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# Building Community-Based Capacity to Meet Ontario's Needs

A BRIEF FROM THE ONTARIO ASSOCIATION OF  
INDEPENDENT LIVING SERVICE PROVIDERS (OAILSP)

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## Executive Summary

### About This Brief

This brief makes the case for renewed investments in Ontario's Independent Living (IL) sector. It argues that even modest investments can pay substantial dividends by creating much-needed community-based service capacity quickly as rising and more complex needs place new and potentially unsustainable pressures on the provincial health care system. Originally designed to meet the needs of persons with physical disabilities and acquired brain injury (ABI), innovative care models pioneered and proven in the IL sector are now successfully being adapted to support growing numbers of persons of all ages with chronic health and social needs. These models advance key health system goals by putting people first, enhancing the client and caregiver experience, and ensuring that persons with high needs can live and work as independently as possible "closer to home." In doing so, they also avoid the massive capital costs and extended timelines required to build new beds.

### About the Ontario Association of Independent Living Service Providers (OAILSP)

Since 1988, *OAILSP* and its forerunner, the *Provincial Association of Senior Managers*, have been the voice of community-based provider organizations across Ontario that deliver essential supports for daily living to persons with physical disabilities.

### The Case for Independent Living

*A Growing Challenge.* Ontarians are living longer and for the most part healthier. Nevertheless, more are experiencing chronic health and social needs which, if not addressed in community settings, can quickly escalate to costly hospital and LTC admissions. However, as recent expert reports have concluded, there is a growing gap between population needs and available home and community care (H&CC). In response, Ontario's *Patients First: A Roadmap to Strengthen Home and Community Care* (2015) sets a bold new course by promising that "everyone who has needs that can be reasonably met in the home or community will receive support to do so."

*How the IL Sector Responds.* IL providers are uniquely positioned to achieve this promise. For over five decades they have supported tens of thousands of Ontarians whose ongoing physical and cognitive needs are so complex they would otherwise have lived most or all of their lives in institutional settings. This includes persons living with combinations of Cerebral Palsy, Arthritis, Stroke, Multiple Sclerosis, Muscular Dystrophy, Spinal Cord Injury (SCI), Spina Bifida, Diabetes and Huntington's Disease, as well as ABI. It also includes growing numbers of high needs older persons, and their caregivers, at risk of losing independence.

To meet these needs, IL providers across Ontario offer a full basket of non-medical community-based supports including: *Supports for Activities of Daily Living* (ADLs) that assist with essential personal needs such as eating, bathing, dressing, toileting, transferring (walking) and continence; and *Supports for Instrumental Activities of Daily Living* (IADLs) that help with vital day-to-day chores such as housework, preparing meals, taking medications, managing money, shopping for groceries, and using the telephone or other forms of communication.

Moreover, for IL providers, “person-centred” care means more than just providing one-off services at a particular location during regular office hours. It means actively managing and coordinating access to the right mix of services, in the right place (where clients live, where they work, or where they go to school), at the right time (up to 24 hours a day, 7 days a week).

Core delivery models developed and proven in the IL community include:

- ✓ *Outreach/mobile* services where clients receive a tailored mix of services and supports for daily living in their choice of care setting (at home, at work or at school), up to 24/7.
- ✓ *Supportive housing* in which clients receive a flexible mix of supports from on-site staff, 24/7, in accessible, often rent-geared-to-income (RGI) apartments.
- ✓ *Direct funding/self-directed care* where clients (and/or families) use personalized budgets to manage all aspects of their own care including service mix and choice of providers.

In addition, IL providers are now creating innovative systems of person-centred care which improve access and equity while making the best use of available resources. Among them:

- ✓ *Transitional care* where high needs clients (e.g., those with ABI or post-stroke occupying hospital alternative level of care (ALC) beds) receive assessment, skills development, and supports for daily living to ensure successful transitions from hospitals and rehabilitation facilities to community, or from community to a more appropriate care setting.
- ✓ *Hub and spoke* models that access resources at designated service “hubs” (often supportive housing buildings) to “radiate out” services to clients and caregivers living in their own homes, 24/7.
- ✓ *Mobile supports for daily living* models that extend the scope and reach of service hubs so that high needs individuals and caregivers living in their own homes can access levels of care comparable to those available in supportive housing or residential LTC beds.
- ✓ *Regional provider networks* that connect providers across entire regions to build collaboration, bridge service gaps and reduce administrative burden for providers and funders ensuring that more resources go directly to client care.

*What Does the Evidence Say?* Ontario evidence shows that IL programs and services:

- ✓ *Respond to unmet needs.* Demand for independent living services now far outstrips capacity resulting in long wait lists and increased burden for caregivers.
- ✓ *Are cost-effective.* Compared to hospitals, IL services and supports are less costly; compared to LTC, IL services and supports are no more costly even when providing similar levels of care. More importantly, because the IL sector can transform existing housing stock, including family homes and private apartments into “virtual supportive housing,” it avoids the massive capital costs and extended time lines required to build new institutional beds.
- ✓ *Produce value at individual and system levels.* Ontario data show that the needs of persons with disabilities living in supportive housing, and those living at home with outreach services, are comparable to, or exceed those living in the community with CCAC home care, as well as residents in LTC. Further, hub and spoke models using mobile supports have been shown to significantly reduce hospital emergency department visits, average length of hospital stays and LTCH wait lists, with potential cost savings of tens of millions of dollars.

## Building Community-Based Capacity to Meet Ontario's Needs: A Brief from the Ontario Association of Independent Living Service Providers (OAILSP)

### 1.0 About This Brief

This brief makes the case for renewed investments in Ontario's Independent Living (IL) sector. It argues that even modest investments can pay substantial dividends by creating much-needed community-based service capacity at a time when rising and more complex population needs are placing unsustainable pressures on hospitals and long-term care (LTC) beds and on the health care system as a whole.

Originally designed to meet the needs of persons with physical disabilities and acquired brain injury (ABI), innovative care models pioneered and proven in the IL sector over the last 50 years are now being successfully adapted across Ontario to support growing numbers of persons of all ages with multiple chronic health and social needs, and their informal caregivers, "closer to home," which is where most say they want to be.

In addition to well-established and proven models such as self-managed care, supportive housing and attendant outreach services, the IL sector is now crafting new innovations such as "hub and spoke" models, mobile supports for daily living, and regional provider networks that integrate services and supports around high needs populations to bridge care gaps, build capacity and improve service access and equity across urban and rural/remote areas of the province.

Moreover, because IL providers have extensive experience using outreach and mobile services to support people with high needs where they live, where they work and where they go to school, 24 hours a day, seven days a week (24/7), they can guarantee levels of care comparable to those in supportive housing and residential care beds, but without the massive capital costs and extended timelines required to build new housing units or beds.

Most importantly, IL providers are deeply committed to "person-centred" care, a key health system goal in Ontario, and a defining element of the Independent Living (IL) philosophy. This philosophy affirms that consumers should make decisions about their own care to the extent they are able. Rather than encouraging dependence, IL models encourage independence by engaging clients and caregivers as active care partners.

This case is backed by evidence. Not only does the IL sector address the health care top line by putting the wellbeing and independence of clients and caregivers first, it addresses the bottom line by building community-based capacity quickly and cost-effectively to relieve growing pressures on costly hospital and residential care beds, thus contributing to system sustainability.

## 2.0 About the Ontario Association of Independent Living Service Providers (OAILSP)

Since 1988, *OAILSP* and its forerunner, the *Provincial Association of Senior Managers*, have been the voice of community-based provider organizations across Ontario that deliver essential supports for daily living to persons with physical disabilities.<sup>1</sup>

*OAILSP* objectives are to build service capacity by sharing expertise and resources across the province; explore developments which advance independent living opportunities and experiences; and advocate for persons with disabilities (including persons of all ages experiencing functional challenges) and the agencies that support them.

## 3.0 The Case for Independent Living

### 3.1 A Growing Challenge

#### Rising and More Complex Needs

Ontarians are living longer and for the most part healthier. Nevertheless, as in other jurisdictions around the world, more people are experiencing complex chronic health and social needs which cannot be cured on an episodic basis in hospitals, but must be managed over the course of a lifetime “where people live.”

The rise of chronic needs is usually associated with population aging; as people get older they are more likely to experience functional challenges. Less remarked is the fact that growing numbers of younger persons with serious medical conditions and physical disabilities, who in the past would have died at birth, or lived most or all of their lives in institutional settings, are now living to adulthood and beyond, albeit with ongoing support needs.

This includes persons experiencing (often in combination) Cerebral Palsy, Arthritis, Stroke, Multiple Sclerosis, Muscular Dystrophy, Spinal Cord Injury, Spina Bifida and Huntington’s Disease, as well as Acquired Brain Injury (ABI) due to a traumatic injury (such as a blow to the head) or a medical event (such as a stroke). Also included are persons experiencing communications disorders (e.g., those who are non-speaking).

Needs are extensive and growing. According to data from the *Canadian Survey on Disability* (2013),<sup>2</sup> one in ten (10.1%) Canadians between age 15 and 64 experience disabilities which significantly restrict their daily activities and require some form of ongoing support; this number rises to more than a third (33.2%) among Canadians aged 65 years and older. In fact,

<sup>1</sup> For more information about the OAILSP, please visit <http://www.oailsp.ca/>

<sup>2</sup> Statistics Canada. *Disability in Canada: initial findings from the Canadian Survey on Disability, December 2013*. Accessed online, January 2017, at <http://www.statcan.gc.ca/pub/89-654-x/89-654-x2013002-eng.pdf>

more than a quarter of all Canadians with disabilities are considered to have a very severe disability requiring a mix of assistive devices, aids, and other health and social supports, on a continuing basis, to maintain independence and wellbeing.<sup>3</sup> In total, almost 4 million Canadians, or 13.7% of the population, experience potentially incapacitating limitations on a daily basis related to pain, flexibility, mobility, mental health, dexterity, seeing and memory.

### A Widening Care Gap

However, as expert observers have concluded, bed-based curative health care systems are poorly equipped to respond to such needs on an appropriate, cost-effective basis; as a consequence, they struggle with costly and often inappropriate utilization.<sup>4</sup>

Two widely used indicators of system performance are hospital Alternative Level of Care (ALC) bed rates and wait lists for alternative care settings such as LTC. In December 2016, 15.8% of all acute or post-acute care hospital beds in Ontario (and between a fifth and a third of beds in the province's northern health regions) were considered ALC,<sup>5</sup> a marked increase from 14.4% in January of the same year.<sup>6</sup> Although individuals in ALC beds no longer require hospital care, and might actually be harmed by extended hospital stays, they cannot be discharged because of a lack of viable community-based care options. Of this number, 45% were waiting for LTC, with close to 1,500 more individuals waiting for assisted living, rehabilitation, or home care adding to already-lengthy wait lists.

A series of provincially-commissioned reports have observed that such challenges are not merely a question of needing more beds; they reflect a systemic gap between changing population needs and system capacity to meet needs appropriately and cost-effectively in the community. For example,

- ✓ In his 2011 analysis of Ontario's persistent ALC problems, Dr. David Walker<sup>7</sup> concluded that for many seniors, a lack of community-based care too often leads to otherwise avoidable hospital admissions, extended hospital stays, further physical and mental decline, and permanent placement in residential LTC.

<sup>3</sup> Statistics Canada. *Disability in Canada: initial findings from the Canadian Survey on Disability, December 2013*. Accessed on-line, January 2017, at <http://www.statcan.gc.ca/pub/89-654-x/89-654-x2013002-eng.pdf>

<sup>4</sup> Williams AP, Lum J., Morton-Chang F, Kuluski K, Peckham A, Warrick N, Ying A. *Integrating Long-Term Care into a Community-Based Continuum: Shifting from "Beds" to "Places."* Institute for Research on Public Policy (IRPP), No. 59, February 2016.

<sup>5</sup> Cancer Care Ontario. *Alternate Level of Care (ALC). January 2016*. Accessed on-line, January 2017, at <https://www.oha.com/CurrentIssues/Issues/Documents/OHA%20ALC%20Report%20-%20January%202016.pdf>

<sup>6</sup> Cancer Care Ontario. *Alternate Level of Care (ALC). December 2016*. Accessed on-line, January 2017, at <https://www.oha.com/Documents/ALC%20Data%20-%20December%202016.pdf>

<sup>7</sup> David Walker. *Caring for Our Aging Population and Addressing Alternate Level of Care*. June 2011. Accessed on-line, January 2017, at [www.eriectclairhin.on.ca/page.aspx?id=5C136F8AD6124428AA3B5766E7F10A68](http://www.eriectclairhin.on.ca/page.aspx?id=5C136F8AD6124428AA3B5766E7F10A68)

- ✓ In his 2012 wide-ranging examination of Ontario's public services, Don Drummond<sup>8</sup> observed that the current health care system is not a system; that it is costly; that it does not produce strong outcomes; and that to address rising complex chronic needs, which account for the bulk of provincial health care costs, Ontario requires a coordinated, patient-centred continuum of care rooted in the community, including home care, health promotion and chronic care.
- ✓ In 2013, Dr. Samir Sinha's provincial seniors strategy<sup>9</sup> similarly concluded that to support Ontario's growing population of seniors, and avoid bankruptcy due to rising health care costs, the province needs an integrated, community-based continuum of care that promotes health and wellness; better access to community-based primary care and home and community care; senior-friendly hospitals with timely discharge to home and community; and short-stay and restorative options in residential LTC with possible discharge back to the community.

However, as Gail Donner's expert panel concluded in 2015,<sup>10</sup> Ontario's home and community care (H&CC) gap may actually be widening. According to Donner, while Ontario has many excellent community-based programs and services to keep people at home "if that is where they want to be," it still does not have a coherent strategy. As a result, there is too much variability in access to services, too little accountability for outcomes and a system that "fails to meet the needs of clients and families".

### Ontario's Patients First Agenda

In response, Ontario's *Patients First* agenda sets a bold new course. Its *Patients First: Action Plan for Health Care* (2015) promises to "put people and patients first" by "improving their health care experience and their outcomes." To do this it aims to "provide care that is coordinated and integrated, so a patient can get the right care from the right providers" and to deliver "better coordinated and integrated care in the community, closer to home."<sup>11</sup>

<sup>8</sup> Don Drummond. *Commission on the Reform of Ontario's Public Service*, 2012. Accessed on-line, January 2017, at <http://www.fin.gov.on.ca/en/reformcommission/chapters/executive-summary.pdf>

<sup>9</sup> Samir Sinha. *Living Longer, Living Well. Highlights and Key Recommendations*. January 2013. Accessed on-line, January 2017, at [http://healthcareathome.ca/centraleast/en/news/Documents/Seniors\\_Strategy.pdf](http://healthcareathome.ca/centraleast/en/news/Documents/Seniors_Strategy.pdf)

<sup>10</sup> Williams AP, Peckham, A, Kuluski K, Lum J, Warrick N, Spalding K, Tam T, Bruce-Barrett C, Grasic M, Im J. *Caring for Caregivers: Challenging Assumptions*. *HealthcarePapers* vol. 15, No. 1, 2015: 8-21. And, Williams AP, Peckham, A, Watkins J, Warrick N, Tam T, Rudoler D, Spalding K. *Caring for Caregivers: Facing Up To Tough Challenges*. *Healthcare Quarterly* Vol. 17 No. 3, 2014: 20-23.

<sup>11</sup> Gail Donner. *Bringing Care Home*. March 2015. Accessed on-line, January 2017, at [http://health.gov.on.ca/en/public/programs/ccac/docs/hcc\\_report.pdf](http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf)

The province's *Patients First: Roadmap to Strengthen Home and Community Care* (2015) goes even further. It promise that "everyone who has needs that can be reasonably met in the home or community will receive support to do so."<sup>12</sup>

In addition, the *Roadmap* aims to:

- ✓ *Improve client and caregiver experience*: clients and caregivers should understand the support they can expect and they experience a timely, responsive system.
- ✓ *Drive greater quality, consistency and transparency*: clients should receive consistent, high quality care informed by experts and evidence.
- ✓ *Plan for and expand capacity*: new investments should increase capacity and improve performance in the home and community care system.
- ✓ *Modernize delivery*: updated funding models, consistent assessment approaches, flexible contracting, workforce stabilization and improved technology should be used throughout the sector.

In December, 2016, Ontario passed its *Patients First Act*. Among its measures, the Act rolls Ontario's 14 CCACs into their respective Local Health Integration Networks (LHINs). According to the Ministry of Health and Long-Term Care website, this Act "will help patients and their families obtain better access to a more local and integrated health care system, improving the patient experience and delivering higher-quality care."<sup>13</sup>

### 3.2 How the IL Sector Responds

Ontario's IL providers are uniquely equipped to advance these goals. For almost five decades they have supported tens of thousands of Ontarians whose ongoing needs are so complex they would otherwise have lived most or all of their lives in institutional settings.

#### Person-Centred Care

In meeting these needs, IL providers are deeply committed to "person-centred care," a signature element of Ontario's *Patients First* agenda.<sup>14</sup> For IL providers, this commitment is more than just a catchphrase; it is rooted in the *Independent Living Philosophy* which insists

<sup>12</sup> Ontario. *Patients First: A Roadmap to Strengthen Home and Community Care*. 2015. Accessed on-line, January 2017, at <http://www.health.gov.on.ca/en/public/programs/ccac/roadmap.pdf>

<sup>13</sup> Ontario Ministry of Health and Long-Term Care. *Ontario passes legislation that delivers better health care for families*. December 7, 2016. Accessed on-line, January 2017, at <https://news.ontario.ca/mohltc/en/2016/12/ontario-passes-legislation-that-delivers-better-health-care-for-families.html>

<sup>14</sup> Ontario. *Patients First. A Roadmap to Strengthen Home and Community Care*. Accessed on-line, October 2016, at <http://www.health.gov.on.ca/en/public/programs/ccac/roadmap.pdf>. And, Ontario, *Patients First: Action Plan for Health Care*. February 2015. Accessed on-line, October 2016, at [http://www.health.gov.on.ca/en/ms/ecfa/healthy\\_change/docs/rep\\_patientsfirst.pdf](http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf)

that all persons, including those experiencing disabilities and functional limitations, have the right to fulfilling lives in the least restrictive settings possible.

In contrast to “provider-centred” models which focus on what providers can offer and expect people to “fit,” the IL philosophy emphasizes that consumers should “self-direct” or “self-manage” to the extent they are able. Rather than encouraging dependence, this philosophy advocates self-reliance and independence as ends in themselves and as means of producing better care decisions which make the best use of available system resources.<sup>15</sup>

This philosophy also aligns with and supports ongoing provincial efforts to enhance the “patient experience” which, according to *Health Quality Ontario* (HQO), is vital to improving health system performance.<sup>16</sup>

### Supports for Daily Living

Rather than aiming to cure underlying chronic health conditions, most of which, by definition, cannot be cured in any case, IL providers aim to help people with disabilities live as independently as possible “with choice, opportunities, and the confidence of full citizenship.”<sup>17</sup>

To do this, Ontario’s IL providers offer a comprehensive suite of person-centred non-medical supports including:

- ✓ *Supports for activities of daily living* (ADLs) that assist with essential personal everyday needs such as eating, bathing, dressing, toileting, transferring (walking) and continence
- ✓ *Supports for instrumental activities of daily living* (IADLs) that help with vital day-to-day chores such as housework, preparing meals, taking medications as prescribed, managing money, shopping for groceries or clothing, using the telephone or other forms of communication.

Further, IL providers have a strong track record of partnering with other providers such as Community Care Access Centres (CCACs) and community agencies to ensure that clients can access a range of other services that they may need. This starts with education and information about available care options so that individuals can make informed choices, another key goal of Ontario’s *Patient’s First* agenda. It includes partnerships and collaborations with other community agencies to connect people to resources such as transportation and adult day programs, home care nursing and rehabilitation, as well as primary health care and specialized

<sup>15</sup> For a more complete discussion of the IL Philosophy, see Toby Harris and Valerie Scarfone. *The Roadmap to Independent Living in Ontario*. May 2014. Accessed on-line, January 2017, at <http://quephindependentliving.org/wp-content/uploads/2014/07/The-Road-to-Independent-Living-Final-May-2014.pdf>

<sup>16</sup> Health Quality Ontario. *Ontario Patient Experience Measurement Strategy*. August 2016. Accessed November, 2016 on-line at <http://www.hqontario.ca/portals/0/documents/system-performance/patient-experience-measurement-strategy-1608-en.pdf>

<sup>17</sup> *Assisted Living Southwestern Ontario*. PPT Presentation. No date.

medical services like oxygen, ventilators, and wound care. When hospital care is required, IL providers offer ongoing monitoring and follow-up: a growing number now actively participate in hospital rounds and discharge planning to ensure timely and successful transitions back to community for persons who might otherwise have to remain in an institutional bed for extended periods.

### *Caring for Caregivers*

Informal caregivers are also part of the equation. While living as independently as possible, many persons with disabilities, particularly children and older adults, still benefit considerably from everyday emotional, personal and instrumental support provided by informal, and often unpaid caregivers such as family, friends, neighbors.

Backed by a rapidly expanding body of international evidence, the importance of the caregiver role is now increasingly acknowledged by experts and policy-makers. For instance, Sinha<sup>18</sup> observes that informal caregivers are “the reason why so many older Ontarians have been — and will remain — able to age in their places of choice for as long as possible.” Donner<sup>19</sup> states that without informal caregivers, “our health care system could not sustain current levels of care in the community.” In fact, Donner concludes that particularly outside of institutional settings, caregivers should be seen as integral to the “unit of care.” However, caregiver contributions may come at a price: *Health Quality Ontario* has shown that as a result of their caregiving activities many informal caregivers will experience distress and burnout.<sup>20</sup>

IL providers acknowledge and support the caregiver role as appropriate. Services designed specifically for caregivers include counselling, education and respite. For example, an award-winning *Caregiver Recharge* program offered in the Mississauga Halton LHIN by a consortium of community service providers including *Nucleus Independent Living*, offers temporary in-home relief to caregivers, so that they “can take a break” for a few hours, a day or a weekend to continue their essential caregiving activities.<sup>21</sup>

Because persons with disabilities may themselves be caregivers to children and other family members, a growing number of IL providers also offer programs specifically tailored to their needs (e.g., some parents may have difficulty holding their children, feeding them or changing diapers).

<sup>18</sup> Samir Sinha. *Living Longer, Living Well. Highlights and Key Recommendations*. January 2013. Accessed on-line, January 2017, at [http://healthcareathome.ca/centraleast/en/news/Documents/Seniors\\_Strategy.pdf](http://healthcareathome.ca/centraleast/en/news/Documents/Seniors_Strategy.pdf)

<sup>19</sup> Gail Donner. *Bringing Care Home*. March 2015. Accessed on-line, January 2017, at [http://health.gov.on.ca/en/public/programs/ccac/docs/hcc\\_report.pdf](http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf)

<sup>20</sup> Health Quality Ontario. *The Reality of Caring: distress among the caregivers of home care patients*. Accessed on-line, January 2017, at <http://www.hqontario.ca/Portals/0/documents/system-performance/reality-caring-report-en.pdf>

<sup>21</sup> For more information on the Caregiver ReCharge program, go to <http://www.centralregistry.ca/crp/home>.

## Core Delivery Models

For IL providers, “person-centred” care means more than just providing one-off services at a particular location during regular office hours. It means actively managing and coordinating access to the right mix of services, in the right place (where clients live, where they work, or where they go to school), at the right time (up to 24 hours a day, 7 days a week (24/7)). In addition to supporting people to live as independently as possible for as long as possible, these core models are now being scaled and spread to support persons of all ages experiencing functional limitations which could otherwise result in hospital or residential care admissions.

Person-centred models developed and proven in the IL community over decades include:

- ✓ *Outreach* services where clients receive a tailored mix of services and supports in their choice of care setting (e.g., at home, at work or at school), up to 24/7. Services are typically provided by personal support workers (PSWs) or attendants under the direction of the consumer and include a tailored mix of supports for activities of daily living (e.g., personal care such as bathing and toileting), as well as supports for instrumental activities of daily living (essential daily tasks such as homemaking and laundry).
- ✓ *Supportive housing* where clients living in accessible, often rent-geared-to-income (RGI) apartments owned by a municipality, charitable organization, or community provider, can receive a flexible mix of supports from on-site staff, 24/7.<sup>22</sup> While supportive housing offers a core basket of services similar to those offered through Outreach, some providers also offer coordinated access to specialized services such as tube feeding, oxygen, tracheostomies, ventilators, wound care and assistance with medications such as insulin.
- ✓ *Direct funding/self-directed care* where clients (and/or families) use personalized budgets to manage all aspects of their own care including service mix and choice of providers. Location is flexible and determined by the consumer. Eligibility criteria, and eligible services are similar to those in Outreach and Supportive Housing/Assisted Living. It is worth noting that Ontario’s current direct funding program offers a proven template for scaling and spreading this approach to other populations such as frail seniors.

## Innovations

Building on these proven core models, Ontario’s IL providers are now creating innovations which combine services and supports in new ways to build system capacity and improve performance. Four such innovations, along with detailed “vignettes” of how they are now deployed “on the ground” in Ontario, are presented below.

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<sup>22</sup> Williams AP, Lum J., Morton-Chang F, Kuluski K, Peckham A, Warrick N, Ying A. *Integrating Long-Term Care into a Community-Based Continuum: Shifting from “Beds” to “Places.”* Institute for Research on Public Policy (IRPP), No. 59, February 2016.

### *Transitional Independent Living Programs*

Transitional programs offer short to medium-term support to move individuals successfully from a hospital or LTC bed back to the community, or to remain in the community longer with an appropriate level of care while waiting for a more appropriate care setting. In addition to supporting people and caregivers, these programs offer important system benefits by releasing hospital ALC beds for more appropriate use, and by maintaining individuals in community settings longer, thus reducing pressure on residential LTC.

One example of many is the *Community Connect (CC)* program, a transitional program offered by *Bellwoods Community Living* in Toronto.<sup>23</sup> As detailed in the provider vignette below, *CC* is a community-based rehabilitation and case management program designed to ease the reintegration back to the community of hospital ALC patients with physical limitations and other chronic conditions including mental health. It provides pre-scheduled 24/7 supports in supportive housing with time in program averaging less than 6 months. *CC* participants can also access *Bellwoods' Mobile Independent Living Education (MILE)* program which provides assessment, case management, therapy supports, education and skills development aimed at equipping high needs individuals who might otherwise be required to live in institutional settings, to live and work independently in the community.

Transitional programs like *CC* address a pressing need: in December 2015, 989 individuals with physical disabilities were waiting for Attendant Services in Toronto and York Region with many waiting in hospital ALC beds.

### *Hub and Spoke Models*

This multi-tier model has its roots in the transportation industry. For example, airlines and railways typically concentrate their assets in central hubs which then service multiple routes like spokes in a wheel.

A growing number of “hub and spoke” models are now being operated across Ontario by long-established and respected IL providers such as the *March of Dimes Canada*,<sup>24</sup> *Participation House Brantford*,<sup>25</sup> *Guelph Independent Living*,<sup>26</sup> and *Cheshire Homes of London*.<sup>27</sup> They leverage resources located at particular locations (often supportive housing buildings) to “radiate” services out to persons living in their own homes or apartments within a given geographic area defined by distance (one to two kilometers) or travel time (10 to 15 minutes). Adult day programs and LTC homes can also serve as hubs to build capacity in key areas such as needs assessment, records keeping, case management, counselling and education, caregiver

<sup>23</sup> Visit the Bellwoods Centres for Community Living website at <http://bellwoodscentres.org/>.

<sup>24</sup> The March of Dimes Canada website is at <https://www.marchofdimes.ca/>.

<sup>25</sup> More information about Participation House Brantford can be found at <http://participationhousebrantford.org/>.

<sup>26</sup> Learn more about Guelph Independent Living at <http://guelphindependentliving.org/>.

<sup>27</sup> More information about Cheshire London can be found at <http://www.cheshirelondon.ca/>.

respite, food preparation, transportation and palliative care. In addition to maintaining people in their own homes longer, these models facilitate quicker and more successful transitions back to the community when a hospital stay is necessary.

To give one example, *Assisted Living Southwestern Ontario (ALSO)*<sup>28</sup> in Windsor (see provider vignette below) operates hubs in 11 supportive housing buildings owned by different providers serving more than 120 residents.<sup>29</sup> Using *ALSO* staff located in these hubs, *ALSO* clients living in their own homes can have several visits a day, either on a pre-scheduled or will-call basis, including care in the middle of the night, comparable to what they would have received in supportive housing, but without the need to build more supportive housing places. This model has proved to be very effective: *ALSO* has successfully transitioned hundreds of high needs individuals from hospital (ALC, CCC and ICU beds) and LTC back to the community.

### *Mobile Supports*

This model is increasingly used across Ontario to support persons with disabilities as well as frail seniors living beyond the range of geographic hubs. By providing a comprehensive basket of supports for daily living on a flexible basis, during the day and through the night, high needs individuals, and their caregivers, can continue to live independently in their own homes with levels of care comparable to those available in supportive housing or residential LTC beds.

Mobile supports offer important advantages. In addition to alleviating the need to build new housing or LTC beds, they allow people to continue to live in their own neighborhoods close to informal caregivers and established social support networks; instead of substituting for these informal supports, mobile services can supplement and strengthen them. They can also reduce the number of difficult resource-intensive transitions between care settings by maintaining people with high needs where they normally live longer.

Among a growing number of mobile initiatives, the award-winning *Supports for Daily Living Program* in the Mississauga Halton LHIN (see vignette below) uses a network of seven supportive housing “hubs” operated by different community providers, with coordinated intake and mobile services provided by *Nucleus Independent Living*.<sup>30</sup> According to the *Nucleus* website: “Supports for Daily Living provides high needs seniors residing in the community with the availability of 24-hour practical assistance with the essential activities of daily living that one cannot perform due to age related physical limitations or impairments. The Supports for Daily Living program is aimed at reducing unnecessary stays in hospital for seniors once their acute care phase is concluded and provides an alternative to Long Term Care.”

<sup>28</sup> More information about Assisted Living Southwestern Ontario is available at <http://www.alsogroup.org/>.

<sup>29</sup> Assisted Living Southwestern Ontario. PPT Presentation. No date.

<sup>30</sup> Nucleus Independent Living. Attendant Outreach Program website. Accessed, October 2016, at <http://www.nucleusonline.ca/services/attendant-outreach-program>

This program has achieved noteworthy success. By assisting high needs older persons and caregivers to remain safely and appropriately in their own homes longer, it has significantly reduced pressures on stretched hospital and LTC capacity, with potential savings estimated in the millions of dollars.

### *Provider Networks*

Individual IL providers offer high value person-centred care within their local catchment areas; provider networks can expand scope and reach over large geographic areas.

One example is the *Northern Group of Independent Living Providers* (see vignette below) that connects seven agencies serving persons with disabilities and caregivers in the North East and Central East Local Health Integration Networks (LHINs), a massive geographic region characterized by sparse populations, long distances, stretched community-based service capacity, and some of the highest ALC rates in the province. Using a “lead agency” model, now increasingly common among community providers across the province, *Northern Group* members share knowledge and best practices, identify common priorities, and plan joint initiatives with one agency identified as the administrative “lead” for each initiative.

In addition to strengthening inter-agency collaboration, building much-needed community-based capacity, and reducing pressure on hospital beds, The *Northern Group* ensures better and more equitable access to care for individuals and caregivers across a vast underserved region. It also avoid duplication of efforts and reduces administrative burden for providers and funders, ensuring that more resources go directly to client care.

### 3.3 What Does the Evidence Say?

In spite of such evident successes, Ontario’s IL sector remains mostly “under the radar” for researchers and policy-makers; there has been little systematic evaluation of IL services and supports in the province. Nevertheless, available evidence suggests that the IL sector meets key needs and produces strong outcomes at individual and system levels.

#### Unmet Needs

While data are limited, an authoritative 2012 province-wide study conducted at the *Toronto Rehabilitation Institute* concluded that:

- There is high demand for specialized disability support services across the province
- Average wait times for attendant services with and without housing can often be measured in years:
  - *Direct Funding Program (Self-Managed Attendant Services)*: average wait times range from 2.25 years to just over 7 years with the longest average wait occurring in Champlain LHIN.
  - *Attendant Outreach Services*: average wait times range from 3 months to 7 years with the longest average wait occurring in North Simcoe Muskoka LHIN.
  - *Assisted Living Services in Supportive Housing*: average wait times range from 0 months to 10 years with the longest average wait occurring in North West LHIN

- *Shared Living*: average wait times ranges from 1 year to 10 years with the longest average wait occurring in North West LHIN.
- Individuals leave wait lists without receiving services
- Caregiver burden/family or caregiver conflict is a common outcome of wait times.<sup>31</sup>

### Costs

It is increasingly acknowledged that community-based care is a cost-effective alternative to care in hospitals and residential LTC, even for persons with high needs.

For example, Jane Philpott, the federal Minister of Health, recently observed that while it costs a minimum of \$840 a day to keep a patient in hospital, and that the national baseline cost is upwards of \$1,000 dollars a day with some patients occupying hospital beds for months at a time, home care, averaging about \$55 a day, seems a better option.<sup>32</sup>

The 2013 Ontario report, *Unleashing Attendant Services for People with Physical Disabilities*, made similar conclusions. For example, compared to the cost of a hospital bed, supportive housing, attendant outreach, and self-managed care are less costly.<sup>33</sup>

Service Location	Average Cost/person
Hospital Bed	\$42,000/month or \$500,000/year
Assisted Living Services in Supportive Housing (average of 4 hours/day)	\$5,000/month or \$60,000/year
Self-managed Attendant Services – Direct Funding (average of 5 hours/day)	\$2,600/month or \$31,000/year
Attendant Outreach Services (average of 2.5 hours/day)	\$2,250/month or \$27,000/year

Residential LTC can also be used as a comparative base. According to the *Ontario Long Term Care Association*, in 2016, provincial funding for a LTC bed was just over \$142 per day (or about \$52,000 per year) with an additional resident co-payment of just under \$60 for a basic long-stay bed (or about \$21,900 per year), for a total annual cost of almost \$74,000/year.<sup>34</sup>

<sup>31</sup> Toronto Rehabilitation Institute – University Health Network. *Home and Community Support Services for Persons with a Physical Disability in Ontario. Wait Lists and Wait Times Description. September, 2012. Accessed on line, October 2016 at <http://alliance.sciontario.org/sites/alliance.sciontario.org/files/attachments/AS%20PLCPPD%20Report%20-%20September%202012.pdf>*

<sup>32</sup> Remarks for the Honorable Jane Philpott, Minister of Health, to the Canadian medical Association Annual General Meeting, August 23, 2016. Accessed on-line, January 2017, at <http://news.qc.ca/web/article-en.do?nid=1116779>

<sup>33</sup> OCSA, *Unleashing Attendant Services for People with Physical Disabilities: Better Quality Service with Immediate Savings to the Health System. March 2013.*

<sup>34</sup> Ontario Long Term Care Association. *About long-term care in Ontario: Facts and figures. Accessed on-line, November 2016, at <http://www.oltca.com/oltca/OLTCA/LongTermCare/OLTCA/Public/LongTermCare/FactsFigures.aspx>*

By this standard, direct funding and attendant outreach services appear less costly than LTC; assisted living in supportive housing, due to higher hours of care, is somewhat more costly. Of course, it is important note that such estimates consider only *operating costs*, the daily cost of operating a bed in a hospital or a LTC facility once it is built; massive differences in *capital costs*, the resources required to build these beds, are usually not considered.

Here, the IL sector offers clear advantages. By using approaches like outreach, mobile, and “hub and spoke” models, it can transform existing housing stock, including family homes and apartments, into “virtual supportive housing” quickly, avoiding the extended time-lines required to build new housing units or beds. This is particularly relevant in major urban centers like Toronto, where due to prohibitive property costs, planners are now predicting a net decline in residential LTC bed capacity which will have to be compensated for elsewhere.<sup>35</sup>

### Outcomes

Although supports for daily living are not usually considered “health care” per se, a growing body of international evidence suggests that particularly when focused on persons and caregivers at risk of loss of independence, coordinated, person-centred community-based care can offer a safe, cost-effective alternative to care in hospitals and residential care beds.<sup>36</sup>

On the other side of the coin, a failure to access such services on a timely basis can lead to health problems, loss of independence, and potentially avoidable stays in institutional settings. Recent analysis of home care assessment data in Ontario’s North West demonstrate that, other things being equal, an inability to use the telephone or to manage finances are significant predictors of referral to residential LTC.<sup>37</sup>

Available evidence in Ontario is highly positive. For example:

- ✓ Assessment data in Waterloo-Wellington show that the needs of persons with disabilities living in supportive housing, and those living in their own residences with outreach services, are comparable to, or exceed those living in the community with CCAC home care, as well as residents in LTC.<sup>38</sup>

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<sup>35</sup> SHS Consulting. *Capacity Plan for Long-Term Care Services in the City of Toronto*. Submitted to Toronto Central LHIN. December, 2016.

<sup>36</sup> Williams AP, Lum J., Morton-Chang F, Kuluski K, Peckham A, Warrick N, Ying A. *Integrating Long-Term Care into a Community-Based Continuum: Shifting from “Beds” to “Places.”* Institute for Research on Public Policy (IRPP), No. 59, February 2016.

<sup>37</sup> Audrey Laporte, Whitney Berta, Jan Barnsley, Janet Lum, A. Paul Williams. *Waiting For Residential Long-Term Care In North West Ontario: The factors associated with Long-term Care waitlist placement*. *Canadian Journal on Aging*, Forthcoming, 2017.

<sup>38</sup> Independent Living Centre of Waterloo Region. *Population profile: a population description, by interRAI assessment information*. October 20, 2015.

- ✓ Using a regional hub and spoke model, including a single point of access, seven hubs and mobile services, the *Supports for Daily Living* program in Mississauga Halton has successfully transitioned thousands of high needs older persons from hospitals and LTC to community, in the process significantly reducing hospital emergency department visits, average length of hospital stays and LTC wait lists, with potential cost savings estimated in tens of millions of dollars.<sup>39</sup>
- ✓ Leveraging its city-wide network of service hubs and mobile services, *Assisted Living Southwestern Ontario (ALSO)*, in Windsor, has transitioned more than 500 individuals from costly hospital ALC, ICU and CCC beds back to the community, improving the quality and appropriateness of their care, while contributing to significant and sustained reductions in hospital ALC rates.

### 3.4 On the Horizon: Supportive Neighborhoods

Going further, IL providers are now actively developing cutting-edge models which leverage community resources beyond the health and social care systems to create new capacity for people of all ages.

The “supportive neighborhoods” model aims to build linkages and collaboration not only with established community providers such as Alzheimer Societies, hospice, hospitals and community support services agencies, but with schools, businesses, voluntary organizations, and municipal governments, to create more inclusive, vibrant and healthy communities.

For example, *Assisted Living in Southwestern Ontario (ALSO)*, is now building on its “hub and spoke” model to create “neighborhoods of care.” These neighborhoods, which could potentially cover an entire city the size of Windsor, will support high needs individuals where they normally live by engaging health and social care providers, as well as faith organizations, schools, local businesses, volunteer and service clubs, transportation services, and cultural resources.

Such approaches have found increasing uptake internationally, particularly in the field of dementia care. For example, Germany has mandated the creation of more than 500 “local alliances for persons with dementia” (lokale allianzen für menschen mit demenz). In addition to engaging health and social care authorities, these alliances extend to municipalities, citizens, businesses, and educational institutions. This approach emphasizes that municipalities are where persons with dementia normally live and where neighbours, decision-makers employers, and other actors in civil society, can work to improve people’s lives.<sup>40</sup>

<sup>39</sup> *Supports for Daily Living. Assisted living for high risk seniors. PPT presentation. Mississauga Halton LHIN. February 6, 2016.*

<sup>40</sup> A March 2017 presentation by Eckart Schnabel, titled *Dementia in Germany – care and policy strategies*, *Living Well with Dementia Symposium, Toronto*, is available on the website of the Canadian Research Network for Care in the Community at <http://www.ryerson.ca/content/dam/crncc/knowledge/eventsandpresentations/2017/Dementia2017/SCHNABEL.pdf>. See also *Lokale Allianz für menschen mit demenz. Bundesministerium für Familie, Senioren, Frauen und Jugend*. Accessed on-line, October 2016, at <https://www.lokale-allianzen.de/index.php?id=100>

Japan's 2015 New Orange Plan for dementia care similarly looks beyond traditional service delivery models to create dementia-friendly communities which support family caregivers, encourage cooperation and remove institutional barriers within government and between providers, incent intergenerational projects and give people with dementia a greater voice. This plan has stimulated an array of grass-roots innovations such as dementia training for front-line bank tellers, grocery clerks and garbage collectors who interact with PLWD and their caregivers on a daily basis. It has also spurred the emergence of dementia open houses in private homes where persons with dementia, informal caregivers and care workers can congregate, share meals and experiences, socialize, provide mutual support, and learn about best practices.<sup>41</sup>

## 4.0 The Bottom Line

The IL sector is uniquely positioned to meet Ontario's rising and increasingly complex needs and advance key health system goals. As such, even modest investments in the sector can be expected to pay high rates of return both for the people and communities it serves and for the health care system.

The case is compelling. It starts with the fact that for almost five decades IL providers, guided by the *Independent Living Philosophy*, have provided person-centred care to tens of thousands of Ontarians whose needs are so complex they would otherwise have lived most or all of their lives in institutional settings. In doing so they have developed and proven approaches to care which support people and caregivers where they live, where they work, and where they go to school, during the day and throughout the night. This means that IL providers can offer levels of care in community settings comparable to those offered in residential LTC and supportive housing, but without the massive capital costs and extended time-lines required to build new housing units or beds.

It is worth emphasizing that these approaches go well beyond conventional service-by-service home care models; they coordinate and integrate a wide array of services and supports around people's needs. Building on the foundation of attendant outreach and supportive housing, they include transitional programs which educate and equip high needs individuals to reintegrate successfully from hospital ALC beds and LTC back to the community; mobile supports for daily living programs which extend the scope and reach of services to persons with high needs and caregivers living in their own homes; hub and spoke models which lever resources available at central locations to build capacity and serve new populations including high needs seniors; and regional provider networks which share resources and best practices to improve access and equity across entire regions, while also reducing administrative burden for providers and funders. Ontario's IL providers are also beginning to work with cutting-edge models now emerging in world-leading jurisdictions like Japan and Germany, which in addition to integrating health and social care, leverage a broad range of community resources to build local capacity and maintain individual wellbeing and independence, in the process, moderating demand for

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<sup>41</sup> Williams AP, Lum J, et al., *Integrating Long-Term Care into a Community-Based Continuum*, 2016.

costly hospital and institutional care.

Available evidence is strongly positive. Not only is there a demonstrated need for enhanced community-based capacity in Ontario to support growing numbers of persons of all ages with high needs, the costs of such care are considerably less than the costs of care in hospitals, and also less than or comparable to the costs of residential LTC. Moreover, community-based supports for daily living have proven effective at reducing pressures on hospital and LTC beds. This leaves room for strategic reinvestments to build additional person-centred community-based capacity quickly, a key priority for policy-makers in Ontario and beyond, and a major prerequisite for health system sustainability.

In sum, Ontario's IL sector is uniquely positioned to advance Ontario's bold new *Patients First* policy agenda. As this brief has demonstrated, reinvestments in the sector can be expected to go a long way toward achieving its promise that "everyone who has needs that can be reasonably met in the home or community will receive support to do so."<sup>42</sup>

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<sup>42</sup> Ontario. *Patients First: A Roadmap to Strengthen Home and Community Care*. 2015. Accessed on-line, January 2017, at <http://www.health.gov.on.ca/en/public/programs/ccac/roadmap.pdf>

## 5.0 Provider Vignettes

### Transitional Care: Bellwoods Centres for Community Living

*Bellwoods Centres for Community Living* in Toronto offers an integrated suite of programs and services for adults experiencing a physical disability or other complex condition. In addition to supportive housing and attendant outreach, Bellwoods offers two innovative programs -- *Community Connect* and *MILE (Mobile Independent Living Education)* -- designed to transition high needs individuals back to the community after a hospital stay and develop the skills needed to live independently. In 2015/2016 two thirds of new clients were identified as ALC.

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Established in 1957, *Bellwoods* offers supportive housing in three buildings that it owns or leases, and in two additional buildings where it supports individual clients in designated apartments. It also offers attendant outreach services to persons with physical disabilities living in the community, on a pre-booked basis, where they live, where they work, or where they go to school. Almost half of Bellwoods clients have been assessed as having “high” or “very high” needs using a standardized assessment tool (RAI-HC), so that many would otherwise qualify for residential LTC.

*Bellwoods* offers two transitional care programs. *MILE (Mobile Independent Living Education)* is a community-based short-term, goal-oriented program for clients 16 years of age and older with a permanent physical disability. Occupational Therapists (OT's), a Registered Nurse (RN) and an Independent Living Educator (ILE) provide rehabilitation services, case management and help with securing needed equipment. With the support of the MILE team, clients develop essential skills and knowledge to live independently in areas such as: home safety and accessibility; mobility and seating; self-care; household management; communication; health and wellness; and system navigation related to funding, housing, and access to community resources.

*Community Connect (CC)* provides short-term (6 month) supportive housing services to ease the transition of individuals designated as ALC from hospitals and LTC homes to an independent living environment. In addition to 24/7 supports for daily living, *CC* provides access to *MILE* to ensure that individuals are well-equipped to continue to live independently after a transition period. Clients are followed after leaving the program to ensure successful independent living over the long term.

Partnerships are key to the success of these programs. For example, since many clients transition from hospitals, *Bellwoods* staff attend weekly rounds and collaborate with hospital staff to plan and prepare individuals and families for discharge, insuring a high level of readiness for independent living in supportive housing after return to the community.

## Hub and Spoke Models/Neighborhoods of Care: Assisted Living Southwestern Ontario (ALSO)

Located in the city of Windsor and the county of Essex, in the Erie St.-Clair LHIN, ALSO supports persons with physical disabilities and acquired brain injury (ABI) as well as growing numbers of high needs seniors. Using an elaborated “hub and spoke model” now covering most of Windsor, ALSO assists hundreds of high needs individuals of all ages to live as independently as possible for as long as possible in community settings. Since February 2011, ALSO has transitioned over 500 people from hospital ALC beds or diverted them from residential long term care (LTC).

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Established in 1938, ALSO was originally designed to provide a comprehensive range of independent living supports for individuals with physical disabilities and acquired brain injury (ABI). In 2011-12, with new funding from the Erie St. Clair LHIN, it expanded to serve frail seniors with functional impairments.

ALSO does this by offering a comprehensive “basket” of supports for daily living to clients living in 11 supportive housing sites (“hubs”) as well as in their own homes within a given geographic radius (“spokes”). This basket includes a full range of attendant services; specialized ABI services; vocational services to help access and maintain employment; client intervention services to provide counselling and support and help clients make connections to other needed services; and social recreation and leisure to help them stay active and connected.

ALSO builds capacity quickly by leveraging existing housing. For example, its 11 supportive housing sites are owned by different not-for-profit organizations offering rent-g geared-to-income accommodation. ALSO locates staff in each of these buildings to support clients flexibly on a 24/7 basis, something not possible with traditional home care.

Pushing further, ALSO uses these 11 supportive housing sites as geographic hubs to radiate out mobile and outreach services for clients and caregivers living in their own homes; services are provided on scheduled or will-call basis, even in the middle of the night, with services “ramped up” or down as needs change. While supportive housing buildings typically serve 12 to 15 clients, these “neighborhoods of care” add 30 to 35 clients to multiply capacity. A recent initiative extends ALSO’s reach to rural areas by assisting clients in those areas to hire local providers with support and assistance from ALSO care coordinators.

ALSO continues to evolve: it is now building new collaborations with organizations such as the Community Care Access Centre (CCAC), Alzheimer’s Society, VON (Victorian Order of Nurses), and a local hospice. In addition to wrapping services around high needs individuals and easing transitions, such collaborations improve quality and access and achieve system efficiencies through the use of specialized teams (e.g., dementia, palliative and ABI), shared assessments and shared services such as transportation.

## Mobile Supports for Daily Living: Nucleus Independent Living

*Nucleus* is a multi-service agency operating in the Mississauga Halton LHIN. Its central intake and mobile services play a pivotal role in the success of the region's groundbreaking *Supports for Daily Living (SDL) Program*. By helping thousands of high needs seniors to remain in their own homes longer, it has reduced hospital emergency department (ED) visits and shortened residential long-term care (LTC) wait lists with potential cost savings of millions of dollars.

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*Nucleus Independent Living* began providing Attendant Services to individuals with physical disabilities in 1983 in two supportive housing projects in Toronto. In 1999 it implemented an Attendant Outreach Program for individuals with physical disabilities living in their own homes.

In 2009 *Nucleus* expanded its service delivery basket and its client base by joining Mississauga Halton's award-winning *Supports for Daily Living (SDL)* program. This program, which provides frequent, urgent and intense non-medical supports, 24/7, has assisted more than 3,500 of the highest needs, highest priority seniors (with MAPLe scores of 3 or more) to remain in their own homes while waiting for permanent placement in a more appropriate care setting such as supportive housing or residential LTC. To do this, the program integrates seven service "hubs" in supportive housing buildings operated different providers; service "spokes" reaching out from these hubs to surrounding areas; and 24/7 mobile services spanning Oakville, Mississauga and parts of Etobicoke.

*Nucleus* plays a pivotal role in the success of the *SDL* program. It provides central intake which results in streamlined referrals, live answered calls, the identification of high priority seniors, and effective waitlist management. It also provides the program's mobile supports for activities of daily living including homemaking and safety checks using trained personal support workers. Services are provided on a personalized basis through the day, evening and overnight. This flexible approach permits a higher frequency of shorter visits, so that high needs seniors can get the help they need when they need it the most, for example, in the morning for dressing and breakfast, at noon, for lunch and medication reminders, in the evening for dinner and preparation for bed, and then throughout the night for transfers and toileting.

With *Nucleus* providing these crucial intake and mobile functions, the *SDL Program* has achieved remarkable success. More than 80% of clients are 75+ years of age and almost three quarters have "high" or "very high" needs. Nevertheless, among these clients, hospital emergency room (ER) visits are down and referrals to LTC homes have been reduced with potential cost savings of tens of millions of dollars.

*Nucleus* also recognizes and supports family caregivers. It partners with *AbleLiving Services (Thrive Group)* to offer a *Caregiver ReCharge Service* that provides temporary in-home relief for primary caregivers who are experiencing high levels of stress as a result of their caregiving activities.

## Provider Networks: Northern Group of Independent Living Providers

The *Northern Group of Independent Living Providers* is a network of seven IL agencies serving persons with disabilities and their caregivers across Ontario's vast and underserved North. In addition to sharing knowledge and best practices, the *Group* uses a "lead agency" model to identify priorities, plan joint programs and reduce administrative burden for individual agencies and LHINs ensuring that more resources go directly to person-centred care.

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The *Northern Group of Independent Living Providers* connects seven agencies serving persons with disabilities and caregivers in the North East and Central East Local Health Integration Networks (LHINs): *PHARA (Physically Handicapped Adults' Rehabilitation Association)*, North Bay; *ICAN (Independence Centre and Network)*, Sudbury; *March of Dimes*, Sault Ste. Marie; *Timiskaming Home Support*, Timiskaming; *KPP (Kawartha Participation Projects)*, Peterborough; *The Friends*, Parry Sound; and *Access Better Living* in Timmins.

Together, these agencies cover a massive geographic region characterized by sparse populations, long distances, and limited community-based service capacity. This region also experiences some of the highest ALC rates in the province (more than a fifth of inpatient hospital beds in the NE LHIN are classified as ALC) with long waits for residential LTC.

Using a flexible "lead agency" model, *Northern Group* members share knowledge and best practices, identify common priorities, and plan joint initiatives with one agency identified as the administrative "lead" for each initiative.

For example, in collaboration with CCACs and hospitals, the *Northern Group* now offers enhanced respite for family caregivers across the region as well as a mobile learning centre to upgrade and assist Personal Support Workers (PSWs). It has also created a groundbreaking post-stroke program which began in Sudbury and then spread to the Sault, Parry Sound, North Bay and Timmins. This program supports individuals who have suffered a debilitating stroke to transition successfully from hospitals back to the community so that they get home sooner and costly hospital capacity is freed up for other purposes. By collaborating with community agencies such as Heart and Stroke, and rehabilitation professionals in four hospitals, this program can offer personalized one-on-one care including in-home assessments, specialized exercise programs, cooking programs, computer-based learning to improve memory and recall, and a "refresh" program to maintain independent living skills well after discharge.

In addition to strengthening inter-agency collaboration, building much-needed community-based service capacity, and reducing pressure on hospital beds, this network ensures more equitable access to appropriate care for individuals and caregivers across chronically underserved rural and remote areas of the province. It also avoids duplication of efforts for partner agencies and LHINs, ensuring that more resources go directly to person-centred care.