what is most important?
the health of Ontarians
and their right to participate
as partners in determining
their care
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,

Dr. Gail Donner, Chair
Dr. Kevin Smith

Cathy Fooks
Dr. Samir Sinha
Donna Thomson
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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
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.

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
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 system1,2. 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

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* 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.


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.
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.

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**Table 1: Profile of Survey Respondents**

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<tr>
<th>Category</th>
<th>Expert Group Survey</th>
<th>LHIN-assisted Public Consultations</th>
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<tbody>
<tr>
<td>Individuals receiving care</td>
<td>56</td>
<td>204</td>
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<tr>
<td>Family members and other unpaid caregivers</td>
<td>191</td>
<td>358</td>
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<tr>
<td>Individual care providers</td>
<td>389</td>
<td>475</td>
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<tr>
<td>Others (e.g., associations and organizations)</td>
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<td>121</td>
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<tr>
<td>Did not specify</td>
<td>71</td>
<td>1,186</td>
</tr>
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<td>Total</td>
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*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 Act. 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), 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.

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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.”

In Ontario, 3.3 million men and women are 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 care.

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 care.

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 support.

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 fee.

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

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 province.

While the MOHLTC has increased funding to CCACs overall by 99% since 2003/04 (an annual average increase of 5.6%), the number of individuals receiving services through CCACs has actually doubled over the same period. 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.

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7 General Social Survey. (2014). Data tables Ontario from the Results from the General Social Survey. The Change Foundation.
11 Ministry of Health and Long-Term Care, 2014.
14 Table 3: Individuals Served by Organization, CCAC MIS Comparative Reports 2013/2014YE (MOH Health Data Branch Web Portal).
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)\(^\text{16}\).
- From 2009/10 to 2011/12, the number of patients waiting for long-term care in Ontario hospitals decreased 32% from 3,145 to 2,141\(^\text{17}\).
- 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 1,000\(^\text{18}\).

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\(^\text{19,20}\)**

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


“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)
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.
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 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 consooler, 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 caregivers\textsuperscript{21}. 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 periods\textsuperscript{22}.

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.


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.

**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 making.

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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 literature\(^24\). 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.

**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.