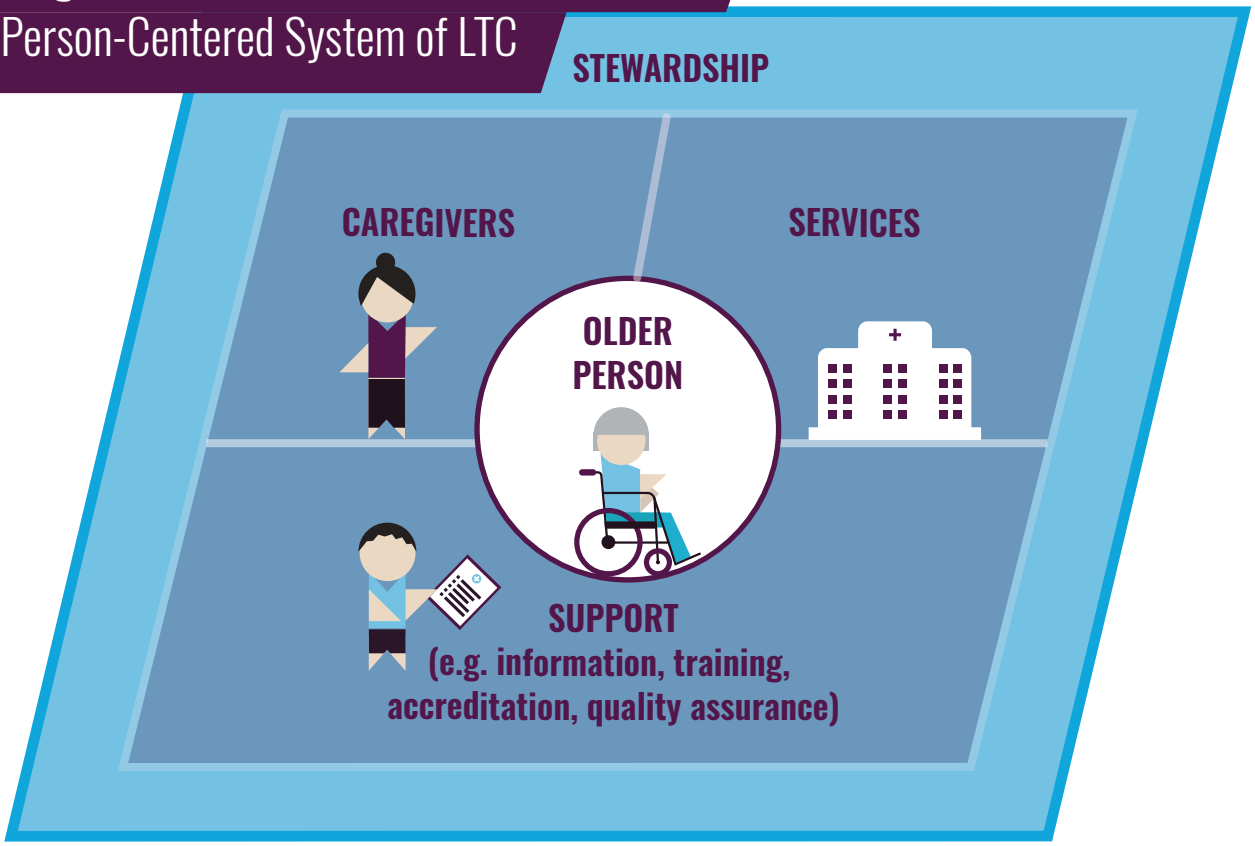
because it allows for the younger generations – either the adult children or grandchildren - to provide care to the oldest generation living there (Battams, 2017). In many circumstances the older generation may be significantly contributing to the provision of child care in a multi-generational household while the parents are at work, school, or are running errands (Battams, 2017). Multi-generational living can not only lower the potential risk for social isolation but can also provide economic advantages for these families, as income sources can be pooled and shared among all the people in the household, which can better protect them from poverty and food insecurity (Battams, 2017).

Adapted from the WHO (2015), Figure 8 describes the elements of an older-person-centred system of long-term care. At the heart of this figure is the older person whose needs should dictate the support and services provided and the role their unpaid caregivers can play in supporting the provision of care.

Figure 8: The WHO - Elements of An Older Person-Centered System of LTC



There are also support services that can be provided to ease the burden of caring for an older adult, such as respite care (WHO, 2015). Providing a range of options, better information, and ensuring care providers have the right training and that accreditation standards continue to ensure that the highest quality of care remains available, also matter to the provision of person-centred care. (WHO, 2015).

An effective person-centred system needs to encourage the use of available data to understand current utilization patterns and what unmet needs may still exist. Good data are also integral to inform decision-making, promote research, share best practices, and to promote knowledge translation. Furthermore, the encouragement of continuous research through the creation of a 'learning system' can enable the development of more innovative and effective models of care that are scalable across Canada. It can further establish the basis for resource allocation discussions, innovation strategies, and *long-term care* policy development.

Of course, this is easier said than done, given that it has been well-established that innovations in the *long-term care* sector can take decades to reach mainstream adoption. The now well-established *PACE Model* of long-term care developed in the United States took 25 years from the development of its original program to enabling legislation that facilitated its widespread implementation across the country (Mui, 2001). Indeed, making lasting changes requires time and collaboration amongst planners and care providers, and it requires some ongoing infrastructure to enable this to occur on more than an ad-hoc basis (Mui, 2001).

What about Self-Directed or Self-Managed Care?

A number of stakeholders raised the notion of self-directed care as the ultimate embodiment of the person-centred approach to *long-term care*. Self-directed care in this sense needs to start with enabling care recipients to be equal partners in their own care planning. Self-directed funding may also be a way to place the person at the centre of their care. Indeed, the past decade has seen growing consumer demand for a greater level of flexibility and control in

managing available personal health care services.

Self-directed care provides individuals, their families, and unpaid caregivers with more choice and control over the long-term care services they want and need (Sinha, 2012). In 2006, Health Canada released a report describing self-directed care programs in Canada (Spalding, Watkins, & Williams, 2006). It described an approach that would allow direct funding to clients who are then free to purchase services from a provider of their choice as a key characteristic of self-directed care (Spalding et al., 2006). Self-directed care programs typically provide funding for a range of personal support services including eating, bathing, dressing, walking, toileting, preparing meals, laundry, transportation, and other services (Spalding et al., 2006).

Funding options for self-directed care can improve both client experience and health outcomes. One study from the United States examined the impact of direct funding models and found that hospital inpatient costs dropped by 39% and long-term care costs were 64% lower for those clients using self-directed care as a result of reduced service use (Kim, Fox, & White, 2006). It is important that self-directed care allows for full flexibility around how funds are used (Sinha, 2012). These kinds of models have been found to contribute to a reduction in pressures on paid care providers due to the potential to leverage the care that is usually provided by family members, friends, and neighbours (Sinha, 2012). These models can also be most effective in supporting individuals who may have limited access to long-term care providers, such as those living in remote, rural, and northern areas (Sinha, 2012). In general, the qualitative research of self-directed funding models has had positive results; care recipients report being more emotionally, socially, and physically satisfied with the quality of care they choose (Ottoman, Allen, & Feldman, 2009; Chopin & Findlay, 2010). In addition to benefits for older adults, their unpaid caregivers also report positive effects with regard to their overall quality of life, with no evidence to suggest negative impacts (Glendinning et al., 2009). Specific elements of self-directed care programs have been shown to have a positive influence on the psychological

well-being of unpaid caregivers (Sinha, 2012). In addition to the amount of funding provided and the flexibility of the funding, these models also offer unpaid caregivers the benefits of having regular contact with trained providers, and the opportunity for respite (Sinha, 2012).

Self-directed care in Australia allows consumers to influence the design and delivery of the services they receive, and it allows them a greater degree of choice in what, where, and when services are delivered (Australian Government, 2015). However, there are some areas of concern with self-directed care, including: administrative costs; issues with the accuracy and complexity of information about the approach; limited choice and flexibility in the services and who provides them; issues with goals not being reflected in the care plans; and, inequities in the access and service availability (Gill et al., 2018).

Similarly, concerns have been raised on the use of this type of funding mechanism in the United Kingdom. It was found that while older people may like the additional choice, it relies on their ability to do much of the decision-making and information-sorting. Choice is also dependent on the options available (Woolham et al., 2017). It was found that older people are majority users of personal social care, but the efforts to promote direct payments amongst older people has been met with limited success (Woolham et al., 2017). It was also found that current policies do not account for the differences between what younger and older populations want through direct payments (Woolham et al., 2017). The piloting of individualized budgets found that some older people reported anxiety and stress about changes to their established support arrangements (Glendinning et al., 2008). Evidence has shown that when older adults do seek out services, it is often at a time of crisis or vulnerability and they therefore can find decision-making difficult (Glendinning et al., 2008). Taking responsibility for their own support can be seen as a burden rather than as empowering (Glendinning et al., 2008). As a result, it may not be as ideal a model to apply in older populations.

Over the last decade, self-directed funding models have been adopted internationally in the provision of

home and community care for people with disabilities. Increasingly, the expansion of these funding models to support the needs of frail older adults is being explored, including in Canada's more rural and northern communities.

Quebec may have done the most to promote the provision of more self-directed care by encouraging older Quebecers to organize and purchase the home care and support they need themselves with the help of both a financial assistance program and a refundable tax credit. While a common, widely applicable approach to supporting self-directed funding models for older adults has yet to emerge, it is clear that the success of such models relies on having well-defined eligibility and responsibility requirements, well-informed and supported clients, families, and unpaid caregivers who understand the full range of options available, and an understanding of the full implications of making certain decisions around self-directed care.

In other jurisdictions, a preferred model of provision has given the responsibility of the administration and reporting of the funding to a care coordinator, who develops a collaborative care plan with the care recipient to ensure their personal needs and preferences can be met. In understanding that self-directed funding options can offer an array of approaches which differ in terms of the level of decision-making, individual autonomy, professional or agency involvement, responsibilities of the client versus the coordinating agency, and many other elements, it will be important that any future models established in Canada to support the provision of care to older adults consider these factors in their development.

2. Supporting System Sustainability and Stewardship through Improved Financing Arrangements, a Strong Health Care Workforce, and Enabling Technologies

It is not an understatement to say that current *long-term care* systems are not adequately meeting the needs of many Canadians who wish to age in place, while unpaid caregivers and care providers of *long-term care* services are doing hard, important work to respond to

the needs of Canadians. The challenges to delivering the best care to Canadians are system-level challenges.

Financing the Future Long-Term Care Canadians Will Need

While Canadians with financial means can purchase additional care as they need it, this isn't the case for many Canadians. A 2015 national survey of 2,008 adults by Ipsos Public Affairs for the CMA found that 63% of respondents said their family was not in a good position (financially or otherwise) to care for older family members if they needed long-term health care, and it worried them greatly (Ipsos Public Affairs, 2015). In its most recent 2019 national survey of 3,352 adults conducted for the CMA, Ipsos found that that 88% of respondents were worried about growing health care costs due to the ageing population, and 58% reported that they believed that many Canadians will delay their retirement in order to afford the health care they need to remain healthy and independent (Ipsos, 2019). These findings speak to the significant diversity around the financial preparedness amongst ageing Canadians.

A recent 2019 national survey of 3,352 adults conducted for the CMA, Ipsos found that that 88% of respondents were worried about growing health care costs due to the ageing population, and 58% reported that they believed that many Canadians will delay their retirement in order to afford the health care they need to remain healthy and independent (Ipsos, 2019).

While some Canadians can and will be in a position to finance all or portions of their own care, many Canadians will have to rely solely on available publicly financed care and the support and care unpaid caregivers may be willing to provide. Those who cannot be enabled to remain at home will likely need to prematurely be placed in a publicly financed nursing home. It is often poorer members of our society who are prematurely moved to nursing homes (Trottier et al., 2000; Jones, 2007), which can lead to higher collective public care costs.

Given that the median savings of Canadian families who are nearing retirement without a workplace pension is only $3,000 (Shillington, 2016), the current traditional approaches of financing *long-term care* services needs to recognize the significant income ranges that older Canadians fall into. As a result, the overall sustainability and ability to provide publicly-funded high-quality health and *long-term care* services in the future may require novel targeted and improved funding approaches that can ensure a greater level of equitable access to care can exist. This will be essential to maintaining the overall sustainability of our health care system.

A recent report by the Conference Board of Canada (2019) found that while a number of older adults and their caregivers can take advantage of existing federal non-refundable tax credits to help offset some out-of-pocket expenses, these mechanisms have remained of little or no value to low or no-income individuals. The tax credits continue to remain underutilized, with only 4.6% of unpaid caregivers receiving money through these sources and still often providing insufficient coverage of out-of-pocket expenses (Conference Board of Canada, 2019). These have been prime reasons behind an increasing number of advocacy organizations including the NIA, CMA, Canadian Nurses Association (CNA), CARP, and others that have been calling on the federal government to make its existing tax credits refundable, as Quebec and Manitoba do. The Conference Board of Canada (2019) has further proposed that a new federal income-tested 'Seniors Care Benefit', similar to the Nova Scotia Caregiver Benefit, be introduced that particularly treats care recipients and their unpaid

caregivers as one unit so that either can easily claim it. This would be one potential way to provide better financial support for older Canadians (Conference Board of Canada, 2019).

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Models to provide 'universal long-term care coverage' have also been implemented in different ways around the world. Some countries use tax-based models in which care is provided by the state and others use public long-term care insurance models (Germany, Japan, South Korea, the Netherlands, Luxembourg, and soon the USA's Washington State), where additional mandatory payroll contributions are required help to fund one's future care needs (Columbo et al., 2011; Lieber, 2019).

Washington State will implement a payroll tax beginning in 2022, where employers will put 0.58% of a state resident employee's paycheck into a state fund (Lieber, 2019). As of 2025, eligible residents will be able to access their new benefit, a $100/day allowance for a variety of long-term care services, for up to a year (Lieber, 2019).

In Canada, Australia, the United States, and United Kingdom, a *mixed system* provides long-term care through a combination of universal and means-tested long-term care entitlements (Columbo et al., 2011). Many of the countries with this type of system, however, do not have a

A Spotlight on South Korea: The Latest Country to Implement Public Long-Term Care Insurance

In 2008, South Korea introduced a social insurance scheme to support the future provision of long-term care which provides coverage for everyone over age 65, as well as age-related long-term care needs for younger people (Kwon, 2009).

Individuals need to be approved for services. They are assessed based on their functional limitations and ability to perform ADLs (Kwon, 2009). Contributions are determined as a fixed percentage of their mandatory health insurance contribution (Kwon, 2009). Overall, financing through this program consists of a government subsidy, co-payment, and an insurance contribution (Kwon, 2009). Depending on income, the co-payment can be waived (Kwon, 2009).

Through this system, the co-payment for nursing home care has been made higher than the co-payment for home-based care in order to further promote choosing home-based care (Jeon & Kwon, 2017). The insurance provides benefits for nursing homes and home-based long-term care as well as cash benefits in exceptional cases (Jeon & Kwon, 2017). Home-based care consists of visit care, bathing, nursing, day and night care, short-term care, and assistive devices (Jeon & Kwon, 2017).

comprehensive single long-term care system, but rather have multiple benefits, programs, or entitlements depending on the target group (Columbo et al., 2011).

Within Canada there have been a variety of approaches taken at the provincial and territorial levels to fund the availability of more home and community-based long-term care. Currently five of the ten provinces have implemented income-based home care mechanisms to recover a portion of the costs of providing an individual home and community-based care based on their actual income (See Table 3).

In Australia, home care is paid for by an income-based fee, but there is a cap on the annual and lifetime amounts that a person pays (Commonwealth of Australia, 2012). It is important to note that low-income older adults do not need to pay for their services (Commonwealth of Australia, 2012).

In the Canadian context, despite recent government investments in the *long-term care* sector, there is still insufficient public funding to meet current demands. The challenge, however, is that public funding alone will unlikely be able to fill the gap between existing need and available services. This is why an increasing number of countries have pursued policies of mandatory long-term care insurance and direct funding, for example. While the notion of long-term care or 'autonomy' insurance was being seriously considered in Quebec a few years ago, nothing has yet been formally established in Canada.

Nevertheless, it is clear that government funding will remain integral to the delivery of care, but Canada will need a deeper, national conversation on the ways that the private and not-for-profit sectors, and Canadians themselves, can become more involved in the future delivery and funding of *long-term care* services.

Table 3: Description of Income-Based Home Care Service Delivery Models in Canada

Province	Description
British Columbia	Those receiving publicly-subsidized home support services pay a daily rate based on income with the exception of the first two weeks of receiving short-term home support services after discharge from hospital or palliative supplies and equipment (Government of British Columbia, n.d.).
Saskatchewan	Individual fees or charges are based on income and the number of services delivered to the client. Professional services such as nursing assessment/care coordination, therapy, or volunteer services are provided without charge to home care clients (Government of Saskatchewan, n.d.).
New Brunswick	Net income is used to calculate contributions towards long-term care service costs (including home support services and services in special care homes, community residences, and nursing homes) (Government of New Brunswick, 2015).
Nova Scotia	Home care costs are based on income and type of services needed. Some services, such as nursing care, are free (Province of Nova Scotia, 2018).
Newfoundland and Labrador	It is expected that individuals pay for home support where possible before requesting a subsidy from the regional health authority. If financial assistance is needed, the regional health authority will complete a financial assessment to determine eligibility for a subsidy and identify whether a contribution needs to be made toward the cost of home support (Government of Newfoundland & Labrador, n.d.).

Strengthening the Long-Term Care Workforce

The expected shortages of unpaid caregivers is as daunting as the current labour shortages in the existing *long-term care* paid care provider workforce. It is no secret in Canada that *long-term care* providers have lower wages than their acute care colleagues, and this has been seen as one of the long-standing reasons why *long-term care* providers remain in short supply.

While improving wage rates and eliminating sectoral pay gaps is seen as one potential enabler to stabilize the *long-term care* workforce, there are other aspects of labour engagement that may improve recruitment and retention rates. The complex nature of *long-term care* systems often fails to recognize on-the-ground logistical concerns for providers. Care providers delivering home and community-based care, for example, may need to travel between home and other settings multiple times in a day, potentially increasing their stress and their ability to spend time with clients. Recruitment and retention strategies are now increasingly focusing on ways that minimize travel and release more of an individual care provider's time to care.

Finding ways to provide PSWs/HCAs scheduling flexibility may be beneficial, especially for those in part-time and casual positions (Panagiotoglou, Fancey, Keefe, & Martin-Matthers, 2017). Indeed, PSWs/HCAs in Ontario, British Columbia, and Nova Scotia noted that a work schedule that minimized travel between clients, left limited gaps in the workday, and effectively minimized disruptions to their schedule would help them to provide better care (Panagiotolgou et al., 2017).

Current training, education, and practice standards for regulated health care providers, such as physicians, nurses, pharmacists, therapists, and social workers are often criticized for being more focused on acute care and for not sufficiently emphasizing the knowledge and skills required to care for an older and frail population. Similar concerns exist around the education, practice, and continuing education standards for unregulated care providers like PSWs/HCAs.

In Manitoba, research found that during staff orientation one nursing home encouraged its staff to envision themselves in their residents' roles, for example, by spending time being put in ceiling lifts, so that they were able to appreciate what it was like to be in the equipment (Choiniere & Lowndes, 2018). This form of training helps to build experiential insight and empathy skills (Choiniere & Lowndes, 2018). PSWs/HCAs are by far the largest group of care providers providing long-term care across Canada and yet they remain a largely unregulated and less prioritized group in health human resource planning discussions

Within long-term care settings, it has also been suggested that mandatory staffing levels should be used to improve the working conditions for staff and allow for the best resident care possible (Jansen, 2011; RNAO, 2019), because understaffing adds to the workload of each provider and can lead to stress and 'burnout' (McGilton et al., 2013; BCCPA, 2018a; Manitoba Nurses Union, 2018). Choiniere & Lowndes (2018) noted that in one Manitoba home, emphasizing integrated teamwork led to a lower staff turnover rate and a lower reliance on casual, or part-time, staff.

Leveraging Family and Community Support in the Northwest Territories to Enable Ageing-in-Place

Another interesting option being explored in the Northwest Territories is paying community members who are providing care to an older adult (Trochu, 2017). Some of the benefits/outcomes of this approach are that the family and community remain key components for client care, there is increased flexibility for clients to be able to meet their care needs, and clients are able to stay in their homes rather than go to a nursing home (Government of Canada, 2018). This would also help unpaid caregivers who are facing financial difficulties (Trochu, 2017).

Where there are persistent staffing shortages, especially in rural and remote communities, other available human resources can be utilized, such as paramedics and community health workers as well as unpaid caregivers and other community members. Leveraging the use of technology has also been helpful in more rural and remote settings to minimize the need to have direct care providers on hand when some monitoring and other communication functions could be virtualized.

Leveraging Current and Emerging Technologies

Increasingly, the sector is looking to technologies to enable the provision of different aspects of *long-term care* to address multiple needs. Furthermore, some jurisdictions such as the United Kingdom are increasingly exploring opportunities to leverage technology as part of a broader solution to address the growing shortage of care providers and funding (Darzi, 2018). Currently, the utilization of technologies is being explored to improve the delivery of *long-term care* in three principal ways.

Technologies that Enable Reaching/Serving More People

Investments in tele-homecare (or remote patient monitoring) programs across Canada have aimed to bring health services to individuals in their homes (Balenko, Conn, & Hagens, 2018). Through these programs, providers (typically a nurse or a paramedic) are given access to the biometric data collected voluntarily by patients living with chronic health conditions such as chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) for review, interpretation, and management remotely as is required (Balenko et al., 2018). The added opportunity to coach and enhance the client's self-management abilities remotely further enhances the potential of these models to serve a greater number of clients with the same number of providers (Balenko et al., 2018). Since 2010, the federally funded Canada Health Infoway agency has sponsored programs that have served 31,500 Canadians with CHF or COPD across the country (Balenko et al., 2018).

Findings from their projects thus far have included: 92% of patients reporting that the digital health tools were easy to use; 91% reporting being

better able to manage their health condition; and 87% having an improved quality of life (Balenko et al., 2018). In Section 3, a more specific example of the Canada Health Infoway community paramedicine remote patient monitoring initiative was highlighted.

Telehealth, *telemedicine*, and other similar technologies can connect care providers to patients as well as primary care providers and their patients to specialists to provide more convenient ways to enable the provision of care especially across significant distances. These connections can now take place via video, text (asynchronous) messaging, and email, and the transmission of images alongside other content can occur as well. These programs can deliver timely and high-quality medical care that could reduce unnecessary hospitalizations and provide better access to providers at a distance, which would particularly benefit those in rural or isolated areas or who are medically complex and living in nursing homes (Gillespie et al., 2019).

In Ontario, the *eShift* model of care, described in greater detail in Section 3, was developed to equip HCAs or PSWs with technology that can closely monitor their palliative care clients and enable timely communication with a specialist nurse to manage more complex issues as they arise. This has allowed more clients to receive palliative care in their own homes, as well as reduced caregiver stress (VON, 2017).

The Ontario Telemedicine Network (OTN) is one of the largest telemedicine networks in the world. Last year, it provided a total of 896,529 virtual visits. It is estimated that this helped patients avoid 270M kilometers of travel and achieved over $74M in cost avoidance savings for Ontario's health system (OTN, 2019). These modalities can enable greater communication, multi-disciplinary collaboration, and coordination of care, thereby improving outcomes and effectiveness of the care that is delivered.

A National Health Service (NHS) pilot program in England provided patients discharged from hospital with Wi-Fi enabled armbands that could monitor their vital signs (i.e. respiratory rate, oxygen levels, pulse,

blood pressure, and body temperature) (Miyashita & Brady, 2019). This pilot program incorporated artificial intelligence technologies to analyze all patient data in real time, which allowed for a much improved prediction of risk of an upcoming negative outcome and permitted better anticipatory management by care teams to occur (Miyashita & Brady, 2019). This novel approach led to significant reductions in hospital readmissions and emergency department visits, and it further decreased the need for home visits, while significantly improving the long-term adherence to treatment plans (Miyashita & Brady, 2019).

Technologies that Allow for Assisted Living

In addition to making physical modifications to the built environment, such as ramps and wider doorways that can enable access, the development of technologies or devices for an individual's caregivers can address certain functional challenges to enable more independent living. Canes, walkers, grab bars, stair lifts, hearing aids, and many other assistive devices have been in common use in a variety of settings. While these technologies continue to evolve, new ones are in constant development, and introduce a wider variety and scope for assistive devices. These include apps that can better support individuals and their unpaid caregivers to learn about, monitor, and manage chronic conditions, as well as robots that can assist in the performing of one's basic tasks.

One particularly adorable assisted living technology is *PARO* – a seal-like robot developed in Japan that has been designed to provide comfort and support to people living with dementia and their associated mood and behavioural symptoms (Petersen et al., 2017). As an alternative to traditional pet therapy, without the negative aspects of using traditional pets, one study demonstrated that the PARO robot decreased stress and anxiety and resulted in reductions in the use of psychoactive medications and pain medications in older adults with dementia (Petersen et al., 2017).

There is a growing interest in the development and use of 'ambient assisted living sensors', which can be used to closely monitor older adults who may be at increased risk of

losing their independence and wish to remain in their own homes (Uddin, Khaksar, & Torresen, 2018). These include: passive infrared (PIR) motion sensors that collect motion data; video sensors that can be used to locate and detect specific incidents like falls; pressure sensors to detect the presence or absence of an older adult on chairs or in beds; and, floor sensors, which can control light switches or detect falls (Uddin et al., 2018). While not yet widely used, the advent of these new monitoring and sensing technologies create the potential for future care innovations based on the data they collect and interpret using artificial intelligence and machine learning applications. Further developments in these areas could pave the way for new models of care and treatment methods that enable older adults to live independently with even greater independence.

Technologies that Connect People to Knowledge and Each Other

Numerous websites and apps have been developed to provide individual and caregiver-oriented information to better educate and empower these individuals with the information they need to better engage in their care. An example of an app developed to help educate unpaid caregivers of those living with dementia is highlighted in Section 3.

Other technologies have been developed to better connect people and their unpaid caregivers to their care teams and education and other resources. For example, *Tyze* is an online platform that can be used to better connect unpaid caregivers, family members, care providers, and others around an individual (Tyze Personal Networks, 2019). The platform also allows for the coordination of appointments and the sharing of information to enable unpaid caregivers and care providers to more easily communicate with each other and to plan an individual's care collaboratively (Tyze Personal Networks, 2019).

Although there are many promising technologies that may enable greater efficiency, improved care outcomes, and quality of life for older adults and their care providers, many of these technologies are not widespread or available at scale and have not yet become established standards of care, although this will likely change over the coming decades.

3. Promoting the Further Adoption of Standardized Assessments and Common Metrics to Ensure the Provision of Consistent and High-Quality Care No Matter Where Canadians Need It

Common data standards and definitions that can be consistently employed across the health care system can provide information that can be shared at the local, regional, provincial, territorial, and national levels. These data would also support analytics that help understand client and unpaid caregiver needs and outcomes across jurisdictions and over time, which could also support planning and decision-making. While common standards and definitions are effectively used across the acute care sector, there is also an opportunity to do the same across the *long-term care* sector. CIHI's work to develop a set of national home care indicators by 2019-20 should inspire further work in this area. Common standards and benchmarks could help ensure that all Canadians receive more equitable access to high-quality long-term care (CHCA, CFPC & CNA, 2016).

InterRAI assessments have been implemented at different stages in various *long-term care* settings across Canada. In countries such as New Zealand and Belgium, the decision to adopt, fund, and implement a common InterRAI long-term care assessment system was achieved at a national level.

In Canada, each province and territory is free to assess and manage its *long-term care* services according to its own needs. Implementing common assessments at a national level is more challenging. One of the objectives of the Quebec Health Ministry's action plan for 2015–2020 is to improve home care services for older adults through systematic evaluation of needs and treatment plans (Ministère de la Santé et des Services Sociaux, 2017), yet it is not currently employing a robust assessment system that is both responsive and predictive of future care needs and that can allow for comparisons of its population and needs with the rest of Canada.

In 2016, the CHCA, the College of Family Physicians of Canada (CFPC), and the CNA, called for direct resources to be made available to

CIHI both to enhance and expand its Long-Term Care Reporting Systems and to broaden the use of InterRAI instruments in order to gather standard information on demographic, clinical, functional, and resource utilization information on Canadians a receiving publicly-funded long-term care services (CHCA, CFPC & CNA, 2016).

4. Using Policy to Enable Care by Presenting Governments with an Evidence-Informed Path Toward Needed Reforms

Adopting a ReAblement Policy

The WHO acknowledges that declines in physical and mental capacity exist on a continuum and that many of these declines are preventable or even reversible (WHO, 2015) through the use of reablement approaches to care. Individual care requirements are not necessarily permanent. Good nutrition, physical activity, rehabilitation, and time could all improve a person's capacity to the point where they need less care than before or no longer require long-term care services at all (WHO, 2015).

A deliberate reablement approach has been shown to positively affect health-related quality of life, service utilization, and functional capacity (Tessier et al., 2016). Programs and policies that emphasize reablement focus on independence and function. In Denmark, municipalities are now required by law to assess whether a person who is receiving home care could benefit from a time-limited reablement scheme adjusted to the needs and capabilities of older users (Ministry of Health, 2017).

The provision of reablement services can be successfully delivered by non-professional care providers like PSWs/HCAs, among whom these services have also been associated with greater job satisfaction that can further advantage both the recruitment and retention of qualified employees which remain major challenges in the home care sector (Tessier et al., 2016). Lewin et al. (2013) further demonstrated that in Australia, by including reablement as a starting point for those individuals who are referred to home care, it could increase cost-effectiveness of the system and may ensure all older home care clients are able to maximize independence as they age.

Reablement was found to reduce the likelihood of home care services for the following three years and the need for a personal care service for the following five years (Lewin et al., 2013).

Promoting Co-Housing and Shared Living Policies

With the cost of housing in urban areas continuing to rise, older Canadians are seeking creative ways to age-in-place. This has led to a growing interest amongst older Canadians in co-housing, shared living, and congregate living models. These types of housing arrangements vary across municipalities, where building and housing permit authorizations are largely determined locally. In Ontario, for example, some municipalities directly fund and enable home-sharing and co-housing projects, while other jurisdictions have enacted policies to restrict the practice.

Improving Immigration Policies to Enable the Recruitment and Retention of International Paid Caregivers

With growing shortages of local community-based care providers, many Canadians have been turning to a long-standing federal immigration program, *The Live-In Caregiver Program*, that allowed a family to sponsor a live-in paid care provider. The program, however, was increasingly seen as overly restrictive, making it difficult for international care providers to eventually become permanent residents – a key motivating factor for entering Canada through this program (Migrant Workers Alliance for Change, 2018). It was also criticized for potentially increasing the risk of care providers being mistreated by families (Migrant Workers Alliance for Change, 2018). This program ended in November 2014.

In June 2019, the federal government announced two pilot programs, *The Home Child Care Provider* and *Home Support Worker*, which will allow paid care providers to receive a work permit if they have a job offer in Canada (Government of Canada, 2019). Once they are working, they can apply for permanent residency after two years of work experience in Canada (Government of Canada, 2019). There are some benefits to these changes including preventing

against abusive workplaces, as the work permits no longer tie the paid care provider to the family that brought them to Canada (Keung, 2019). Also, it allows their loved ones to work and study in Canada (Keung, 2019). However, new concerns have arisen including applicants' requirement to prove they have enough money to provide for themselves and their families in Canada (Keung, 2019). Advocates say this is difficult for many applicants due to low incomes or may put them in debt (Keung, 2019). In addition, there are minimum education and language criteria that must be met, which may be a barrier to those with the necessary skills, but without formal qualifications or documentation (Keung, 2019).

Introducing the Proposed Ontario 'Golden Girls Act'

Legislative steps are currently being taken in Ontario to encourage affordable housing solutions for older adults and to encourage local municipalities to recognize that unrelated older adults living together can lead to significant health, economic, and social benefits (Legislative Assembly of Ontario, 2019). A private member's bill introduced in February 2019, titled the 'Golden Girls Act', seeks to amend the Ontario Planning Act to prevent municipalities from using local bylaws to prohibit unrelated seniors from living together. The idea of the private member's bill came from four unrelated women in Port Perry, Ontario, who are living under the same roof with a communal dining and living room, and kitchen (Kalinowski, 2019). They renovated their home to include accessibility features and a suite for a potential live-in caregiver (Kalinowski, 2019). At the time of writing this report, the Bill has been referred to the Standing Committee on General Government for further consideration (Legislative Assembly of Ontario, 2019).

Conclusion and Next Steps

This first policy paper in the NIA's *Future of Long-Term Care Series* has set the context for an important evidence-informed conversation that needs to take place around the future provision of *long-term care* in Canada. The research and engagement that led to the development of this paper has revealed a current system and state of *long-term care* provision across Canada that is hard to define and to quantify. It is currently leaving too many Canadians and their unpaid caregivers with unmet needs. The NIA has outlined key challenges, opportunities, and enablers that will be integral in getting all stakeholders better aligned towards where Canadians say they want and need us to be.

The forthcoming policy paper in this series by Drs. Bonnie-Jeanne MacDonald, Michael Wolfson, and John Hirdes will further investigate and project the future *long-term care* costs facing Canada over the coming three decades. This paper will represent the most comprehensive analysis to date in Canada that will further employ advanced analytic techniques such as micro-simulation and other methods to provide all stakeholders with the clearest view of what future *long-term care* needs in Canada may likely cost.

Finally, the third and concluding paper of this series will bring together the NIA's experts in financial and health policy with the aim of presenting feasible and fiscally responsible policy paradigms, scenarios, and directions with the goal of ultimately providing Canadians with the right mix of *long-term care* services and policies that all Canadians will want to have in place to ensure that Canada can truly become the best country to grow up and grow old in.

Appendix A: Glossary and List of Acronyms

Activities of Daily Living (ADLs): The WHO defines these as 'the basic activities necessary for daily life, such as bathing or showering, dressing, eating, getting in or out of bed or chairs, using the toilet, and getting around inside the home' (WHO, 2015).

Alternate Level of Care (ALC): 'is used to describe persons who occupy a bed in a facility but no longer require the intensity of resources and services provided in that setting.' (CIHI, 2017b).

Designated Buildings: referring specifically to types of long-term care that are provided in a designated building designed or organized to facilitate the provision of long-term care (including nursing homes, retirement homes, assisted living facilities, and supportive housing building models) as opposed to a private residence or community-based setting.

Health Care Aides/Personal Support Workers: Health Care Aides or Personal Support Workers are the care providers most often providing long-term care, and they often assist with the provision of personal hygiene and care such as bathing, dressing, toileting, mobilization and meal time support (Barken & Armstrong, 2018). Other names include health aides, care aides, or nursing aides.

Healthy Ageing: 'the process of developing and maintaining the functional ability that enables well-being in older age.' (WHO, 2015).

Home and Community Care: care that is provided in home-based settings rather than in a hospital or nursing home, and which allows individuals to remain independent in the community (Government of Canada, 2016a). This type of care can be provided by regulated health care providers (i.e. nurses, therapists), but also by non-regulated care providers such as personal support workers (PSWs) also known as health, continuing or simply 'care aides' (H-/C-/CAs) or nursing aides, volunteers, and unpaid caregivers (i.e. friends, family, and neighbours) (Government of Canada, 2016a).

Independent living: involves older adults living by themselves and looking after themselves. Older adults may rely on family members and friends or neighbours to help them to live independently, or they may hire a care provider to come in and help with tasks or purchase services such as 'meals on wheels' to do so (Government of Canada, 2010). A key defining feature of what constitutes this definition of 'independent living' is that support services are not provided by the residence in which a person lives (Government of Canada, 2010).

Instrumental Activities of Daily Living (iADLs): The WHO defines these as 'activities that facilitate independent living, such as using the telephone, taking medications, managing money, shopping for groceries, preparing meals and using a map.' (WHO, 2015).

Long-Term Care Homes (Nursing Homes): designated building-based place for individuals to live and receive 24/7 supervised care but also a range of professional health and personal care services, and supports with activities such as the provision of meals, laundry, and housekeeping. As this type of care is not insured under the CHA, each province and territory develops their own legislation and accompanying policies and regulations to govern the provision nursing home care in their jurisdiction (Government of Canada, 2004).

Long-Term Care: The NIA defines *long-term care* as: A range of preventive and responsive care and supports, primarily for older adults, that may include assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) provided by either not-for-profit and for-profit providers, or unpaid caregivers in settings that are not location specific and thus include designated buildings, or in home and community-based settings.

Note: To clearly indicate when the NIA's definition of long-term care is being referred to throughout this report, we have presented it in italics.

Supportive Housing/Assisted Living/Retirement Homes: describe a different type of living arrangement in a specific location. The defining feature of this type of housing is that the support services are included in a resident's monthly rent. These services vary but can include meals, assistance with bathing, or an on-call nurse or a non-regulated care provider (Government of Canada, 2010). These types of housing options can be owned and operated privately, while others are owned and operated by not-for-profit organizations including faith-based groups. Lastly, some are government-owned and operated by local municipalities for example (Government of Canada, 2010).

Unpaid Caregiver: 'the people – family, friends, neighbours – who provide critical and ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability or end-of-life circumstances.' (The Change Foundation, 2016).

List of Acronyms

Canada Health and Social Transfer (CHST)

Canada Health Transfer (CHT)

Canada Social Transfer (CST)

Canadian Association for Long-Term Care (CALTC)

Canadian Federation of Nurses Unions (CFNU)

Canadian Institute for Health Information (CIHI)

Federal, Provincial and Territorial (FPT)

General Social Survey (GSS)

Ontario's Ministry of Health and Long-Term Care (MOHLTC)

National Institute on Ageing (NIA)

United States National Institute on Aging (US-NIA)

World Health Organization (WHO)

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