

Bringing CARE HOME



March 2015

what is most important?

the health of Ontarians
and their right to participate
as partners in determining
their care

The Honourable Dr. Eric Hoskins
Minister of Health and Long-Term Care
Hepburn Block, 10th Floor
80 Grosvenor St.
Toronto, ON M7A 2C4

January 30, 2015

Dear Minister Hoskins,

We are pleased to submit the Report of the Expert Group on Home and Community Care, **Bringing Care Home**. Over the last several months, we have thought hard about what we've heard from the citizens of Ontario—those who need care at home and those who provide it, both unpaid and paid, and the many organizations that have an interest in and care about health care in Ontario.

In our deliberations, we have focused on what is most important—the health of Ontarians and their right to participate as partners in determining their care. We are aware that Ontario cannot promise all citizens access to every service they may **want**, but we also know that Ontario can do better in helping people access the services they **need**. Our recommendations will assist in advancing the transformation from a home and community care system based on the needs and preferences of providers to one based on the needs and preferences of the client and family—bringing care home rather than providing homecare.

Our proposed changes are not merely about service provision, but about a necessary paradigm shift towards a client and family-centered system that is transparent and accountable.

We recognize that nurturing a shift of this significance is a complex and complicated task that cannot be accomplished overnight. We are also aware that the implementation challenges, especially in the current fiscal climate, are significant. However, we are confident that the talent and dedication exist to ensure success.

Thank you for the privilege of doing this important work. We have benefited greatly from the advice and help of clients and families, providers, researchers and organizations. We have especially appreciated the support of people in your Ministry and in your Office.

The Expert Group hopes that **Bringing Care Home** will ensure that Ontario has the home and community care system that Ontarians need, want and deserve.

Sincerely,
Original signed by,

Dr. Gail Donner, Chair

Joe McReynolds

Dr. Kevin Smith

Cathy Fooks

Dr. Samir Sinha

Donna Thomson

The Expert Group hopes that **Bringing Care Home** will ensure that Ontario has the home and community care system that Ontarians need, want and deserve.



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ACKNOWLEDGEMENTS

On behalf of the Expert Group on Home and Community Care, I would like to thank the Minister of Health and Long-Term Care, Dr. Eric Hoskins, for this incredible and meaningful opportunity to contribute to improving the care of Ontarians.

We have been fortunate to have the help and support of a number of groups and individuals:

- The Ministry of Health and Long-Term Care – particularly Nancy Naylor, Tamara Gilbert, Debra Bell, Dr. Michael Hilmer and Annie Tam – for their ongoing support and providing background information and data related to home and community care. These individuals were consistently willing to do all they could to help us achieve our objectives. I would especially like to thank Deputy Minister, Dr. Bob Bell, for his support and encouragement and Associate Deputy Minister, Susan Fitzpatrick, for providing ongoing advice and always being available when I called.
- Jacob Mksyartinian and Lindsay Hunter from the Minister's Office, who were always available to discuss our work and provide support.
- The Leadership Council of the Local Health Integration Networks for assisting the Expert Group in reaching a broad cross section of clients, families and providers through regional public engagement activities.
- Marcella Sholdice, project manager, who analyzed the survey results, submissions and other data and worked closely with the Expert Group to help us get it right. Aleksandra Kulesza ably supported Marcella in a variety of research and analytical tasks.
- Subject matter and health care experts, who were interested in and enthusiastic about our work and willingly shared their knowledge and experience.
- The many providers, associations and organizations that responded to our survey, submitted briefs and recommendations and attended consultations in person. We would like to thank them for their commitment to home and community care and for helping us do our work.
- Helena Axler, who facilitated our provider consultation with assistance from Susan Tremblay. They were instrumental in providing an open environment to ensure that we could hear the voices of providers.

The Expert Group's work would not have been possible without the significant input from the individuals who need and use home and community care every day, and from their families, friends and volunteers. We were determined from the beginning to hear and listen to these voices. We thank you most sincerely for responding to our survey and participating in the public engagement activities held on our behalf by the LHINs. Marcella Sholdice and I read every one of the 3,600 survey responses, and they guided our work and inspired us to do our very best to honour their advice. We hope that **Bringing Care Home** does justice to their ideas for change.

And finally, as Chair, I want to thank the Expert Group members for their unwavering dedication and commitment to this task. I could not have asked for more from anyone especially from a group of volunteers. You not only came to every meeting and participated in every conference call, you were passionate, engaged and helped me know and contribute more than I ever expected when we began our work. My heartfelt thanks.

—Gail Donner, Chair, Expert Group on Home and Community Care

[We] read every one of the 3,600 survey responses, and they guided our work and inspired us to do our very best to honour their advice.

EXECUTIVE SUMMARY

In Ontario, our health system aims to put clients at the centre with the *right care, at the right time, in the right place*. And the right place for many Ontarians is in their homes. We are serving increasing numbers of people and families in their homes, and providing increasingly more complex care over a longer period of time.

With no coordinated system strategy for home and community care, these pressures are creating challenges that need urgent attention. There is too much variability in access to services and too little accountability for outcomes. Everyone – clients and families, providers and funders – is frustrated with a system that fails to meet the needs of clients and families. Stakeholders may not agree on what the solutions are; however, no one thinks the status quo is an option.

In response to the growing challenges in this sector, the Minister of Health and Long-Term Care appointed the Expert Group on Home and Community Care with a mandate to provide input on strategies to address these issues. The Expert Group reviewed over 200 published and unpublished articles, reports and briefing documents related to home and community care; conducted a survey of stakeholders (1,147 responses), asked the Local Health Integration Networks (LHINs) to conduct a survey of their communities on the Expert Group's behalf (2,344 responses), and held two sessions with service providers (77 participants). The Expert Group also received 27 submissions from interested parties.

We listened – we debated – and we have proposed a way forward.

Client and Family-Centered Care

When services are provided in an individual's home, other family members, including the extended family, friends and neighbours, are often involved in providing care. The residents of Ontario told us that they want the family to be the 'client' and the planning and delivery of care to be truly client and family-centered. Although policy makers and providers have long supported the principle of family-centered care, home and community care continues to look more like it is focused on what the providers want, rather than on the needs and preferences of clients and families.

A Home and Community Care Charter outlined in this report provides guiding principles for family-centered home and community care in Ontario and what clients and families can expect from publicly-funded home and community care services.

Support for Family Caregivers

Family caregivers urgently need respite along with access to information about available public and private services and how to access them, as well as education and training to support them. On average in Canada, family caregivers provide about seven hours of help to family and friends for every two hours of professional care*. Our health system could not sustain the current levels of care in the community without the continued contribution of family caregivers. If we expect family caregivers to continue to support and care for their loved one, we need to support them.

A "Basket of Services"

Clients, families and many care providers do not know what services are publicly funded and under what conditions, and the assessment process for determining eligibility is not transparent. Stakeholders expressed 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. They also wanted this information to be easily accessible.

To the degree possible, access to and funding of the 'basket of services' should be consistent across the province, although there may be variations from the core basket to accommodate regional needs.

* Statistics Canada. (2014). *Receiving care at home. Spotlight on Canadians: Results from the General Social Survey*. Bleakney, A., & Sinha, M.

Capacity Planning

Ensuring that Ontario's health system has the capacity and resources to deliver the core 'basket of services' is the responsibility of the Ministry of Health and Long-Term Care. The 14 LHINs must be responsible for a system capacity plan that considers the interrelationships between services along the full continuum of care regardless of where care is delivered. The LHINs should lead this planning exercise, which should identify and address gaps in care and services against provincial standards. Building capacity in certain areas may mean that the LHINs will need the flexibility to allocate funds where they are needed most within their region.

Primary Care

Timely and meaningful communication is needed among primary care providers, hospitals and other members of the home and community circle of care. At a strategic level, primary care should be better aligned with other sectors and more accountable for client and system outcomes. For those primary care providers that have service agreements with the Ministry of Health and Long-Term Care (MOHLTC), the LHINs should monitor and report on performance against agreed upon outcomes.

Improved Approaches to Service Delivery

The Expert Group has identified three populations with different intensity and duration of care needs:

1. **Individuals with short-term post-acute medical or surgical needs.** The clinical services required for this population are relatively well defined according to clinical guidelines and care paths, and can be standardized across the province. Accordingly, funding for this population lends itself well to an outcomes-based payment approach. The MOHLTC should proceed with its plan to issue a request for expressions of interest to develop integrated funding models for home and community care for populations with short-term post-acute needs.
2. **Older adults and other individuals with functional limitations and/or chronic health issues.** This population requires supports tailored to their unique needs for a longer term, and often throughout their life. Services for these populations should be bundled and delivered through a designated 'lead agency' that is willing to develop and deliver the full range of care and services for one or more defined populations within a defined geographic area within a defined funding envelope.
3. **Individuals with medically complex and long-term needs that cross ministries.** These families are identified as a separate group because of the extraordinary and life-long responsibilities of the family caregivers. Because the family caregivers must deal with programs from more than one ministry, they are generally already quite experienced care coordinators and are prepared to extend their role to also manage the purchase of these services. Resources should be made available to self-directed funding for this population.

Structural Considerations

Although the issue of the structure of the home and community care sector was outside the mandate of the Expert Group, it was the subject of much of the feedback we received from clients, families and providers. Many told us that families have to deal with too many different agencies and that the current structure is cumbersome, has too much overlap, is not efficient and is not delivering the services that families need.

It is clear that the current structure is not working. The Expert Group has proposed that the sector's immediate efforts address the functional changes needed. If form follows function, we believe that the structure we need to enable and sustain these functional changes will become clear over time.

Increased Accountability for Performance

The LHINs and Health Quality Ontario are currently working together to develop system-level quality indicators for home and community care and to ensure that these indicators are aligned across all sectors of the health system. Once performance indicators are implemented, the MOHLTC and the LHINs will have the tools they need to work towards a more accountable and high-performing home and community care sector.

Implementation Considerations

Implementation of all of the recommendations can begin immediately, and most can be fully implemented within the medium term (i.e., two to three years). However, the culture shift required to achieve real system transformation in home and community care will require time and effort and cannot be accomplished in the short run. This will be a complex and complicated initiative.

Concluding Remarks

The Expert Group found many ‘pockets of excellence’ in home and community care in Ontario, led by many individuals and organizations committed to providing quality care to the families they serve. However, these programs are often implemented on such a small scale that they cannot contribute in a meaningful way to the system-wide culture shift needed to ensure a high-performing system that is truly client and family-centered.

Our recommendations help define family-centered care and how the system can best support clients and families to thrive in the community. We have also made recommendations about how care providers need to work together and with families to deliver truly family-centered care, how the system can support the circle of care in that role, and how we need to ensure accountability for delivering a high-performing home and community care sector in Ontario.

We can do better, we need to do better, and we need to change now.

Recommendations

These recommendations are intended to provide a starting point for beginning the culture change needed to create a truly client and family-centered home and community care sector. It was not possible in the five short months we had to complete our work to address every important issue in this sector. Many important issues are not addressed in our recommendations but are identified in the report as areas for further consideration.

Recommendation 1: That the Ministry of Health and Long-Term Care endorse the principles of client and family-centered care as expressed in the proposed Home and Community Care Charter and incorporate them into the development of all relevant policies, regulations funding and accountability strategies for this sector.

And that the Local Health Integration Networks, working with the Ministry of Health and Long-Term Care, use the proposed Home and Community Care Charter for the planning, delivery and evaluation of home care and community services.

Recommendation 2: That the Ministry of Health and Long-Term Care provide more resources to increase the availability of services that support family caregivers and, in particular, increase the capacity for in-home and out-of-home scheduled and emergency respite services. When respite services are identified as being needed by a family caregiver(s), these services should be explicitly included in the care plan.

Recommendation 3: That the Ministry of Health and Long-Term Care explicitly define which home care and community services are eligible for provincial funding (i.e., the available ‘basket of services’) and under what circumstances. A clear statement of what families can expect and under what circumstances should be made easily accessible so that families can better anticipate and participate in the creation of sustainable care plans. Eligibility for all services should be determined using a common standardized assessment tool that is also publicly accessible.

Recommendation 4: That the Ministry of Health and Long-Term Care take a leadership role in working collaboratively with other ministries in defining a single and coordinated basket of services for clients and families whose needs cross multiple ministries.

Recommendation 5: That each Local Health Integration Network submit to the Ministry of Health and Long-Term Care an evidence-informed capacity plan for its region indicating where there are shortfalls and how any gaps in home care and community services will be addressed. These plans should use a common provincial framework using standardized data sets and tools, and the plans should be updated every three years.

Recommendation 6: That the Ministry of Health and Long-Term Care allow the LHINs discretion to direct funds to reflect the priorities within their region to meet client and family home care and community service needs, even if that means re-allocating money across the various funding envelopes.

Recommendation 7: That the Deputy Minister of Health and Long-Term Care, through the Council of Deputy Ministers, take a leadership role in developing an integrated plan for defining and delivering a single, coordinated needs-based statement of benefits (i.e., an inventory of home and community services) for children and adults with long-term complex needs and their families provided by all relevant Ontario ministries (e.g., Ministry of Children and Youth Services, Ministry of Community and Social Services, Ministry of Municipal Affairs and Housing, Ministry of Transportation).

Recommendation 8: That Local Health Integration Networks, in collaboration with the LHINs’ Primary Care Leads, develop and implement strategies to improve two-way communication between primary care providers and home and community care providers.

Recommendation 9: That, where performance agreements with primary care providers exist (e.g., with Family Health Teams and Community Health Centres), the Local Health Integration Networks take responsibility for managing performance against the service standards in these agreements and making these results publicly available.

Recommendation 10: That the Ministry of Health and Long-Term Care proceed to issue its planned Integrated Funding Project Expression of Interest to develop models for home and community care for populations with short-term post-acute needs.

Recommendation 11: That the Ministry of Health and Long-Term Care direct the Local Health Integration Networks to select and fund the most appropriate lead agency or agencies to design and coordinate the delivery of outcomes-based home and community care for populations requiring home and community care for a long term within their LHIN.

Recommendation 12: That the Ministry of Health and Long-Term Care take a leadership role in working collaboratively with other ministries in defining a single and coordinated needs-based envelope of funding for services for clients and families whose needs cross multiple ministries.

Recommendation 13: That the Ministry of Health and Long-Term Care increase the funding available for self-directed funding for clients and families with high needs and that care coordinators work with families and support them whether they choose self-directed funding or an agency provider.



Recommendation 14: That Health Quality Ontario, working in partnership with the Local Health Integration Networks, finalize and implement system performance indicators and, in consultation with providers and families, develop and implement a scorecard for the home and community care sector. The scorecard should be publicly reported, and all publicly-supported home care and community support service providers should be required to submit quality improvement plans on an annual basis.

Recommendation 15: That the Ministry of Health and Long-Term Care tie funding for home and community care services (e.g., home care, community support services, primary care) to the achievement of clearly defined outcomes and results.

Recommendation 16: That the Ministry of Health and Long-Term Care appoint Home and Community Care Implementation Co-Leads (one Co-Lead from within and one from outside of the Ministry), with appropriate support, to guide and monitor the implementation of the recommendations in this report, reporting annually to the Minister of Health and Long-Term Care.

CARE
at HOME

**A vital link
in Ontario's
health care
system**



INTRODUCTION

In Ontario, our health system aims to put clients at the centre with the *right care, at the right time, in the right place*. And the right place for many Ontarians is in their homes*. Over one million Ontarians and their families receive home and community care today.

With appropriate supports, many individuals of all ages can remain in their homes, return home more quickly from hospital, or delay or even avoid the need for admission to a hospital or long-term care home. By helping these people remain in their homes as long as possible, quality of life is often sustained or improved, and the health system can reduce the use of less appropriate and more expensive health care services such as emergency rooms, hospitals, and long-term care homes.

Pressures for Change

The aging of Ontario's population is well documented along with its impact on the health care system^{1,2}. In addition to the growth in the number of patients, the health system has also begun to rely on the home and community sector to care for increasing numbers of high needs individuals who require more intense care and services for a longer period of time. Indeed, the number of clients receiving services through Community Care Access Centres (CCACs) has doubled since 2003/04³ and is expected to continue to grow as the population ages.

Ontario has many excellent programs designed to keep people at home if that is where they want to be. However, it does not have a coordinated and integrated system to ensure it can meet – and can continue to meet – the needs of Ontario citizens. Clients, families and providers have raised issues about the limited resources, inefficient structures and processes, lack of collaboration among stakeholders, and minimal performance measures that plague home and community care today.

With no coordinated system strategy for home and community care, these pressures have resulted in many challenges for clients, families and providers:

- Clients, particularly those who are not urgently ill, are finding themselves increasingly on wait lists or being deemed ineligible for publicly-funded services they once had. Clients and families do not understand what services they can expect, and services received may depend in large part on where they live.
- Families feel they are not always receiving the support they need, especially respite care, to keep them healthy and safe while they provide care for their loved one.
- Service providers have found the billable rates for hours and visits as defined in their contracts frozen in 2003 and again in 2008. In a sector where wages are already lower than

With no coordinated system strategy for home and community care, these pressures have resulted in many challenges for clients, families and providers.

* Note: A client's 'home' is wherever that person resides. It can be a private residence, supportive housing, retirement home or just about anywhere except a hospital. A person's community includes more than just a residence; it includes any location where services are provided for individuals who live at home, including, for example, clinics, schools and recreation centres.

¹ Commission on the Reform of Ontario's Public Services. (2012). *Public Services for Ontarians: A Path to Sustainability and Excellence*. Queen's Printer for Ontario.

² Government of Canada. (2013). *Living Longer Living Well*. Sinha, S. K.

³ Community Care Access Centre. (2013). CCAC MIS Comparative Reports 2013/2014: Tablet 3: Individuals Served by Organization. Retrieved from Ministry of Health Data Branch Web Portal.



in the hospital sector, and stability of the work force and meaningful work are difficult to achieve, it is becoming increasingly difficult to attract and retain qualified staff.

- As new initiatives are introduced, the 14 CCACs have been asked to take on an increasing array of services, including service delivery for some new programs. CCACs often have difficulty managing within their budgets due to the combined effect of higher volumes, higher needs and longer times on service than anticipated.

In the past five years, more than one-half of the 14 CCACs in the province have undergone some sort of review or assessment, often triggered by their struggle to manage rapidly growing volumes within the allocated funds. Accordingly, there has been increased attention to and questioning of the role of the CCACs. Ontario's Auditor General is currently reviewing the CCACs' operating costs and service contracts, with a report expected at the end of March 2015.

Stakeholders may not agree on what the best solutions are to ensure that the home and community care sector in Ontario can thrive. However, they do agree that something **must** be done, and done quickly if we wish to continue to support care-at-home as a critical part of our health care strategy.

The Home and Community Care Review

In response to the growing challenges in this sector, the Minister of Health and Long-Term Care appointed the Expert Group on Home and Community Care with a mandate to provide input on strategies to address these issues. Terms of Reference for the Expert Group are provided in Appendix A; short biographies of the Expert Group's members are provided in Appendix B.

The Expert Group reviewed over 200 articles, reports and briefing documents related to home and community care, including a jurisdictional review on home care service delivery and a recent 2014 review of integrated and coordinated care models. The Group also conducted a survey of stakeholders (1,147 responses), asked the LHINs to survey their communities on the Expert Group's behalf (2,344 responses), and held two sessions with service providers (77 participants). The Expert Group also received 27 submissions from interested parties. A profile of the survey respondents is provided in Table 1. A detailed description of the Expert Group's approach to its work is documented in Appendix C.

In short, the Expert Group spent most of its time listening primarily to the voices of those who need and use home and community care and their families and to those who plan and provide that care. Everyone had suggestions for improvement. We listened, debated and proposed a way forward.

Table 1: Profile of Survey Respondents

	Expert Group Survey	LHIN-assisted Public Consultations
Individuals receiving care	56	204
Family members and other unpaid caregivers	191	358
Individual care providers	389	475
Others (e.g., associations and organizations)	440	121
Did not specify	71	1,186
Total	1,147	2,344

Overview of the Report

Bringing Care Home is about the need for change. It is about how to shift the culture of home and community care to one that starts with clients and families and works with them to co-design their care based on what they need. It is about being clear with them about what the publicly-funded system can do to help and working with them to meet their needs including accessing services that are not part of the public system. It is about doing better. And it is about the need to change now – before the growth in demand and need is so great that we are forced to change in ways that are neither planned nor desirable.

The report continues as follows:

- In “**Where We Are,**” we provide a brief history and overview of publicly-funded home and community care in Ontario.
- In “**What We Heard,**” we present a summary of the key themes from the consultations with clients, families and providers.
- In “**What We Need,**” we present our response to the key themes and recommendations to address the identified issues along with some considerations for the implementation of those recommendations.
- Our final section highlights areas that we did not investigate in any depth, but that we believe to be deserving of further work.

 We can do better than this.”
(Family caregiver)



WHERE WE ARE: HOME AND COMMUNITY CARE IN ONTARIO

This section provides a brief history of publicly-funded home and community care in Ontario, followed by an overview of the sector in Ontario today including the services, the providers and our investment in this sector, as well as a summary of the sector's contribution to our health system.

Brief History of Publicly-Funded Home and Community Care in Ontario

The *Canada Health Act* of 1984 recognizes home care as an element in the category of 'extended health services'; which means that home care is not publicly funded under the Act⁴. However, Ontario has long recognized the value of home care as an integral part of an effective health system and introduced its first publicly-funded home care program in 1970. These programs typically included nursing, therapies and personal supports.

Community support services were developed over many years, often in response to a specific need that was identified by a community group. In the early 1980s, Ontario began to fund these services to help older adults and persons with disabilities receive the help they needed to stay in their homes.

In 1997, under the *Long-Term Care Act 1994*, 43 CCACs were established in Ontario to:

- Provide simplified access to home and community care;
- Deliver and make the arrangement for the delivery of home care services to people in their homes, schools and communities;
- Provide information and referral to the public on community-related services; and
- Authorize admissions to long-term care homes.

In 2006, the 42 CCACs were amalgamated to align with the boundaries of the 14 newly formed Local Health Integration Networks (LHINs)⁵, which had been established in 2006 with a mandate to plan, fund and integrate health care services in their regions.

Ontarians now have access to a broad range of services to help them maintain their health, safety and independence in the home. Some services are also available to support the family and other family caregivers* who provide much of their care.

In Ontario,
3.3 million
men and
women
are family
caregivers.

⁴ Canadian Home Care Association. (2008). *Portraits of Home Care in Canada Executive Summary*.

⁵ Ministry of Health and Long Term Care. (2007). Community Care Access Centres: Client Services Policy Manual, Section 1.6. Retrieved from http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/ccac_mn.html.

* Note: Many terms are used for family and friends who provide care in the home but are not paid to do so (e.g., caregivers, family caregivers, carers). The Expert Group uses the term "family caregivers."

An Overview of Home and Community Care Today

What Is Home and Community Care?

The Ministry of Health and Long-Term Care (MOHLTC) distinguishes between home care and community services, which are collectively referred to as ‘home and community care’:

- Home care includes nursing, therapies, homemaking, personal support services and other related services. These services are provided by service provider organizations that have a service agreement with a CCAC.
- Community services include non-clinical supports such as meals, transportation, supported living, home help and other assistance. These services are provided through Community Support Service (CSS) agencies that are funded through the LHINs.

A detailed list of home care and community services is provided in Appendix D.

Who Provides Home and Community Care?

In 2012, approximately nine out of 10 Canadians who received care in the home relied on family caregivers, and 29% of these individuals had been receiving care from their primary caregiver for 10 or more years. On average, care receivers had about seven hours of help from family or friends, and about two hours of professional care⁶.

In Ontario, 3.3 million men and women are family caregivers, and 48% are caring for a parent or in-law. Almost 850,000 of these caregivers provide more than 10 hours of care a week, including transportation, domestic tasks both indoors and out, scheduling appointments, managing finances and providing personal care⁷.

Publicly-funded home care services are provided through 14 CCACs that assess an individual's care needs and coordinate access to contracted services. CCACs also provide information on and referrals to community support and other local services and screen individuals for eligibility for admission to long-term care homes and placement to other services (e.g., adult day programs, assisted living and supportive housing). These services are purchased through over 260 contracts for nursing, therapy and personal support⁸.

In addition, LHINs provide services through service accountability agreements with over 800 CSS agencies across the province to provide a number of services including meals, transportation, supported living, home help and other assistance. Some of these services are publicly funded; others are offered for a fee⁹.

In 2013/14, over 700,000 Ontarians accessed home care services through Community Care Access Centres (CCACs)¹⁰, and almost 1.5 million Ontarians were served by CSS agencies, acquired brain injury programs and assisted living in supportive housing services¹¹.

What Does Ontario Invest in Home and Community Care?

Total 2013/14 funding in Ontario for home and community care was \$3.2 billion, which was approximately 6% of the health budget for all programs and services (\$48.9 billion). Approximately two-thirds of this funding flows through the province's 14 CCACs; almost \$500 million flows to over 800 CSS agencies across the province¹².

While the MOHLTC has increased funding to CCACs overall by 99% since 2003/04 (an annual average increase of 5.6%)¹³, the number of individuals receiving services through CCACs has actually doubled over the same period¹⁴. The Ontario Association of Community Care Access Centres further reports that the number of long-stay, high-needs clients it has been serving has increased 73% since 2009/10¹⁵.

⁶ Statistics Canada. (2014). *Receiving care at home. Spotlight on Canadians: Results from the General Social Survey*. Bleakney, A., & Sinha, M.

⁷ General Social Survey. (2014). Data tables Ontario from the Results from the General Social Survey. The Change Foundation.

⁸ Ontario Association of Community Care Access Centres. (2014). *Making way for change: Transforming home and community care for Ontarians*. p4.

⁹ 2013-2014 Ministry of Health and Long-Term Care Public Accounts. Retrieved from <http://www.fin.gov.on.ca/en/budget/paccts/2014/>

¹⁰ Ontario Association of Community Care Access Centres. (2014). *Making way for change: Transforming home and community care for Ontarians*. p1.

¹¹ Ministry of Health and Long-Term Care, 2014.

¹² 2013-2014 Ministry of Health and Long-Term Care Public Accounts. Retrieved from <http://www.fin.gov.on.ca/en/budget/paccts/2014/>

¹³ 2013-2014 Ministry of Health and Long-Term Care Public Accounts. Retrieved from <http://www.fin.gov.on.ca/en/budget/paccts/2014/>.

¹⁴ Table 3: Individuals Served by Organization, CCAC MIS Comparative Reports 2013/2014YE (MOH Health Data Branch Web Portal).

¹⁵ Ontario Association of Community Care Access Centres. (n.d.). Average Monthly Active Complex and Chronic referral per cent change from FY2009/2010 to 2013/2014.

How Does Home and Community Care Contribute to Our Health System?

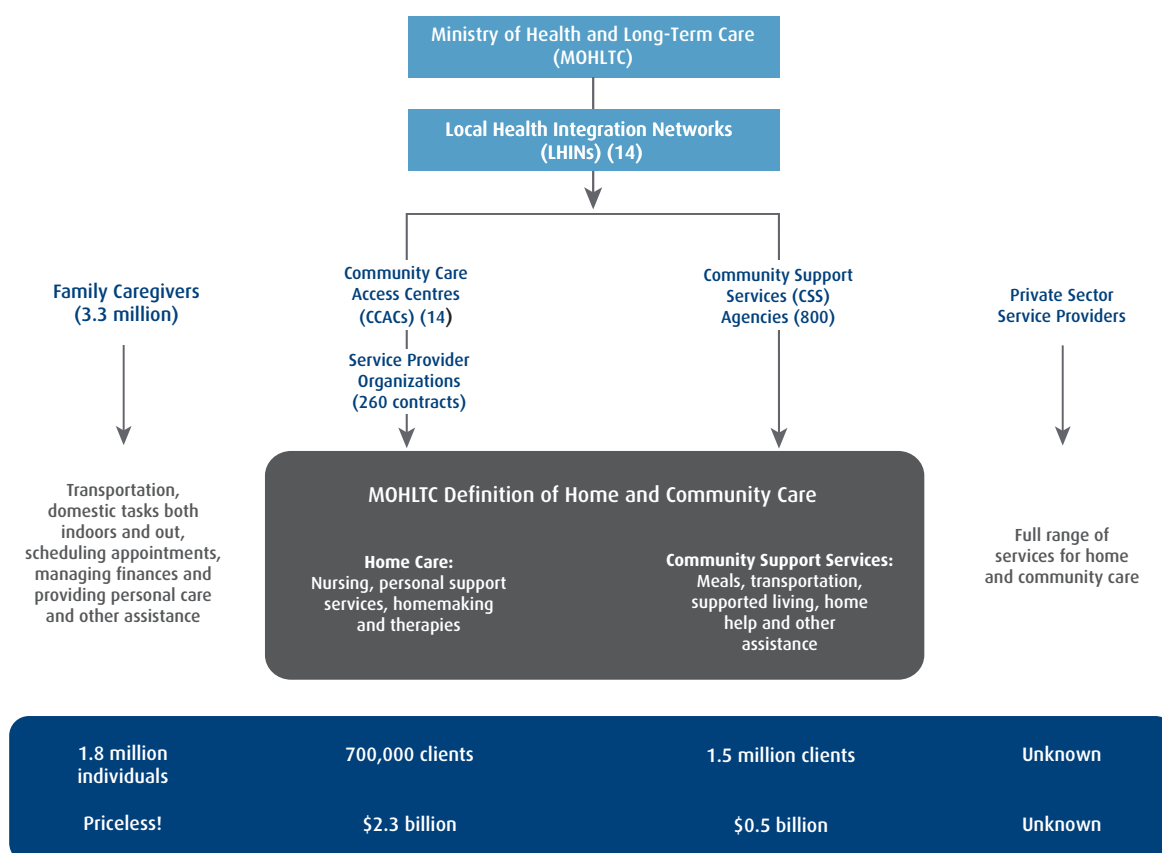
Ontario's investment in home and community care services is one factor in the trend towards improved performance in institutional care:

- The number of patients discharged to home care services after a hospital stay has increased by 42% (from 110,759 in 2008/09 to 157,485 in 2012/13)¹⁶.
- From 2009/10 to 2011/12, the number of patients waiting for long-term care in Ontario hospitals decreased 32% from 3,145 to 2,141¹⁷.
- From 2009/10 to 2011/12, the placement rate of Ontarians 75 and older into long-term care homes has declined 26% from 5.8 to 4.3 per 1,000¹⁸.

The Government of Ontario has recognized the critical importance of home and community care, and the Ministry of Health and Long-Term Care has identified it as a priority area. Funding to this sector has increased over the past few years with a commitment to continue these increases.

Figure 1 presents a summary description of home and community care in Ontario.

Figure 1: Home and Community Care in Ontario^{19,20}



¹⁶ Inpatient Discharges Main Table (CIHI Discharge Abstract Database (DAD)). (January 2015). Intellihealth Ontario, Ministry of Health and Long-Term Care.

¹⁷ Government of Ontario. (2012). ALC Performance Summary from November 2009 to October 2012. OHA ALC Survey Results and WTIS: ATC ALC Data.

¹⁸ Government of Ontario. (2012). The Quarterly Report, Spring/Summer. Ministry of Health and Long-Term Care.

¹⁹ Government of Ontario. (2014). *Foundation Briefing: Home and Community Service Sector* [PowerPoint slides]. Retrieved from Implementation Branch in Ministry of Health and Long-Term Care.

²⁰ Statistics Canada. (2014). *Receiving care at home. Spotlight on Canadians: Results from the General Social Survey*. Bleakney, A., & Sinha, M.



I only can say
from personal
experience: It is
very scary and
worrisome to
grow old today,
especially if you
are one of the low
income society."

(Individual receiving services)



WHAT WE HEARD: STAKEHOLDERS SPEAK



Within the home and community care sector, the Expert Group found many success stories and pockets of excellence and innovation that reflect best practices and result in superior outcomes. However, despite these achievements and the dedication and hard work of providers, the home and community care sector is not delivering the full range of services that the public needs or wants. Indeed, many survey respondents expressed a strong desire for the MOHLTC to increase access to existing services and to fund additional services.

Ontarians told us that they want:

- Care that is truly family centered.
- Clarity about what services are available.
- Clear and accessible communication about the basket of publicly-funded services available,
- Better coordinated and integrated services.
- Responsive approaches to service delivery.
- Increased accountability for performance.

In this section, we present what we heard from stakeholders during our consultations.

Provide Care that is Truly Family-Centered

The strongest theme in the Expert Group's consultations was that the "client" needs to be defined as more than just an individual in need, and the entire "family" is the client.

Family caregivers provide most of the home care in Ontario. Without their continued support, the burden on the public system would be even greater. Family caregivers need to be supported in this role with a broader basket of services that helps meet more than just the client's clinical needs.

Stakeholders also told the Expert Group that clients and families need to be actively involved in the development and implementation of their care plan, and that they need flexibility in tailoring the plan to their family's unique and evolving situation.

Understand that it is a unit of care – stop considering the needs of everyone separately”.

(Health care professional)

I don't think that we can emphasize sufficiently the importance of the patient voice in these dialogues.”

(Association)



Families – especially those receiving services from a variety of agencies and/or ministries – also expressed the need for a single point of contact for the coordination of care and for access to information and services. They also asked for a common comprehensive client record that is accessible by all. Technology is seen as an enabler for improved communication within the circle of care.

I I don't have any more time. My life has not been my own for the past 5 years. I HAVE NOT BEEN AND AM NO LONGER A DAUGHTER but a caregiver, a nurse, a cleaning lady, a cook, a personal shopper, a consoler, etc..." *(Family caregiver)*

"The principal caregiver must be ranked right up there with the cared for...If they are in the dumps, it affects the cared for, therefore, if you neglect the caregiver, you are neglecting, to an extent, the cared for." *(Family caregiver)*

"Invest in your unpaid caregivers – these are the people who are not getting paid for overtime, they will work the crazy hours and you don't need a scheduler to book them... Caregivers need the support to know they are doing the right thing. They need someone who can help them in times of stress – a 24hr help line would be great. I have been up late at night with a cold thinking "what do I do if I am sick tomorrow???" I have no one who I can ask to answer that question." *(Family caregiver)*

"Overall, greater flexibility and fewer rigid, hard rules. Listen to the caregiver and the patient to what would best meet their needs." *(Family caregiver)*

Make sure the care provided is what is needed by the person. If he/she needs someone to take them for a walk, instead of housework, then the care provider should know this when visiting that person.” *(Family caregiver)*

“I am a caregiver to my husband who has diabetes, peripheral neuropathy, heart disease/fibrillation, and kidney failure. I am 75 years old and in good health, however, sometimes I get overwhelmed trying to fit into each day the responsibility of keeping up our home, looking after my husband, and having some “self” time. I have a housekeeper through Community Care, however, there are always other jobs that need to be done as well as the expense of driving my husband to and from the hospital for dialysis and to various doctor’s appointments.” *(Family caregiver)*

“Give me a single point of contact for my CCAC needs. Right now I have 3 contacts at my nursing company (not including my nurses), 2 CCAC case managers, and a CCAC rapid response nurse. That is WAY TOO MUCH! I have to contact 2 different people to order supplies, and 3 people to change nursing shift times.” *(Family caregiver)*

“THE SINGLE MOST EFFECTIVE STRATEGY, in my opinion, would be to REORGANIZE THE SYSTEM SO THAT EACH PATIENT WITHIN THE SYSTEM HAS A SINGLE CASE MANAGER/ADVOCATE/FACILITATOR.” *(Family caregiver)*

“In this day and age when files are or should be electronic, I don’t understand why my family member’s records are not all in the same file, accessible by all CCAC levels... frustrating for family members to see such a waste of time and resources.” *(Family caregiver)*

Be Clear About What Services Are Available

The second major theme from the consultations was that families do not understand what services are available and under what circumstances. There were many calls for a clearly articulated statement of publicly-funded and unfunded services that clients and families can access and more transparency regarding the assessment process to determine eligibility.

“A simple menu of options, that was transparent and clear, that was available both in the community and to hospital providers, that was explicit and provided predictable budgetary results for the CCAC would go a long way toward addressing some of the inequities in the system.” *(Health professional)*

“Identify common transparent standards for service allocation and service levels to enable patients to know exactly what service levels and how much home and community care ‘funding’ they can expect based on their care needs.” *(Organization)*

Families and providers also felt that the scope of funded services should be expanded to encompass the entire continuum of care from health promotion and prevention to end-of-life care. Funded services should include non-clinical supports that help maintain independence such as homemaking, meal preparation, supportive housing, a daily telephone call to check on them, transportation, a 24/7 help line, and respite services for caregivers. There were also requests for specialized services for some complex high needs and/or vulnerable populations and for specific geographic areas.

Families also want flexibility in determining which of the available services they need most.

Deliver Better Coordinated and Integrated Services

The third major consultation theme from our consultations was that families want services that are better coordinated and integrated at several levels:

- Service delivery: When several organizations are providing care and services to the same clients and families, they are often not working together to coordinate the delivery of these services.
- Primary care: The delivery of primary care should be better aligned with home and community care. Communication between primary care providers and service providers is poor (e.g., discharge summaries not sent or sent too late to be useful, communication between physicians and care coordinators is poor). Primary care providers are not always consulted in the development of home and community care plans, nor are they provided with provider assessments, care plans and reports.
- Services from other ministries: Greater integration is needed where a family needs services from more than one ministry within the Government of Ontario.

A short-term institutional stay is in many ways just one more element of an individual's home and community care plan. Indeed, the need for improvements in discharge planning from hospital was frequently noted in the survey responses and speaks to the need for better integration of services at these critical transition points from home to hospital to home. The potential role of community paramedicine in enabling the provision of home and community care was also frequently identified.

Scheduling could be a lot better... I did not know who was coming in... That information was day by day." *(Family caregiver)*

"Unreliable and fragmented services scheduled according to provider, not around patient needs." *(Organization)*

"Partnership between Ministry of Health and Ministry of Child and Youth Services and Community and Social Services. My children are 15 and 22 both complex medical care with feeding tubes, trach, seizures, complex respiratory issues and moderate to profound developmental delays. Services and programs provided by CCAC don't address their developmental needs, behaviours, special considerations for accessing community and interacting with others. Services provided by the other two ministries don't address most of the medical care needs my children face daily. These kids do not fit nicely into any box but that shouldn't stop them from accessing appropriate services, supports, and resources." *(Family caregiver)*

One of the greatest opportunities to improve home and community care is to improve primary care so it is better equipped to serve its required role as a strong foundation for the rest of the health system.” (Association)

“To improve the connection between home care and primary care is to centralize responsibility for access, assessment and service planning, and system navigation within each LHIN.” (Organization)

Provide Efficient Approaches to Service Delivery

The fourth major consultation theme was that clients, families, caregivers and organizations perceived that the current system had areas of duplication and inefficiency. Suggestions for improving efficiency included the use of technology to support communications (e.g., telemedicine), a common electronic medical record accessible by everyone on the care team, centralization of services to reduce duplication and streamline access, and strategies to reduce administrative costs.

“More physicians who Skype, or the equivalent... Dragging our butts (my father and I) in over a two-hour drive from Muskoka to Toronto, by ambulance, only to be told radiation has failed and treatments will stop, driving home another 2 hours through a massive thunderstorm, using the resources of paramedics who could be saving lives, is a shameful way to treat a father and daughter. Fast forward to 2013 (–trip #29 is this week).” (Family caregiver)

“One electronic health records system that can be accessed or be given to clients and families that can be shared with all home and community care providers. This would decrease the duplication of assessments and question asking period.” (Organization)

“Create a central point of access, assessment and system navigation for geographic areas. This will reduce duplication of services, improve access, and avoid additional costs to address system fragmentation.” (Organization)

“Lower administrative costs across smaller organisations and use funds to have larger organisations support smaller organisations for things such as HR, Payroll, Insurance, maintenance; make sure that administration of programs, in its definition, is well understood and that those who accept the role do more than act as a paymaster while holding a % of funds for administration purposes (paymaster vs lead).” (Organization)



Increase Accountability for Performance

The final theme was the need for more accountability in the system beginning with evidence-informed population-based capacity plans that can help uncover existing needs, gaps and opportunities for improvement in home and community care. Stakeholders identified the need to measure and report on system performance, and use service contracts to manage accountability for performance of service providers.



There needs to be more transparency and accountability.” *(Family caregiver)*

“Broader shift towards population needs based planning.” *(Association)*

“Collect data and use it to inform the efforts to improve the system.”

(Health professional)

“Establish standards... ensure standards are followed... establish consequences for non compliance... make findings open to public.” *(Health professional)*

“What is required is a new contracting system geared at multiservice providers whom are held accountable for client outcomes. Contracts that cover multiple services with funding tied to client outcomes would positively contribute towards collaboration, integrated care, coordinated care plans and innovative models of service delivery, thus positively impacting population health.” *(Organization)*



WHAT WE NEED: THE RESPONSE TO STAKEHOLDER VOICES

Having listened to the voices of stakeholders, the Expert Group has identified the key issues and provided recommendations to address them.

Real Family-centered Care

When services are provided in an individual's home, the client is not the only person affected. Other family members, including the extended family, friends and neighbours, are often involved in providing care.

The needs of family caregivers should be included in the initial and ongoing assessment, and should be addressed in the care plan to ensure that they are well supported in their caregiver role. A recent Ontario study found that care plans for individuals with multiple chronic needs in community settings should include an assessment that considers the care needs for both the person requiring care and the caregivers²¹. An evaluation of the Caregiver Framework for Seniors Project, which expands the "unit of care" to include the family caregiver, found that improved support for family caregivers helped them cope with caring for longer periods²².

The Expert Group believes that both the 'client' and the 'family' should be central in the delivery of home and community care, and that our health care system needs to think more broadly beyond the individual receiving care. Accordingly, the 'client' for home and community care is the 'family' and is defined to include not only the individual in need and but also other unpaid caregivers such as family, friends and neighbours. The members of the extended 'family' should be defined by the individual receiving care, and family members have the right to determine how involved they can or cannot be in providing the needed care.

Home and Community Care Charter

The Expert Group developed a Home and Community Care Charter based on the principle that everyone who has needs that can be reasonably met in the home or community will receive assistance to do so. Home care is not a casual or optional service – it is a **necessary** service for clients and families who receive care.

Both the client and the family should be central in the delivery of home and community care, and our health care system needs to think beyond the individual receiving care.

²¹ Williams, A.P., Peckham, A., Watkins, J., Warrick, N., Tam, T., Rudoler, D., & Spalding, K. (2014). Caring for Caregivers: Facing up to Tough Challenges. *Healthcare Quarterly* 17(3): p 20-23.

²² Warrick, N., Peckham, A., Watkins, J., Padjen, M., & Williams, A.P. (2014). Caring for Caregivers of High-Needs Older Persons. *Healthcare Quarterly* 17(3): p 24-29.

Home & Community Care Charter

Home Care Clients Expect That:

1. They can include their 'family' – however they wish it defined – as an equal partner in the formal care team that supports them.
2. A single care coordinator will work with the client and family to identify their needs and the most appropriate services to meet those needs.
3. The care coordinator and primary care providers will communicate regularly and in a timely fashion. Where appropriate, technology will be used to facilitate timely and ongoing communication among members of the circle of care.
4. Care plans will include an assessment and documentation of the family's capacity to provide care and ensure appropriate supports are provided to avoid caregiver burnout.
5. There will be clear communication about what services to expect from the publicly-funded home care system and easy access to information about those services and eligibility criteria through a single call centre and website.
6. Home and community care will include both clinical and non-clinical supports that help maintain independence including homemaking, meal preparation, supportive housing, transportation and respite services for caregivers.
7. The ability to access or use privately-funded services will not affect an individual's eligibility for publicly-funded services.
8. To the degree possible, the number of service agencies assigned to provide care will be minimized, and where there are multiple agencies involved, the single care coordinator will ensure the integrated provision of services.
9. A single, integrated client record containing relevant personal health information and a care plan will be accessible to every member of circle of care, including the client and the family. Privacy is ensured by allowing the client to authorize access to specific members of the circle of care.
10. Care in the home will be respectful of cultural values and traditions.
11. A timely and transparent appeals or remediation process will be available if the system does not deliver what the family expected.

The role of the care coordinator is critical to ensuring client and family centred care. Care coordination should include support in navigating all publicly and non-publicly funded home and community services the family wishes to access including services provided by other ministries. Care coordinators then help to evaluate, reassess and adjust the plan as needed and ensure it is shared with the entire circle of care. The circle of care should be the entire team that provides care and services for the individual in need and the family, which includes the client, the family and all services providers, including those outside of the services funded by the MOHLTC.

1

Recommendation 1: That the Ministry of Health and Long-Term Care endorse the principles of client and family-centered care as expressed in the proposed Home and Community Care Charter and incorporate them into the development of all relevant policies, regulations funding and accountability strategies for this sector. And that the Local Health Integration Networks, working with the Ministry of Health and Long-Term Care, use the proposed Home and Community Care Charter for the planning, delivery and evaluation of home care and community services.

The Expert Group's first recommendation is a system recommendation that must be embraced by all stakeholders – service providers, planners and funders. This represents a significant paradigm and culture shift, especially for planners and providers, and will necessitate education and support as well as evaluation that measures whether the shift has occurred. If we do not begin to work strategically and methodically towards a truly client and family-centered approach, home and community care in Ontario will continue to be fragmented and inconsistent and will fail to meet the needs of clients, families and the health system.

Support for Family Caregivers

Our health system relies heavily on family caregivers and could not sustain the current levels of care being provided in the community without their continued contribution. Ensuring these family caregivers are well supported is critical to the ongoing sustainability of the home and community care sector.

The Canadian Caregiver Strategy has identified five elements of support for caregivers, which are consistent with what stakeholders told the Expert Group:

1. Safeguard the health and well-being of family caregivers.
2. Minimize the financial burden placed on family caregivers.
3. Enable access to user friendly information and education.
4. Create flexible workplace/educational environments that respect caregiving obligations.
5. Invest in research on family caregiving as a foundation for evidence-informed decision making²³.

²³ Canadian Caregiver Coalition. (2008). *A Framework for a Canadian Caregiver Strategy*.

Providing this support will require that a number of services and resources are made available to families in their role as family caregivers.

The need for respite was a major theme in the survey responses and is supported in the literature²⁴. Although respite services are listed as one of the publicly-funded services within home and community care (see Appendix D), the Expert Group heard that these services are limited and insufficient to meet the needs of family caregivers, and access is inconsistent across the province. Access to both in-home and out-of home scheduled and emergency respite services should be more broadly available to enable family caregivers to continue to care for family members at home, avoid caregiver burnout and potentially decrease the need for long-term care home placement.

Family caregivers also need access to information about what types of services are available, what types of financial support (both public and private) are available, and how to access services along with education about the individual's health issues and access to training and support in the care of their family member.

2

Recommendation 2: That the Ministry of Health and Long-Term Care provide more resources to increase the availability of services that support family caregivers and, in particular, increase the capacity for in-home and out-of-home scheduled and emergency respite services. When respite services are identified as being needed by a family caregiver(s), these services should be explicitly included in the care plan.

Clarity About What Services Are Available

Although the Expert Group did not conduct a needs assessment, the survey respondents were clear that the current scope of available services was not sufficient to support people in their homes. Specifically, there was overwhelming support for the following enhancements in services:

- Services to address needs along the full continuum of care, from health promotion and prevention to end-of-life care.
- Support services that can enable individuals to remain independent longer and more safely in the community, for example, transportation and housing services.
- Services that are appropriate to the unique needs of specific populations including, for example, frail older adults, children with disabilities, First Nations, palliative patients, as well as individuals with dementia, mental health and addictions issues, or other complex and/or chronic conditions. Those providing care to these populations must have the relevant education and training.

Although it is acknowledged that not all home and community services are funded through the MOHLTC, there is wide-spread confusion about what services are funded and under what conditions. The existing list (see Appendix A) does not include any information on the eligibility criteria or the level of service provided. Eligibility criteria vary by CCAC (and sometimes even within a CCAC) and across CSS agencies. In addition, the process for determining eligibility or communicating the eligibility criteria is not transparent to clients, families or other stakeholders, including primary care providers.

²⁴ Allie Peckham, Karen Spalding, Jillian Watkins, Cindy Bruce-Barrett, Marta Grasic and A. Paul Williams. Caring for Caregivers of High-Needs Children. *Healthcare Quarterly* 17(3): p 30-35.

Defining a 'Basket of Services'

The MOHLTC needs to explicitly define a provincial baseline for:

- What services are publicly funded²⁵ (e.g., a 'basket of services'),
- Under what conditions (i.e., the eligibility criteria by patient population) these services will be publicly funded and to what extent, and
- The process by which a client and family will be assessed for services.

This information needs to be publicly and easily available and written in language that is accessible so that clients, their families and care providers can understand whether they qualify for specific services.

Families also want flexibility in determining which and how much of these services they want to receive. For example, although an individual may be eligible for assistance with bathing, a family member may be able to provide this assistance in the evening, and the individual might prefer more assistance with a social activity.

Funding also varies by jurisdiction. The budgets for CCACs largely reflect historical trends. Although the introduction of some reforms that introduce population-based funding formulas will begin to address these inequities, high growth communities will continue to feel cost pressures more acutely while these formulas are being phased in. Funding for community support services was initially determined based on what services were already available in a region. Accordingly, if a region did not have a particular service (e.g., transportation) at that time, individuals living in that region would have no access to this service even though it is theoretically a funded service.

To the degree possible, access to and funding of the 'basket of services' should be consistent across all LHINs. Although there may be variations* in the number and type of services offered to reflect local conditions (e.g., additional transportation assistance in northern and rural communities), the funded services should be the same across all LHINs.

3

Recommendation 3: That the Ministry of Health and Long-Term Care explicitly define which home care and community services are eligible for provincial funding (i.e., the available 'basket of services') and under what circumstances. A clear statement of what families can expect and under what circumstances should be made easily accessible so that families can better anticipate and participate in the creation of sustainable care plans. Eligibility for all services should be determined using a common standardized assessment tool that is also publicly accessible.

4

Recommendation 4: That the Ministry of Health and Long-Term Care take a leadership role in working collaboratively with other ministries in defining a single and coordinated basket of services for clients and families whose needs cross multiple ministries.

²⁵ Note: The discussion of what services are publicly funded must be undertaken in the context of the total funding that is available for home and community care.

* Note: See Appendix E for a brief discussion on standards vs. standardization.

Capacity Planning

Ensuring that the health system has the capacity and resources to deliver the funded core 'basket of services' will require a system capacity plan that recognizes the interrelationships between services along the full continuum of care regardless of where care is delivered (e.g., policies and practices that affect the length of a hospital stay will have an impact on both hospital operations and home and community care). This planning function needs the leadership of the MOHLTC to establish the capacity plan for the province and the 14 LHINs to plan for their regions.

5

Recommendation 5: That each Local Health Integration Network submit to the Ministry of Health and Long-Term Care an evidence-informed capacity plan for its region indicating where there are shortfalls and how any gaps in home care and community services will be addressed. These plans should use a common provincial framework using standardized data sets and tools, and the plans should be updated every three years.

Most LHINs have undertaken some form of capacity planning, and have been frustrated by their inability to move funding from one part of the system to another to address gaps in care and services. If these planning exercises are to be effective, LHINs will need the flexibility to allocate funding where it is needed most within their region.

6

Recommendation 6: That the Ministry of Health and Long-Term Care allow the LHINs discretion to direct funds to reflect the priorities within their region to meet client and family home care and community service needs, even if that means re-allocating money across the various funding envelopes.

Another challenge to system capacity planning is that not all health information databases are linked, which makes it extremely difficult to find reliable and meaningful information about utilization across the system, especially for services that are not funded through the LHIN. Common databases across all regions and all sectors must be developed if we are to monitor and evaluate system outcomes in a reliable and responsible manner.

It should be noted that clients do not always receive all of their care within one LHIN. The Toronto Central LHIN, for example, includes many tertiary hospitals that provide care for patients from outside of the LHIN's boundaries, and then discharge these patients to their home community in another LHIN. These patient flows need to be considered in the LHINs' capacity plans and will require the exchange of data and plans between the LHINs.

Services that Are Better Coordinated and Integrated

Care at home, especially when needs are complex, requires care and services from a host of agencies and programs. Families may have to deal with two or more agencies providing in-home care and two or more ministries supporting those programs. It also requires that the role of the primary care provider be aligned with the continuum of services.

Coordinating Care at Home

Currently in Ontario, services for a single client or family are often provided by a number of different agencies. For example, nursing services may be provided by one agency and personal support services by another. In some areas, home care providers and CSS agencies may not be aware that their client is receiving services from another agency. As a result, more than one agency is often assessing and planning for client needs in isolation. As well, service delivery is not coordinated, resulting in scheduling of visits that often feels haphazard and inconvenient for the client and family. Clients need to receive all care and support in a manner that appears seamless to them.

Engaging Other Ministries

Individuals with complex or multiple medical needs who require supports beyond what the MOHLTC provides often receive benefits from more than one ministry (e.g., Ministry of Children and Youth Services, Ministry of Community and Social Services, Ministry of Municipal Affairs and Housing, Ministry of Transportation). The complexity and lack of integration among the various programs across these ministries makes them extremely frustrating and time consuming for families to navigate. Greater integration and cooperation among the various ministries would be of great benefit to these families.

7

Recommendation 7: That the Deputy Minister of Health and Long-Term Care, through the Council of Deputy Ministers, take a leadership role in developing an integrated plan for defining and delivering a single, coordinated needs-based statement of benefits (i.e., an inventory of home and community services) for children and adults with long-term complex needs and their families provided by all relevant Ontario ministries (e.g., Ministry of Children and Youth Services, Ministry of Community and Social Services, Ministry of Municipal Affairs and Housing, Ministry of Transportation).

Engaging Primary Care Providers in Home and Community Care

Having an involved primary care provider is critical to the success of any home care plan. Evidence suggests that patients with access to coordinated, comprehensive and continuous primary care tend to have better health than patients who do not.²⁶ However, the Expert Group found that family physicians and other primary care providers are not always an integral part of the care team for these families and that communication between primary care providers and the care team is often inadequate.

8

Recommendation 8: That Local Health Integration Networks, in collaboration with the LHINs' Primary Care Leads, develop and implement strategies to improve two-way communication between primary care providers and home and community care providers.

²⁶ Starfield, B., Shi, L., & Macinko, J., (2005). Contribution of primary care to health systems and health. *Millbank Quarterly* 83(3): p. 457-502.

The Ontario Medical Association defines integrated primary care as follows: *“An appropriately integrated primary care system ensures that patients move seamlessly between providers and care locations including the home, family practice clinic, community, specialty care and hospital or any other institutional setting. Active integration at the community level and between practice sites can result in shared efficiencies, better patient care, improved capacity and greater patient and provider satisfaction. To achieve this goal administrative and system barriers need to be overcome... Integrating the clinical and community care record can remove barriers to collaborative care and network all providers with the patient.”²⁷*

There are three system level challenges in aligning primary care with other components of home and community care:

- Many Ontarians still do not have a primary care provider, despite investments in the education of more family physicians and nurse practitioners over the past five to 10 years to increase the supply of primary care providers in Ontario. Investments in family health teams, nurse practitioner-led clinics, community health centres, and Health Links have helped to improve access to primary care.
- Many individuals with complex medical conditions have difficulty finding a family physician who will accept them as a patient, despite significant investments in funding models that are, in part, intended to encourage family physicians to accept these patients.
- Home and community care is funded through the LHINs, whereas most primary care practitioners are funded directly by the MOHLTC. Many of the strategies and services needed for more integrated care may already be part of the service agreements between primary care providers and the MOHLTC, and integration could be improved by assigning responsibility for managing those agreements to the LHINs.

Despite the acknowledgement of this challenge in many policy papers and reports^{28,29,30,31,32} primary care is still somewhat disconnected from other dimensions of home and community care, particularly in remote and rural communities.

Primary care was not explicitly in the Expert Group’s mandate; however, the engagement of primary care is a critical success factor for home and community care reform and many stakeholders, both families and providers, identified it as an issue of concern. Unless primary care and home and community care are well aligned, the needed transformation will not be possible. A critical enabler for this alignment is to manage the delivery of primary care through the same entity that manages other elements of home and community care: the LHINs.

9

Recommendation 9: That, where performance agreements with primary care providers exist (e.g., with Family Health Teams and Community Health Centres), the Local Health Integration Networks take responsibility for managing performance against the service standards in these agreements and making these results publicly available.

²⁷ Increasing Efficiency in the Family Practice Setting Working Group (2011). *Increasing efficiency in the family practice setting: Report of the working group to the Primary Healthcare Planning Group*. Toronto, ON: Primary Healthcare Planning Group.

²⁸ Jaakkimainen, R.L., Barnsley, J., Klein-Geltink, J., Kopp, A., & Glazier, R.H. (2011). Did changing primary care delivery models change performance? A population based study using health administrative data. *Biomedical Central Family Practice*. 12:44.

²⁹ Institute for Competitiveness & Prosperity. (2014). *Building better health care: Policy opportunities for Ontario*.

³⁰ Health Council of Canada. (2013). *Progress Report 2013: Health Care Renewal in Canada*.

³¹ Aggarwal, M., & Hutchinson, B. (2012). *Toward a Primary Care Strategy for Canada*. Canadian Foundation for Healthcare Improvement.

³² Health Quality Ontario. (2014). *A Primary Care Performance Measurement Framework for Ontario: Report of the Steering Committee for the Ontario Primary Care Performance Measurement Initiative: Phase One*. Toronto: Queen’s Printer for Ontario.

Although many family health teams have service agreements with the MOHLTC, most of the performance standards are currently related primarily to volume of services. The Primary Care Performance Measurement Steering Committee at Health Quality Ontario is working on system-level indicators and practice-level indicators that will be publicly reported³³. These indicators should be incorporated into all relevant performance agreements. The Committee's work will enhance the LHINS' ability to monitor performance of some primary care providers in their region.

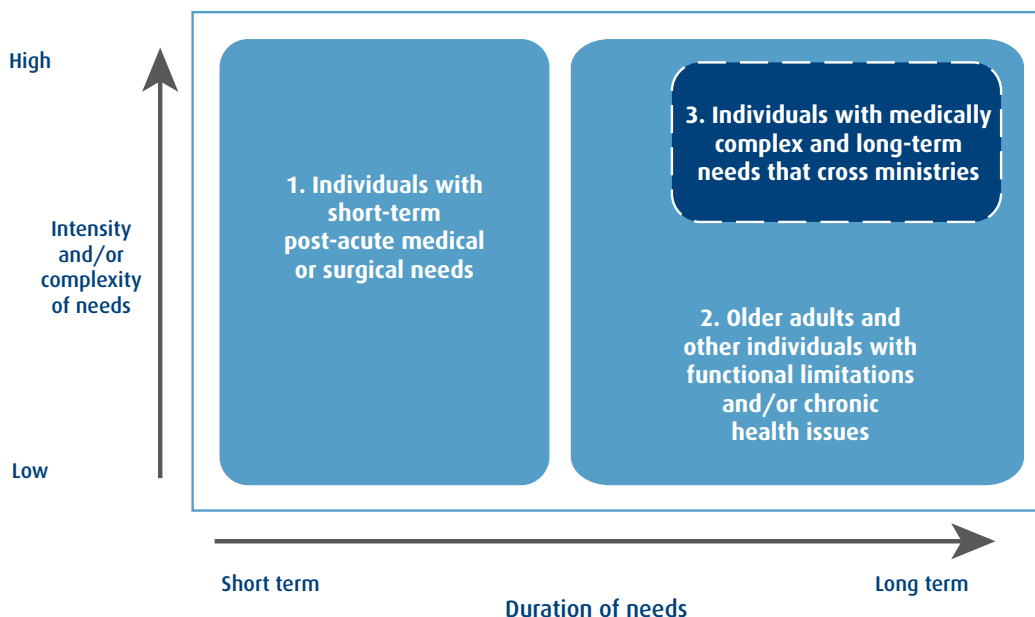
Also, the MOHLTC has appointed an Expert Panel on Primary Care that is expected to provide recommendations for primary care reform. The Expert Group urges the MOHLTC to consider the implications of the Primary Care Expert Panel's recommendations on the need for greater integration of primary care into home and community care.

Improved Approaches to Service Delivery

The Expert Group has identified three distinct populations with different intensity and duration of care needs (see Figure 2):

1. Individuals with short-term post-acute medical or surgical needs.
2. Older adults and other individuals with functional limitations and/or chronic health issues.
3. Individuals with medically complex and long-term needs that cross ministries.

Figure 2: Home and Community Care Populations



³³ Health Quality Ontario. (2014). A Primary Care Performance Measurement Framework for Ontario: Report of the Steering Committee for the Ontario Primary Care Performance Measurement Initiative: Phase One. Toronto: Queen's Printer for Ontario.

1. Individuals with Short-term Post-acute Medical or Surgical Needs

This population includes individuals admitted to hospital for either a medical condition (e.g., stroke, pneumonia) or surgery (e.g., cancer, cardiac, joint replacement) who require support during the post-discharge recovery period. Some patients with chronic health conditions who are admitted to hospital may also be part of this population.

The clinical services required for this population are relatively well defined according to clinical guidelines and care paths, and can be standardized across the province. For example, post-natal home care and post-surgical wound care are already well defined for a home-care environment. Although personal supports required may vary by family, the needs will be relatively common across families for this population and will only be required in the short term.

Accordingly, funding for this population lends itself well to a defined envelop of funding for bundled services. The MOHLTC has already announced that it will be issuing a request for expressions of interest to develop integrated funding models for home and community care populations with short-term post-acute needs. The objectives of this initiative are to promote patient-centered care across the care continuum, improve quality of care, reduce unwanted or unwarranted variation of patient care pathways and inform future policy. It is the MOHLTC's intention to identify such providers in each of 10 LHINs.

10

Recommendation 10: That the Ministry of Health and Long-Term Care proceed to issue its planned Integrated Funding Project Expression of Interest to develop models for home and community care for populations with short-term post-acute needs.

2. Older Adults and Other Individuals with Functional Limitations and/or Chronic Health Issues

For this population, clients and their families require support for a longer term, and often throughout their life span. This broader population group is made up of many smaller populations, each with unique needs. For example:

- Frail older adults and other individuals with functional limitations and/or chronic disease(s) that limit their independence.
- Individuals with one or more chronic disease (e.g., diabetes, chronic obstructive pulmonary disease) who are at high risk of complications and who would benefit from education about their condition and clinical support, tailored to their specific disease(s).
- Individuals with conditions such as dementia, mental health or addiction issues or other conditions that require ongoing access to specially trained providers.

Services for these populations would be best bundled and delivered through a designated 'lead agency' that is willing to develop and deliver care and services for one or more defined populations within a defined geographic area.

A lead agency will be an organization – or partnership of two or more organizations – that agrees to undertake the delivery of the full basket of home and community care for one or more populations in a defined geographic area within a defined funding envelope based on population needs. The lead agency will be expected to design and coordinate the delivery of services according to best practice guidelines and provincial standards and ensure that these services are well integrated with primary, home and community and acute care providers. The lead agency will be held accountable for achieving the defined outcomes for each population within the defined funding envelope.

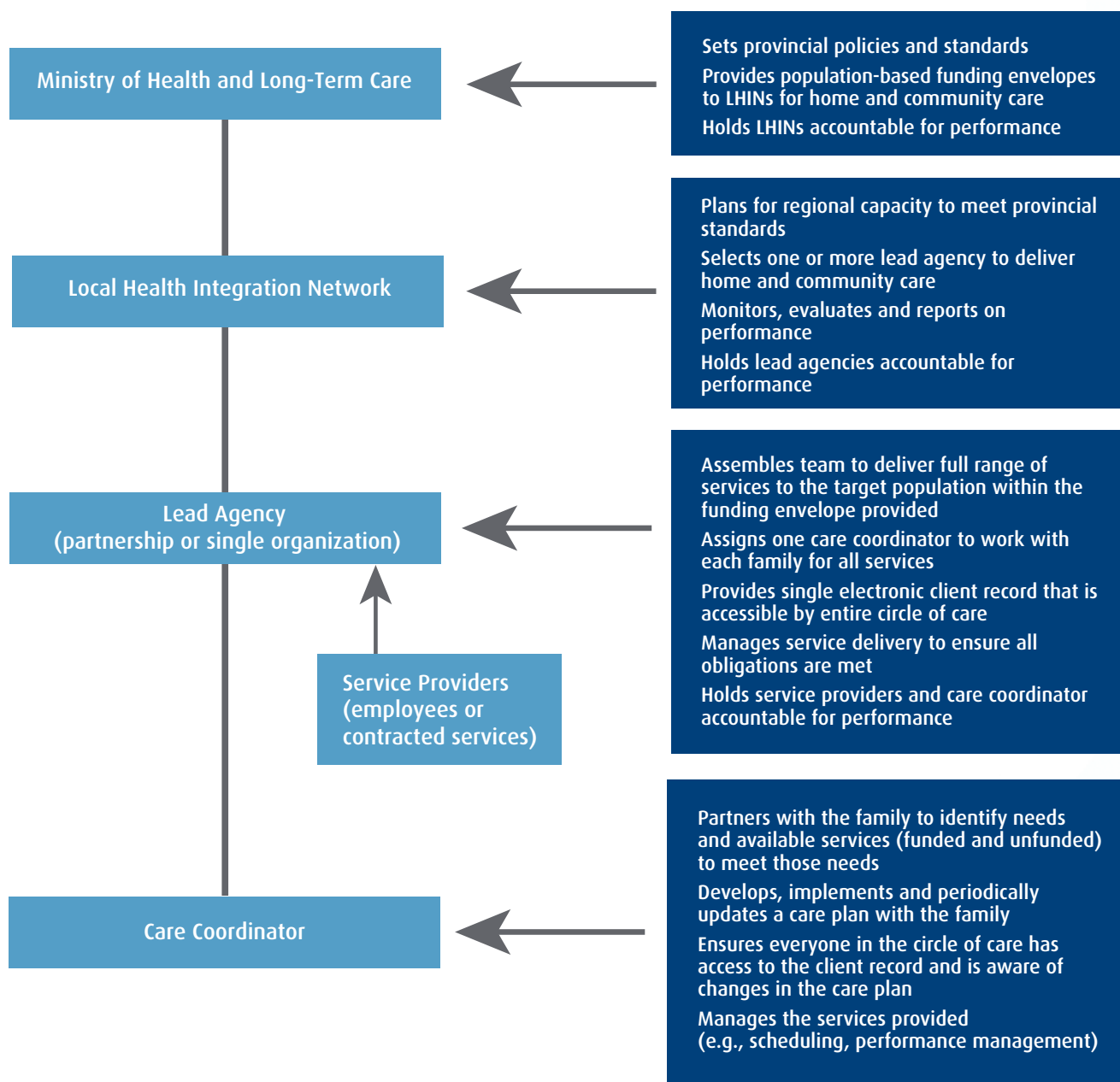
The lead agency could be, for example, a CSS agency, a service provider or a CCAC alone or in partnership with each other. The number of lead agencies within a LHIN will depend on population needs (as determined in the capacity

planning exercise described in Recommendation 5) , the LHIN's geography, the level of interest and capacity among organizations in the LHIN to take on this role, and the number of lead agencies the LHIN is willing to manage.

One of the key benefits of the lead agency model for clients and families is that all services are provided through a single agency that is held accountable through a service agreement for the delivery of high quality home and community care. The family needs to deal with only one care coordinator in one organization for all care and services.

The roles and responsibilities within the lead agency model are summarized in Figure 3.

Figure 3: Roles and Responsibilities within the Lead Agency Model



The concept of a lead agency is a logical next step after the proof of concept being undertaken with the MOHLTC's Integrated Funding Project described in the previous section and supported in our Recommendation 10. Assuming this approach achieves the target objectives, the LHINs should be encouraged to expand this approach to more client populations through the lead agency model.

11

Recommendation 11: That the Ministry of Health and Long-Term Care direct the Local Health Integration Networks to select and fund the most appropriate lead agency or agencies to design and coordinate the delivery of outcomes-based home and community care for populations requiring home and community care for a long term within their LHIN.

Every lead agency should be required to meet these minimum requirements for their service delivery model:

- Reflect a client and family-centered care model that includes caregiver support.
- Identify one care coordinator for each family.
- Offer the full bundle of services for the defined population.
- Document the funded services in a care plan and work with the family to determine which of those services will be provided.
- Provide assistance to the family to find any unfunded services required.
- Ensure that every individual receiving services is assigned to a primary care provider and incorporate an explicit role for a primary care provider.
- Provide a care plan with timelines available to all members in the circle of care. Service providers should be required to have technology-supported strategies to facilitate this communication.
- Incorporate strategies to ensure that in-home appointments are kept as scheduled (e.g., replacement sent if a care provider is unable to make the visit).
- Include a formal evaluation by an independent third party.

3. Individuals with Medically Complex and Long-term Needs That Cross Ministries

Within the population with long-term needs, the Expert Group has identified a subset comprising children and adults with long-term complex needs who often suffer from relatively rare (e.g., muscular dystrophy, genetic disorders) and multiple medical conditions and usually receive services from two or more ministries. These families were identified as a separate group because of the extraordinary and life-long responsibilities of the family caregivers.

For each family, care must be tailored to the unique situation and sustained over the long term. As the individual ages (e.g., a child enters school, a youth wishes to live independently from his or her parents), the disease progresses, and/or the family caregivers age, the need for care will change. Therefore, flexibility in determining and changing the service mix and intensity is essential.

Families in this sub-population almost always qualify for services from two or more ministries, and they expressed frustration over the amount of time needed to deal with so many individual programs at so many ministries.

12

Recommendation 12: That the Ministry of Health and Long-Term Care take a leadership role in working collaboratively with other ministries in defining a single and coordinated needs-based envelope of funding for services for clients and families whose needs cross multiple ministries.

Clients and families in this population expressed a strong desire for increased access to a self-directed funding program, in which they are given an envelope of funding that they can use as required (e.g., to hire personal support workers, to train friends and family as caregivers or to purchase respite services). Because the family caregivers must deal with programs from more than one ministry, they are generally already quite experienced care coordinators and are prepared to extend their role to also manage the purchase of these services.

The MOHLTC does have a self-directed funding program; however it is limited to adults with physical disabilities and to attendant care. This program currently has 725 beneficiaries³⁴ and over 400³⁵ individuals on the waiting list, with wait times ranging from two to over seven years. The MOHLTC is currently exploring the introduction of a broader self-directed funding program. The Expert Group believes this program should be targeted initially to this population. However, not all families in this population will choose to participate in a self-directed funding program.

13

Recommendation 13: That the Ministry of Health and Long-Term Care increase the funding available for self-directed funding for clients and families with high needs and that care coordinators work with families and support them whether they choose self-directed funding or an agency provider.

The Expert Group recognizes that direct funding is complex and, in addition to funding, the program will require policies to ensure the equity of access and safety for the individuals receiving services, their families and their providers.

For the small number of clients and families in this population, a simpler process should be developed for allowing exceptions to the current funding maximums to accommodate their extraordinary circumstances.

Procurement of Services

Many concerns have been raised about the contracting* of services in the home and community care sector, including frustrations with the current freeze on CCAC contracts with services providers. The issues are complex and complicated and will not be easy to resolve. However, serious effort should be made to solve these issues to ensure that providers and the public have confidence in how the sector is managed.

The Expert Group understands that other processes, including the Auditor General's Value for Money Audit, are in place to examine the current situation and to explore alternative procurement strategies for home and community care.

³⁴ <http://news.ontario.ca/mohltc/en/2014/01/helping-ontarians-with-disabilities-live-independently-1.html>

³⁵ <http://www.dfontario.ca/info/announcements.html>

* NOTE: The Expert Group uses the term 'contracting' to refer to the procurement of services provided at the appropriate price recognizing the complexity involved in delivery of that care. The successful contract should be outcomes based (i.e., should specify the performance expected from the contractor). The use of the term contracting is not intended to suggest that the current arrangement is preferred.

Regardless of what process is used, the procurement for these services should follow principles of good practice (e.g., transparency, value for money, accountability, separation of the purchaser and provider roles).

Getting the Most Out of Available Resources

The home and community care sector must be adequately funded to meet the growing need for services. Recognizing that there are limited funds available for home and community care, the Government of Ontario may need to consider innovative strategies to ‘stretch’ the public funds including, for example:^{*}

- Moving away from a one family – one visit model, where every service is delivered one-on-one in the home and creating more opportunities for clustered care or care in congregate settings as well as ambulatory clinics, where appropriate transportation services are available.
- Creating incentives to encourage more people to volunteer their time and services as unpaid caregivers (e.g., facilitating the use of high school students as volunteers, encouraging corporate caregiver support programs).
- Aggressively exploring opportunities for operational efficiencies (e.g., more effective management of medical supplies for home visits, greater support for back-office integration for all stakeholders in the sector).
- Investing in technology at the system level as a means to improve efficiency through, for example, telecommunications including telemedicine, telehomecare and telemonitoring along with other forms of information sharing that can help to reduce duplication, improve communication and enable other models of delivery. Ontario has already made significant investments in some of these technologies, and additional investment may be nominal.

Increased Accountability for Performance

According to the Excellent Care for All Act: *“a high quality health care system is one that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focussed, and safe.”*

A first step towards a high-performing system of home and community care is to understand the desired outcomes against each of the dimensions of a high-performing system, and then determine how to measure progress against those goals. The articulated goals need to reflect the principles of client and family-centered home and community care as described in the Home and Community Care Charter.

The home and community care sector currently has some reliable data on utilization and outcomes (e.g., inter-RAI Home Care and Community Health Assessment data, utilization data through CCACs and CSS agencies), but these data are not consistently used to support quality improvement in the sector. These data need to be used more consistently for the measurement and monitoring of performance against the desired outcomes^{*}.

Measuring performance alone is not sufficient to encourage system change. The LHINs also need to report results against these metrics and develop funding strategies that hold providers accountable for the achievement of these goals. The LHINs and Health Quality Ontario are currently working together to develop system-level quality indicators and to ensure that these indicators are aligned across all sectors of the health system. This work should build on the Home and Community Charter provided in this report and include indicators for client and family experience.

^{*} NOTE: See Appendix F for examples.

^{*} Note: Outcomes are the results we expect from a high performing home and community care sector. Health system outcome measures include, for example, health outcomes, client and family experience and the cost. These outcomes are established by the MOHLTC.



14 **Recommendation 14:** That Health Quality Ontario, working in partnership with the Local Health Integration Networks, finalize and implement system performance indicators and, in consultation with providers and families, develop and implement a scorecard for the home and community care sector. The scorecard should be publicly reported, and all publicly-supported home care and community support service providers should be required to submit quality improvement plans on an annual basis.

Once performance indicators are implemented, the funders (MOHLTC and the LHINS) will have the tools they need to work towards a more accountable and high-performing home and community care sector.

15 **Recommendation 15:** That the Ministry of Health and Long-Term Care tie funding for home and community care services (e.g., home care, community support services, primary care) to the achievement of clearly defined outcomes and results.



IMPLEMENTATION CONSIDERATIONS

The recommendations in this report have the potential to transform home and community care in Ontario into a truly client and family-centered and high-performing system. Implementation of all of the recommendations can begin immediately, and most can be fully implemented within the medium term (i.e., two to three years). However, the paradigm and culture shifts required to achieve real system transformation will require time and effort and cannot be accomplished in the short run. This will be a complex and complicated initiative.

There are already many excellent and innovative strategies that have shown promise and might warrant broader implementation at this time. The Expert Group suggests that the LHINs review these strategies with the intent of determining which might be ready for system-wide implementation. (See Appendix F for examples.)

MOHLTC and the LHINs

In general, the Expert Group has identified the MOHLTC as being responsible for policies and actions that have a provincial reach. These actions include several immediate steps that are needed to signal to Ontarians that the MOHLTC is committed to beginning the proposed changes.

Recommendations in which the LHINs are asked to take responsibility are, in general, related to regional planning and the implementation of specific activities. The LHINs must work together to set those standards or, at least, to set a minimum standard. It will be important for the LHINs to work together to ensure that access to services is consistent across the province.

Enablers for the Implementation Plan

The Expert Group identified several prerequisites for the successful implementation of its recommendations:

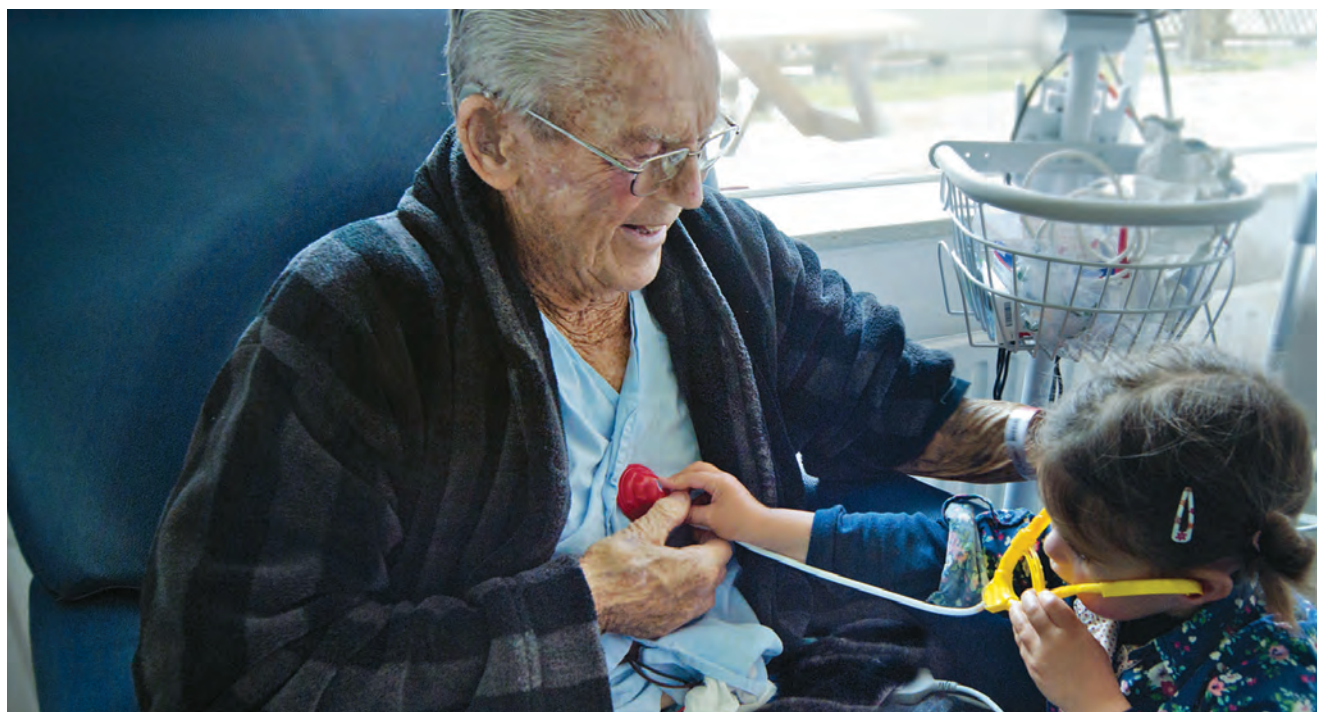
- The recommendations to the LHINs will require dedicated resources from within either the LHINs or sector partners. The MOHLTC will need to work with all of the LHINs to ensure they are ready to undertake these responsibilities and are supported as needed through this transformation process.
- Until all primary care providers are held accountable for the terms of their services agreement, primary care will not be fully and successfully aligned with home and community care.
- Research is needed to provide robust evidence for best practice in clinical care and service delivery models. Ontario needs programs like the Ontario Home Care Research and Knowledge Exchange to support and disseminate findings and train more scholars.
- System planning and evaluation, performance monitoring and research all require more comprehensive and reliable system-wide data collection on utilization and outcomes.
- A human resource plan is needed to address shortages of health human resources. Such a plan should address the lack of care providers in rural and remote communities and include strategies for closing the gap in wages across the province and between sectors and working towards sustainable full-time employment for workers in this sector.
- Every worker is entitled to a safe environment. When the work place is the client's home, it is more difficult to ensure a safe environment for both the client and the care provider. Strategies and policies are needed to provide a safe workplace for home and community care providers.



Managing the Implementation

The Expert Group recognizes that the implementation of its recommendations will require commitment, time and leadership to stimulate the paradigm and culture shifts required to transform the sector. For similar initiatives, the MOHLTC has appointed a provincial lead to guide the implementation of key strategies. The Expert Group endorses this approach in the implementation of the recommendations in this report.

16 **Recommendation 16: That the Ministry of Health and Long-Term Care appoint Home and Community Care Implementation Co-Leads (one Co-Lead from within and one from outside of the Ministry), with appropriate support, to guide and monitor the implementation of the recommendations in this report, reporting annually to the Minister of Health and Long-Term Care.**





BUT THAT'S ONLY THE BEGINNING...

The planning and delivery of home and community care to clients and families is complex and complicated. It was not possible in the five short months we had to complete our work to address every important issue in this sector. We offer this list to help guide the next steps in the health system transformation process and hope the Implementation Co-Leads, with support from the MOHLTC and the LHINS, will ensure these issues form part of the agenda for change.

Vulnerable Populations

Vulnerable populations are those who are at risk, who often suffer from stigma and for whom care and services are still not adequate. We heard from many respondents to our surveys that those populations need attention urgently, and we hope that the MOHLTC will support more work in these areas:

- We encourage the newly formed Ontario Mental Health and Addictions Leadership Advisory Council to include home and community care in its attention to and monitoring of the Ontario Mental Health Strategy.
- End-of-life care has received considerable attention in the media, and we heard many comments about need from our survey participants. Ontario has a number of creative programs in end-of-life care; the LHINS should examine those programs that work and plan system wide end-of-life home and community care. The LHINS should also consider the findings on palliative care reported in Ontario's Auditor General 2014 annual report³⁶.
- All care providers need to be mindful of the values and lifestyle of their clients, particularly for those who may be marginalized (e.g., new immigrants, the Lesbian Gay Bi Transgender Queer community, those with mental health or addiction issues). Care providers need training and education to understand these needs and to know how to deliver culturally sensitive services.
- Although representatives from First Nations organizations were invited to participate in our

provider consultations, the Expert Group did not engage directly with First Nations. It is clear that specific strategies and programs for home and community care need to be developed in partnership with First Nations people to ensure they have access to home and community care and that the services received are culturally sensitive. We encourage the LHINS to begin this process as soon as possible, where they have not already done so.

Caregiver Support

In **Bringing Care Home**, we pay special attention to the needs of unpaid caregivers, those individuals who are family, friends and neighbours of individuals receiving care. We know that these people work tirelessly to help their loved ones stay at home where they want to be. We also know that many are at risk of burnout or illness.

The Expert Group recommended a continued and increased emphasis on support, especially respite care; however, many more supports are necessary. We would like to see attention paid to relieving the financial and emotional burden on unpaid caregivers. This relief can come in a variety of ways, through tax benefits, employer assistance programs and incentives, some of which would be in the Federal Government's jurisdiction. We encourage the MOHLTC to explore the opportunities for enhancing support to caregivers.

The Future Structure of Home and Community Care

Although the issue of the structure of the home and community care sector was outside the mandate of the Expert Group, it was the subject of much of the feedback we received from clients, families and providers. Many told us that families have to deal with too many different agencies and that the current structure is cumbersome, has too much overlap, is not efficient and is not delivering the services they need.

We focused our attention on the functions in the sector and on what could be done to build on existing investments and programs. Restructuring – without functional changes – will not achieve the transformation

³⁶ Office of the Auditor General of Ontario. (2014). *2014 Annual Report*.



of the home and community sector that is needed. Indeed, a large-scale restructuring could also distract the sector from addressing these functional issues and potentially compromise service delivery during this period of change.

It is clear that the current structure is not working. The Expert Group has proposed that the sector's immediate efforts address the functional changes needed. If form follows function, we believe that the structure we need to enable and sustain these functional changes will become clear over time.

CONCLUDING REMARKS

The Expert Group found many 'pockets of innovation' in home and community care in Ontario, led by many individuals and organizations committed to providing quality care to the families they serve. However, these are often implemented on such a small scale that they cannot contribute in a meaningful way to the system-wide paradigm and culture shifts needed to ensure a high-performing system that is truly client and family centered as well as transparent and accountable.

Our recommendations help to define truly family centered care and how the system needs to support clients and families to thrive in the community. We have also made recommendations about how care providers need to work together and with families to deliver real family-centered care, how the system can support the circle of care in that role, and how we need to ensure accountability for delivering a high-performing home and community care sector in Ontario.

We can do better, we need to do better, and we need to change now.

APPENDIX A: EXPERT GROUP TERMS OF REFERENCE

Home and Community Care Vision Health Care Experts Draft Terms of Reference

Context

On January 30th, 2012, the Minister of Health and Long-Term Care released *Ontario's Action Plan for Health Care* (Action Plan) to ensure that supports and resources are in place for all Ontarians to maintain their health, have improved access and stronger links to family health care, and to receive the right care, at the right time, in the right place. The Action Plan's vision for person-centred care requires a strengthened community continuum and a shared commitment to achieving value and quality.

The Ministry has made significant progress towards the Action Plan. Key initiatives include implementation of 47 Health Links covering 650,000 complex, high needs patients; 30,000 more house calls; and more Ontarians with access to family doctors. However, additional progress in home and community care has been identified as an Action Plan and transformation priority, including enhancing the quality of home care services and offering a broader range of services in the community.

In support of the Action Plan and transformation, on Thursday, April 24, 2014, the Minister committed to a vision of home and community care (the Vision):

- *A reliable, robust and accessible home and community support system that is patient centred and highly integrated with the other health and community supports to allow Ontarians to live as well as possible in the community.*
- *A home and community support system that is accountable and transparent and provides value to both patients and taxpayers.* (Appendix A for the full text)

The Minister has invited several persons with key health system expertise to provide input to the Ministry on strategies to enable implementation of the Vision.

Accountability

Health care experts will provide input to the MOHLTC. The MOHLTC executive sponsor for this work will be Nancy Naylor, ADM, Health System Accountability and Performance Division (HSAPD). MOHLTC support will be led by the Implementation Branch (HSAPD) and includes administrative support related to coordinating orientation sessions, providing support in accessing interjurisdictional and other research/researchers in home and community care and participating in any patient/client consultations which may be organized by the Ministry.

Purpose

Health care experts will provide input to the Ministry on strategies to enable implementation of the Vision. The input should be provided in writing through a report providing several key recommendations. In developing its recommendations, the following should be considered:

1. Service variability – consider opportunities to reduce service variability and enhance transparency;
2. Price and investment variability – consider opportunities to address price and investment variability to maximize value and promote fairness; and
3. Innovation and new approaches to care delivery.

Process

The duration of this request for input will extend over a period of approximately 6 months, beginning in August 2014.

The health care experts' recommendations will be informed by:

- recent recommendations/reports to government related to home and community care sector, where opportunities exist to build on previous advice/activities;
- input from home and community care stakeholders; for example, client and caregiver associations, service provider associations etc; and
- other sources of leading evidence and research.

Health care experts are invited to participate and will be eligible for reimbursement of all eligible expenses in compliance with the terms of the Travel, Meal and Hospitality Expense Directive (no other remuneration).

Milestones

The Health Care Experts are expected to provide a progress update to the Ministry by October 31, 2014 and a final report on January 31, 2015.

Membership

Six health care experts selected to provide feedback:

- Gail Donner, Chair
- Joe McReynolds
- Cathy Fooks
- Kevin Smith
- Samir Sinha
- Donna Thomson

APPENDIX B: EXPERT GROUP MEMBERSHIP

Dr. Gail Donner is a Professor Emeritus and is the former Dean of the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. She is co-founder of donnerwheeler, a career consulting firm in Toronto. Gail has held a variety of positions in nursing practice, education and administration and has been active on a number of health care and community Boards and Committees. She has also held a number of government and community appointments, including External Chair, Long-Term Care Task Force on Resident Care and Safety; Member, Metro Toronto District Health Council Hospital Restructuring Committee; and Chair, Air Ambulance Review, Ministry of Health, Ontario.

Cathy Fooks is the President and CEO of The Change Foundation – a health policy think tank focused on improving the patient and caregiver experience. Prior to her position at the Foundation, Cathy was the first Executive Director of the Health Council of Canada. She has also served as the Director of the Health Network with the Canadian Policy Research Networks and in senior roles with the College of Physicians and Surgeons of Ontario, the Institute of Clinical Evaluative Sciences, the Premier’s Council of Health, Well-Being and Social Justice and the Premier’s Council on Economic Renewal. She was a senior policy advisor to two Ministers of Health.

Joe McReynolds is a principal consultant at McReynolds and Associates. Joe has extensive executive and governance experience in the not-for-profit and crown agency fields. Joe was the founding Chair and President of the Central West Local Health Integration Network, the CEO of the Ontario Community Support Association, Chair and Director with the Halton/Peel District Health Council and spent many years as a public sector senior executive in Social Services, Municipal Government and Economic Development and Trade.

Dr. Samir Sinha currently serves as the Director of Geriatrics at Mount Sinai and the University Health Network Hospitals in Toronto and also holds the Peter and Shelagh Godsoe Chair in Geriatrics at Mount Sinai Hospital. In 2012, Samir was appointed as the expert lead of Ontario’s Seniors Strategy to advise the Government of Ontario on how to support older adults to stay healthy and live at home longer. He is an Assistant Professor in the Departments of Medicine, Family and Community Medicine, and the Institute of Health Policy, Management and Evaluation at the University of Toronto and an Assistant Professor of Medicine at the Johns Hopkins University School of Medicine. Samir further serves as Chair of the Health Professionals Advisory Committee of the Toronto Central LHIN and Medical Adviser to the Toronto Central Community Care Access Centre.

Dr. Kevin Smith is the President and CEO of St. Joseph’s Health System in Hamilton and CEO of Niagara Health System. Kevin is an Associate Professor in the Department of Medicine, Faculty of Health Sciences at McMaster University. Kevin also participates in a number of provincial and national government bodies including the Association of Canadian Academic Healthcare Organizations and the Council of Academic Hospitals of Ontario, and is Chair of the Board of the Canada Foundation for Innovation. Kevin is a frequent advisor to governments and the private sector in health care, health research, public policy and governance.

Donna Thomson became a disability activist following the birth of her son, Nicholas, who has severe disabilities and is medically complex. Her book, “The Four Walls of My Freedom”, is a narrative of her own experience as a family caregiver as well as a reflection on the way our society cares for vulnerable citizens. Donna also cares for her mother. Donna is the Special Advisor for Caregiving at Tyze Personal Networks and is a Board Member of NeuroDevNet, a Canadian Centre of Excellence. She is the co-founder of Lifetime Networks Ottawa, a PLAN affiliate and a member of the Cambridge University Capability Approach Network. Donna is also an instructor at the Advocacy School in Ottawa, where she teaches families how to employ best practice political advocacy tools when advocating for care. She has spoken widely in Canada and abroad on disability and family wellbeing. Donna writes a blog, the Caregiver’s Living Room.

APPENDIX C: EXPERT GROUP APPROACH TO THE WORK

Review of Existing Literature and Reports

The Expert Group began its work by reviewing available published and grey literature and reports. Many of these reports were provided by the MOHLTC as background to the home and community care sector. Other reports were identified by members of the Expert Group, and yet others were submitted to the Expert Group by stakeholders. Additional materials were identified by researchers who were consulted regarding their work in the sector. In total, the Group reviewed over 200 documents.

Stakeholder Survey

The second step was to solicit input from a broad range of stakeholders through a public web-based survey, asking respondents about successes and challenges in the home and community care sector, and suggestions for innovation and improvement with the following five open-ended questions:

1. What are the three greatest sources of frustration for individuals in need and their families/unpaid caregivers who are receiving home and community care? What are the home and community care sector's three greatest successes? What specific change(s) could be made to address these frustrations and/or build on these successes?
2. What are three specific changes you believe would increase the coordination and integration of services (e.g., hospital transitions, primary care, home and community care, social services) for individuals in need and their families/unpaid caregivers so that they can be active participants in planning and managing their own care and be well supported in that role?
3. What are three specific ways that providers of home and community care could better meet the needs of individuals in need and their families/unpaid caregivers?
4. Health care consumes a significant portion of the provincial budget, and these costs are growing. What innovations and new approaches to care delivery could be made to maximize the value of our investment in home and community care? Where are the greatest opportunities for impact?
5. Please comment on any additional issue that is not addressed in the above questions but that you feel will help the Expert Group develop its recommendations.

Stakeholders were also invited to submit a completed survey by mail or email to the Expert Group. The survey was distributed directly to key stakeholders in the sector, as identified by the MOHLTC and through contacts of the Expert Group members. In addition, the Expert Group asked the LHINs to forward the survey to stakeholders within their geographic area. Many CSS agencies forwarded the survey to their employees and clients, and many associations forwarded it to their membership.

The Expert Group received 1,147 responses to the survey, including 56 from individuals receiving services and 191 from family caregivers. (See Table 1 in the body of the report.) Many organizations sent submissions to the Expert Group in addition to their survey responses.

LHIN-Assisted Public Engagement

As one component of its public consultations, the Expert Group asked each of the LHINs to reach out to individuals and families in their region to ask: *What is the single most important thing that the Ministry of Health and Long-Term Care could do to improve home and community care for you?*

All 14 LHINs sponsored public engagement on our behalf, including web-based surveys and a 'virtual café', as well as exploring the issue in other scheduled forums, providing feedback from 2,344 respondents, including 204 individuals receiving care and 358 families. These results were incorporated into the Expert Group's deliberations. The profile of responses from the LHIN consultations is shown in Table 1 in the body of the report.

Provider Consultations

The Expert Group also invited service providers to participate in two in-person sessions. The objective of the sessions was to provide the participants with a preliminary summary of the themes from the stakeholder consultations for validation and to solicit their expert opinions on how the health system could address the identified issues.

Seventy-seven representatives of service provider organizations, CSS agencies, CCACs and LHINs attended the two sessions, representing 47 organizations, as listed in Table D-1.

Table D-1: Organizations that Participated in the Provider Consultation Sessions

Addictions and Mental Health Ontario
Alliance of Professional Associations for Community Based Therapy Services
Alzheimer Society of Ontario
Association of Family Health Teams of Ontario
Association of Ontario Health Centres
Canadian Mental Health Association
Canadian Red Cross
Cancer Care Ontario
CBI Health Group
Central West CCAC
Centre for Addiction and Mental Health
Circle of Care
Closing the Gap Healthcare
Community and Home Assistance to Seniors
Dietitians of Canada
Erie St. Clair CCAC
Home Care Ontario
Mississauga Halton CCAC
Nurse Practitioners Association of Ontario
Ontario Association of Community Care Access Centres
Ontario Association of Non Profit Homes and Services for Seniors
Ontario Association of Social Workers
Ontario Association of Speech Language Pathologists and Audiologists
Ontario Brain Injury Association
Ontario Coalition of Senior Citizens Organizations
Ontario Community Support Association
Ontario Hospital Association
Ontario Long-Term Care Association
Ontario Nurses Association
Ontario Physiotherapy Association
Ontario Retirement Communities Association
Ontario Society of Occupational Therapists
Ontario Telemedicine Network
Provincial Council for Maternal and Child Health
Registered Nurses Association of Ontario
South West CCAC
SPRINT Senior Care
St. Elizabeth Health Care
Toronto Central CCAC
Toronto Central LHIN

United Senior Citizens of Ontario
VHA Home Health Care
Victorian Order of Nurses
Waterloo Wellington CCAC
West Neighbourhood House
William Osler Health System
Yee Hong Centre for Geriatric Care

Meetings With Subject Matter Experts

The Expert Group Chair met with 11 subject matter experts as list below.

G. Ross Baker, PhD, Professor, Institute of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto.

Susan Bronskill, MSc, PhD, Program Lead, Health System Planning and Evaluation Research Program, Institute for Clinical Evaluative Sciences.

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Analysis and Reporting

Expert Group members were provided with all of the reports and papers available to the group, the detailed and summary survey results from the stakeholder consultations and LHIN-assisted public engagement process, and all submissions. In addition, all Expert Group members participated in the two provider consultation sessions and received a summary of those proceedings.

The Expert Group also met twice with the LHIN Leadership Council to explore in more detail some of the system-level challenges identified through our consultations and potential solutions.

The Expert Group met six times in person and almost every week by teleconference to review the findings from the research and to develop conclusions and recommendations as documented in this report.

APPENDIX D: SERVICES INCLUDED IN MOHLTC DEFINITION OF THE HOME AND COMMUNITY SECTOR

The following lists are the services provided by the MOHLTC through the programs and service providers indicated, and limited to only those services that are defined as part of the Home and Community Care sector by the MOHLTC. These lists do not provide information on criteria for eligibility or the level of service that can be received by an individual.

1. CCAC services:

- Nursing services
- Physiotherapy services
- Occupational therapy services
- Speech-language pathology services
- Social work services
- Social service work services
- Pharmacy services
- Personal support and homemaking
- Related medical supplies and equipment
- Diagnostic and laboratory services
- Respiratory therapy services
- Dietetics services

2. Community Support Services (CSS):

- Meal services e.g. meals on wheels and community dining programs
- Transportation services
- Caregiver support services e.g. counselling and group support programs
- Homemaking
- Adult day programs e.g. for persons with Alzheimer's disease, post-stroke, frailty
- Home maintenance and repair services
- Friendly visiting services e.g. trained volunteers visit patients in their home
- Security checks and reassurance services e.g. trained volunteers call patient to check on their safety, wellbeing
- Social or recreational services
- Aboriginal support services
- Public education services relating to Alzheimer's and related dementias
- Patient intervention and assistance services (as defined in the regulations)
- Emergency response services (as defined in the regulations)
- Foot care services
- Home help referral services (as defined in the regulations)
- Independence training (as defined in the regulations)
- Palliative care education and consultation services
- Psychogeriatric consulting services relating to Alzheimer disease and related dementias (as defined in the regulations)
- Public education services relating to Alzheimer disease and related dementias
- Services for persons with blindness or visual impairment (as defined in the regulations)
- Services for persons with deafness, congenital hearing loss or acquired hearing loss (as defined in the regulations)
- Personal support worker services (effective July 1, 2014)

3. Assisted Living Services in Supportive Housing

4. Acquired Brain Injury Services

Source: Government of Ontario. (2014). *Foundation Briefing: Home and Community Service Sector [PowerPoint slides]*. Retrieved from Implementation Branch in Ministry of Health and Long-Term Care.

APPENDIX E: STANDARDS VS. STANDARDIZATION

Standards are the provincial performance specifications (established by the MOHLTC) that are expected to contribute to the achievement of the desired system outcomes:

- A minimum standard (e.g., all family caregivers must be assessed for the need for respite services and, if needed, these services must be provided) applies to all situations, and no jurisdiction should provide any less than the defined minimum standard of service.
- An average standard (e.g., a proposed “basket of services”) defines the average level of services required, ideally defined by population. The services provided to any single client and family will depend on need and may be more or less than the standard “basket”; however, the service should never be less than the defined minimum for any single service. The average “basket of services” should be used to establish the funding envelope for each LHIN.

Although **standards** are essential, **standardization**, where appropriate, is beneficial but not necessary:

- LHINs should have the flexibility to redefine the “basket of services” within the LHIN to reflect local or regional needs (e.g., allocate a greater proportion of funds to transportation in rural and remote communities), as long as the minimum standards are met. Similarly, at the client level, the “basket of services” can be tailored to meet the family’s unique needs (e.g., no meals but more personal support) as determined by the family and the care coordinator.
- LHINs should also have the flexibility to determine the best service delivery model(s) for the region, as long as the service standards are maintained.

APPENDIX F: SELECTED EXAMPLES OF INNOVATION IN HOME AND COMMUNITY CARE IN ONTARIO

The following programs are examples of innovation in the procurement or delivery of home and community care in Ontario. This selected list provides highlights of some examples where innovation currently exists in the sector. For more information on any program, click on the program name.

Program Name or Category	Sponsoring Organization(s)	Description
Client and Family-Centered Care		
<u>Caregiver ReCharge Services</u>	Alzheimer Society of Peel, Nucleus Independent Living and Links2Care. Caregiver ReCharge Funding support from the Mississauga Halton LHIN.	Primary informal caregivers who are exhibiting signs of extreme stress and/or burnout due to caregiving can contact the Central Registry for services in the Mississauga Halton LHIN to arrange for respite services.
<u>Changing the Conversation</u>	Toronto Central CCAC with its service provider partners	The approach to care uses open-ended questions to help home care staff understand what is most important to the clients they serve and then to adjust their care accordingly.
<u>Corporate Caregiver Support programs</u>	Employers	Corporations are encouraged to be creative in accommodating employees who are caregivers. These programs may include permission for a leave of absence, flexible shifts and hours (for example, transfer from night to day shifts), or transfer to a more convenient location.
<u>Culturally appropriate services</u>	Yee Hong Centre for Geriatric Care	The Centre plans and delivers high quality and culturally appropriate services to enable seniors to live their lives to the fullest – in the healthiest, most independent and dignified ways.
<u>Northumberland PATH</u>	The Change Foundation	In Northumberland PATH, patients and caregivers partner with providers across the community and system to co-design changes to improve healthcare transitions and experiences. A first for Ontario, the project shifts who and what drives healthcare change, and tests the difference it delivers.

Program Name or Category	Sponsoring Organization(s)	Description
Navigation and Coordination		
<u>Caregiver Framework for Children with Medical Complexity</u>	Led by Hospital for Sick Children in partnership with TC CCAC and Holland Bloorview Kids Rehabilitation Hospital Funded by the Toronto Central LHIN	The Caregiver Framework recognizes that navigating a fragmented care system may contribute to caregiver stress. This framework manages the immediate crisis, but also builds longer-term capacity and resilience through professional care managers who work with the family caregivers to identify problems, co-create solutions and anticipate what is needed to support the child with medical complexity.
<u>Caregiver Framework for Seniors Program</u>	Alzheimer Society of Toronto in partnership with the Toronto Central CCAC and CSS agencies	This framework aims to increase caregiver resiliency and capacity to continue to provide care. Care coordinators negotiate flexible support packages in consultation with caregivers to meet their self-reported needs.
<u>Wesway Caregiver Program – Family Directed Respite Funding</u>	North West LHIN	This program takes the approach that families are key resources and are most knowledgeable about the frequency, duration and type of breaks needed by family caregivers. It supports family caregivers by providing care for the child, adult or senior. Caregivers decide how they would like to receive respite care; Wesway pays for approved costs.
Integrated and/or Population-Based Service Delivery		
<u>Community and Home Assistance to Seniors (CHATS)</u>	CHATS is a not-for-profit charitable organization with more than 500 volunteers	Offers a full range of in-home and community services that enable seniors to continue living in their own home. Services include, for example, in-home help and care, Meals on Wheels, transportation, home safety services, wellness/social programs, diversity outreach programs, caregiver support and education, hospital-to-home transition.
<u>Health Links</u>	Ministry of Health and Long-term Care and the Local Health Integration Networks	This program provides coordinated, efficient and effective care to patients with complex needs who are high users of the health system. All health care providers work as a team to design an individualized, coordinated care plan for each patient and ensure that each patient has care providers who ensure the plan is being followed. Each has a care provider they can call who knows them, is familiar with their situation and can help.

Integrated and/or Population-Based Service Delivery (cont'd)

<u>Integrated Comprehensive Care Program</u>	St. Joseph's Health System (funded by the Ministry of Health and Long-Term Care)	This is a pilot project to test a model of integrated case management across hospital and community care and to develop a population-based funding model for specific clinical streams to incentivize the health care providers. The program offers client-centered care, care coordinators, integrated care team, shared electronic health record, simple technology, and access to medical care for post-acute populations.
<u>Integrated Palliative Care Program</u>	Toronto Central LHIN	This program was awarded the Minister's Medal Honouring Excellence in Health Quality and Safety for creating a single integrated care team around each client and family. In addition to increasing the number of palliative patients who achieved their wish of dying outside of a hospital, it also reduced the risk of emergency room visits and hospitalizations by 30%.
<u>SMILE</u>	South East LHIN	Developed in 2008 in consultation with seniors and health service providers, this program provides access to services for seniors and their caregivers that make it possible for frail seniors who are at risk of loss of independence to stay in their homes. Funded services include meals, housekeeping, shopping, laundry, running errands, transportation to and from health care appointments and seasonal outdoor chores.
<u>Supports for Daily Living</u>	Mississauga Halton LHIN	Supports for Daily Living is a resource manual for developing an effective assisted living program for high-risk seniors in any community.
<u>Toronto Ride</u>	Collaborative partnership of 14 not-for-profit CSS agencies. Funded by Toronto Central LHIN	Toronto Ride provides door-to-door transportation services in the Toronto area to seniors (55 years and older) and adults with disabilities who are not eligible for Wheel-Trans.

Program Name or Category	Sponsoring Organization(s)	Description
Technology Solutions		
<u>Mobile Innovation</u>	St. Elizabeth and Samsung Canada	This partnership provides Samsung mobile technology, including GALAXY tablets to health care workers who will use the devices to connect the circle of care in new ways, from scheduling appointments to planning and navigating routes to electronically recording patient data.
<u>MyChart</u>	Sunnybrook Health Sciences Centre	MyChart is an online website where patients can create and manage their personal health information based on clinical and personal information. Families can grant access to anyone they chose. The chart includes personal and family health details, online appointment requests, clinic visit notes, personal address book compiled by the patients, test results and links to relevant disease-specific information and online events.
<u>myPSW</u>	Privately owned	myPSW provides families direct access to a network of local PSWs and facilitates all transactions through the use of electronic time-sheets. myPSW requires all listed PSWs to provide an electronic facsimile of their PSW Certificate, police check and professional liability insurance.
<u>Tyze Connecting Care</u>	St. Elizabeth Health Care	Tyze is a private online community that is centered around one client and family. Families, friends, neighbours and health care professionals use a Tyze network to communicate and work together to care for that individual.

Program Name or Category	Sponsoring Organization(s)	Description
Programs for First Nations Populations		
<u>Dennis Franklin Cromarty (DFC) High School Suboxone Treatment Program</u>	Co-funded by First Nations and Inuit Health and the North West LHIN.	This project offers integrated treatment and supportive care for students from northern First Nations who are addicted to OxyContin. It provides clinical treatment, education and supportive care.
Diabetes Point of Care Testing ³⁷	North West LHIN	This program provides equipment and training for workers to conduct HbA1c testing within their home communities. Testing HbA1c is normally a several week process involving multiple appointments for the patient and shipping blood samples to external labs. Now, community nurses can conduct the same test with the patient present and receive results in 6 to 10 minutes. Testing is currently in use with four individual First Nations as well as several Indigenous health providers that serve various communities.
<u>Fort Albany Geriatric Clinic</u>	Project team included North East Specialized Geriatric Services (NESGS); Health Sciences North (Sudbury) and local providers	A specialist geriatric team travelled to Fort Albany on the James Bay Coast to conduct geriatric clinical assessments, in collaboration with local providers in patient-focused clinics, to assess 27 elders. The team developed a geriatric assessment tool specifically for Aboriginal people, and created individual care plans that local health care professionals can implement, with ongoing support provided through telemedicine appointments. In addition, the team will provide training to Peetabek Health Services and WAHA staff to aid in providing continuity of care beyond the life of the clinic.
<u>Grow your Own PSW Program</u>	Partnership of Red Cross, Moose Cree Education Authority, Mushkegowuk Employment and Training Services, Moose Cree First Nation, Peetabek Education Authority, Weeneebayko Area Health Authority (WAHA), Fort Albany First Nation and Northern College. Supported by the North East LHIN	A culturally appropriate PSW training program was delivered in the communities of Moose Factory and Fort Albany that was designed to have the students working at the same time as they train while remaining in the home community. The North East LHIN also supported the students' participation in specialized diabetes foot-care training, which was important due to the high prevalence of diabetes in the James/Hudson Bay area.
<u>New First Nation Assisted Living for High Risk Seniors Programs</u>	North East LHIN	This "hub and spoke" service delivery model allows assisted living services to be delivered to 10 high-risk seniors in seven First Nation communities spanning across 300 kms along the north shore.

³⁷ No website available.

Home & Community Care –

We can do better, we need to do better, and we need to change now.