

# HEALTH COMES HOME: A CONVERSATION ABOUT **THE FUTURE OF CARE**

PART 1



# COMING TOGETHER IS A BEGINNING; KEEPING TOGETHER IS PROGRESS; WORKING TOGETHER IS SUCCESS.

- HENRY FORD

Ontario's health care system, like health care systems across the world, is in transition. Advances in health knowledge, practice, technology and pharmacology are helping people to live well longer and have more of their health care needs met in their homes and communities, rather than more traditional care in institutions. The profile of needs is changing from episodic illnesses to the long-term management of chronic diseases. In 2016, seniors will make up a larger share of Ontario's population than children under the age of 15 years and by 2027, the first of the Baby Boom Generation will turn 80.

This will be a different generation of seniors, comfortable with technology and with different expectations for a health care system that engages them and adapts to their needs and preferences. Over the next 25 years, the arrival of new people will account for almost three-quarters of the population growth in Ontario. As our province ages and becomes more diverse, our health care system must adapt to changing needs and public expectations for choice, flexibility, quality and value for money.

Given these realities, many people – patients, family caregivers, governments, health care providers and citizens at large – are concerned about how we will provide high-quality, affordable health care in the future. These questions present very real challenges, but also offer important opportunities to begin a thoughtful dialogue about how to effect a positive and lasting transformation of Ontario's health care system. To bring about this transformation, we must begin to build the foundation today.

This is the first in a series of papers Ontario's Community Care Access Centres will develop that are intended to serve as a starting point for a broad dialogue on how we can tackle the common challenges and harness the opportunities – with a

shared understanding of where we are going and resolve to take the journey together. In developing this series of papers, we talked to health system thought leaders, health care providers and, most importantly, patients and their caregivers. We also looked at evidence and considered the experience of other jurisdictions in Canada and the world.

In this initial paper, we will embark on making the case for change and look at the beginnings of transformation that are already taking place in Ontario. Future papers will consider health system transformation through the lens of four patient populations: seniors with complex health needs, people with chronic health care needs, people who need hospice palliative care and children with complex health needs. Through our research and interviews, we have distilled a set of questions that we believe will offer a starting point for discussion and debate on the best way to move forward together:

**What should we expect from our health system?**

**How will we come together to meet the needs of patients?**

**How will we pay for a transformed system?**

**How will we value and care for our informal caregivers?**



# FUNDAMENTAL TRUTHS SHAPING THE FUTURE OF HEALTH CARE

While the questions raised in this paper will be considered in the context of the next 5 to 25 years, it is important to recognize that Ontario has begun transformational change in all of these areas, guided most recently by *Ontario's Action Plan for Health Care* and the *Seniors Strategy*. There is broad agreement that a strengthened home and community care system is a critical component of sustainable health care designed to support the continuum from primary to acute to tertiary care. There is also growing consensus that better, more integrated health care models are needed for the most complex patients. While strong systems will always be required to support patients with acute needs, there is growing recognition that we cannot afford to ignore the importance of health promotion and wellness to prevent or delay the need for more costly health care.

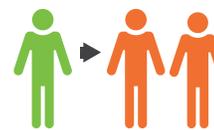
Home and community care is increasingly recognized for its ability to respond to a wide range of needs and to address the universal and passionate desire of patients to receive care at home whenever possible while also reducing the cost of providing health care. Home and community care is well established to be less costly than care traditionally provided in acute or other institutions. While recent investments in home and community care have been made and have been valuable, it will take time, investment and collaboration among all partners and stakeholders to realize the full potential of a reoriented health system.

In building a more connected and effective health care system that delivers high-quality care, we believe that there are some fundamental truths that need to be addressed that will shape how health care is delivered in the future.

## Shifting demographics will require new approaches to caring for Ontarians

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number of centenarians will triple and the number of adults aged 85 and older will quadruple. By 2030, more than 1 in 5 Ontarians will be seniors, compared to just fewer than 14 per cent today.<sup>1</sup> To address this reality, our current health care system must evolve to one that will better address the burden of chronic disease and the reality of age-related health challenges. The challenges posed by an aging population are not limited to an increased number of aging citizens who become ill and require health care services. The caregivers who provide the majority of care for seniors and others with health challenges are getting older as well, as is our health care workforce. The average age of family physicians and registered nurses in Canada is just over 50 years and just over 45 years, respectively.<sup>2</sup> Only one-quarter of Ontario's personal support workers, who provide the lion's share of in-home care for seniors, are under the age of 40 years.<sup>3</sup>

A number of reports have highlighted that a small proportion of the population account for a large share of health care expenditures.<sup>4</sup> While the majority of high-cost patients are seniors, it is important to remember that this group actually represents a small minority of the overall seniors' population.

"If left unaddressed, our demographic challenge could bankrupt the province. This means our demographic challenge should be seen as a demographic imperative, which amounts to an enormous opportunity for Ontario to better understand and meet the needs of its aging population."

Dr. Samir Sinha, *Living Longer, Living Well*.

<sup>1</sup> Ontario's Long-Term Report on the Economy, Ontario Ministry of Finance, June 2010.

<sup>2</sup> Canadian Institute for Health Information.

<sup>3</sup> "Ontario Personal Support Workers in Home and Community Care: CRNCC/PSNO Survey Results."

<sup>4</sup> Five percent of Ontarians account for 66% of the expenditure on health care in Ontario. Institute for Clinical Evaluative Sciences. Wodchis, W et al. 2012. High Cost Users of the Ontario Health System: Preliminary Analyses. Toronto, Ontario.



## 5% OF ONTARIANS ACCOUNT FOR 66% OF THE EXPENDITURE ON HEALTH CARE IN ONTARIO

This fact makes it imperative that our society take advantage of opportunities to support people to stay well and maintain independence, recognizing that health is about more than health care. We need to be aware that income security; strong, safe communities; and stable housing are important contributors to good health and need our collective attention.

Seniors are not the only population driving the need for change in our health care system. Through advances in care, more and more children with complex health conditions and disabilities are living successfully in the community and surviving into adulthood. As they approach adulthood, they and their family caregivers face what is currently a difficult transition from the children's service system to an adult system that is not currently organized or resourced in the same way to meet their health and support needs.

Ontario's population is also becoming more diverse. Ontario can already claim the most culturally diverse population in Canada.<sup>5</sup> Over the next 25 years, new Canadians will make up an increased share of Ontario's population, particularly in urban areas.<sup>6</sup> This diversity will have implications for people's choices and preferences in the delivery of health care.

As the population ages and becomes increasingly diverse, it is essential to recognize the changing health needs of our citizens, and understand how critical it is to create flexible, collaborative care models to better serve those who need the system most. Ontarians have been clear in their desire to

have health care delivered as close to home as possible, and to live in their own homes for as long as possible. This means ensuring access to robust, flexible, responsive care in the home and community, designed to meet these changing needs – including a hospice palliative care system that supports people who wish to die in their own homes. In short, we need to prepare now to build a health care system that will more effectively and economically meet the needs of Ontarians in their homes and communities, including our highest-needs patients.

### We will need to deliver more effective health services for less money

Of the Organization for Economic Cooperation and Development (OECD) countries, Canada is among the top in health care spending. In spite of this, our overall health results are not matching this investment. For this level of investment, Ontarians are increasingly calling for more accountability and they expect health outcomes that realize the full potential of the health care system. Health system planners and providers are increasingly expected to demonstrate their effectiveness and that they are spending taxpayer resources efficiently.

Ontarians, like all Canadians, value our publicly-funded health care system. At the same time, it is understood that economic and demographic pressures and trends will continue to challenge the “universality” of the health care system. Income disparities and inequitable access to health services not covered by public health insurance in Ontario can cause variations in health outcomes among the 20-30 per cent of citizens that do not have supplemental or employer insurance.<sup>7</sup> These challenges need to be met while at the same time ensuring the ongoing sustainability of the health system. Our health care system must do more for less, while continuing to drive effectiveness, quality and transparency.

#### Health Facts

- More than 1 in 10 Canadians self-report their health status as poor or fair
- Almost half of Canadians aged 65 years or older report having two or more chronic diseases
- More than 1 in 3 Canadians over the age of 45 years provide informal care to a senior
- Although 90 per cent of Canadians indicate that they would like to die at home, 70 per cent die in hospitals or long-term care homes

<sup>5</sup> Ontario Ministry of Citizenship and Culture, [www.ontarioimmigration.ca/en/about/OI\\_ABOUT\\_PEOPLE.html](http://www.ontarioimmigration.ca/en/about/OI_ABOUT_PEOPLE.html)

<sup>6</sup> Ontario Population Projections Update: 2012-2036 Ontario and Its 49 Census Divisions, Ontario Ministry of Finance, Spring 2013.

<sup>7</sup> Life and Health Insurance Industry Fact Sheet, Canadian Life and Health Insurance Association, 2012.

Recent economic analyses suggest that while some Canadians are saving more, the debt burden remains high and the average debt is growing more for seniors than any other age group.<sup>8</sup> In August 2013, a CIBC survey indicated that more than one-third of parents with children under the age of 25 years will have to work longer and sacrifice retirement savings to help their children with education costs. The gap between the richest 10 per cent and the poorest 10 per cent of Ontarians is widening.<sup>9</sup> These trends and disparities must be included in our considerations as we make choices and prioritize the competing values of our health care system. This will include difficult debate about what services are paid for from the public purse, and what the standard of available services should be across the province in the years to come.

### **We have a more empowered citizenry wanting to be engaged in making choices about their own health and health care**

A shift in the dynamic between the individual and the health care provider is well underway. Increased access to information empowers patients and families to learn about their health and their health care options. Although the knowledge gap between the average individual and his or her care provider is unlikely to close completely, more people are seeking to understand their options to make the best decisions together with their health care providers. Health system providers therefore need to embrace and encourage their patients' active participation in managing their own health care needs. Health system planners and those who are educating the providers of the future need to consider the implications of this changing relationship.

More engaged and informed patients and families increase expectations for the system as a whole, including expectations for flexibility and choice in the delivery of care. Customer service expectations that are traditionally seen in other industries, such as retail, restaurants and hospitality, are increasingly influencing the health care sector. These expectations will have important implications for Ontarians' overall level of satisfaction with their health care providers and the health care system. Patients and families are asking difficult questions about the availability of services in their region or why the nature of service offerings differ based on where they live. Recognizing the opportunities created by this shifting dynamic will be an important element in designing the health system of the future.

### **Technology will be a critical enabler of higher quality care and cost efficiencies**

The rapid pace of technological innovation will continue to shape possibilities for delivering care. More than ever before, technology has the potential to transform health care delivery models. It can electronically integrate fragmented health records to allow care providers to safely, effectively and efficiently share patient information, including with patient and caregivers. It can support the implementation and standardization of leading care practices, reduce duplication, and enhance quality of care and patient safety. And it can help build capacity to coordinate and manage care to best meet the needs of patients, directly and at a distance through tele-health and tele-home care technologies. It can also empower patients to engage with their health care providers and more effectively manage their own care.

Advancements in clinical information systems and analytics allow the system to provide data that supports decision making in real time to manage risks and keep Ontarians as healthy as possible. It also allows for better system-wide planning based on current and reliable data.

Other examples of advancements in technology include:

- Diagnostics and treatments that allow less invasive care, which results in greater patient comfort, lower care costs (e.g., cataract and laparoscopic surgeries) and shorter hospital stays.
- Medical technologies that allow care to be provided in the home and community that would otherwise have only been provided in hospitals or long-term care homes (e.g. management of patients who are on chronic ventilation systems).
- Integration of medical equipment and information systems that directly capture important patient care data, which allows remote monitoring and care from within a patient's home.

Investment in these technologies and others to come will be essential for addressing the future health needs of Ontarians. Tomorrow's seniors and caregivers will have integrated smart phones, tablets and whatever the next generation of personal technology offers into their daily routines. At every level, from the patient to the individual provider to the system, we must embrace the potential that technology offers and reduce the barriers to its adoption.

<sup>8</sup> Equifax Canada's Q2 2-13 National Consumer Credit Trends Report.

<sup>9</sup> Ontario's Growing Gap: Time for Leadership, Armine Valnizyan, Canadian Centre for Policy Alternatives, May 2007.

# TRANSFORMATION INITIATIVES UNDERWAY

The fundamental truths that are shaping the future of health care are informing health care system transformation efforts now underway in Ontario.

The recently announced investment of \$700 million by 2015-16 to reduce wait times for home care and provide options for care closer to home is evidence of some initial steps taken to shift traditional service delivery models. It recognizes that a strong home and community sector is a key component and contributor to a high-performing health care system.

As the health system seeks to support patients in their homes and communities, we will need to ensure that a flexible range of home and community care can be appropriately scaled and resourced to handle the increased complexity and volume of patients in the years to come. The impact of the shift to more complex home and community care on other parts of the health care system will also need consideration.

**Our shifting demographics will require new approaches to caring for Ontarians**

- Improved access to exercise classes and falls prevention
- Investment in home and community care
- Increased focus on innovative, coordinated care delivery for the most complex patients (e.g., Health Links)
- Development of evidence-based standardized care pathways

**We will need to deliver more health care for less money**

- Gradual shift from traditional global funding mechanisms to patient-based, outcome focused funding models where “money follows the patient” through health system funding reform
- Shift of care into alternative care settings that are less expensive, deliver quality and create capacity to better meet the needs of patients (e.g., virtual wards, Ontario Telemedicine Network, Independent Health Facilities, home monitoring of patients)
- Policy enabling health care providers to maximize their scope of practice

**A more empowered citizenry will be more engaged in making choices about their health care**

- Increase expectations for health providers to adopt a strategic focus and build cultures that focus on patient safety, quality and the overall health care experience
- Public reporting standards that make information more accessible and increase the overall transparency of operations and performance

**We must embrace technology as a critical enabler of high quality care and cost efficiencies**

- Investment in new diagnostic and monitoring technologies that link patients and providers and enable patients to receive care in their own homes
- Increased connectivity across the health care system and progress towards an electronic health record that will improve access to patient information and improve quality and safety

# THE CHALLENGE AHEAD

Incremental change will not likely move us far enough or fast enough to address future needs. Competing stakeholder priorities, conflicting legislation, fragmented accountability, and misaligned funding incentives are all significant barriers to meaningful health system transformation.

Given the need for transformation and a long-term vision, we asked health system leaders from across Ontario and Canada to provide their perspectives on what it will take to prepare Ontario for the inevitable growth in demand and expectations for home and community care. The experiences of other jurisdictions were examined, as were developing innovative practices from Ontario. This process uncovered important foundational questions that will need to be addressed in preparing for the future.

## How will we come together to meet the needs of patients?

There are a number of examples across the province of improving the quality of care and the efficiency of service delivery through collaboration among health care providers. Evolving care models, such as Health Links, are examples of efforts to connect providers and build shared approaches to caring for patients. However, many questions still remain about how to build a health care system that is flexible enough to address local health needs, that fosters innovation and that standardizes measures of access and quality of care.

It is widely recognized that to improve the health of our citizens, we need to not only continue to better integrate health services but expand our thinking to include a more proactive focus on health promotion and wellness as critical components of our care delivery models. Our health system must evolve into one in which:

- The patient and his/her caregivers are integral to the health care team, participating in all matters that affect them
- Primary care is integrated with other players across the health system

- Home and community care optimizes its capabilities to handle the increasing demands of more patients and more complex care needs
- Our institutions are supported in focusing on providing care to people with the most acute and complex needs

To accomplish this, it will be essential for all sectors to come together and provide value that is greater than the sum of its parts. We need to ask, what is the best way to achieve that, and what are the steps to getting there?

Forward-looking human resource planning is necessary to ensure that Ontario will have the capacity and skills to adapt to changing roles, increased diversity and the unique needs of seniors and other patient populations with complex, long-term needs.

Increased focus and attention on the social determinants of health (such as childhood environments, income, availability and quality of education, food, housing, employment, working conditions and social services) and their effects on health are another aspect of our health system in transition. We will need to create the conditions in multiple areas of society for citizens, police, municipal housing, and other key players to work together to improve health and health care. It will require professional associations to provide support for their members to be innovative and maximize their potential contribution. It will require government to reexamine and reframe its current mandate, legislative, and funding models to enable greater collaboration and transformation.

### Local Health Services in Ontario

- 155 hospital corporations operating 211 sites
- 14 Community Care Access Centres
- Over 600 long-term care homes
- Over 12,000 family physicians operating in a variety of models, including 170 Family Health Teams and 32 Community Health Centres
- Thousands of community support service agencies, supportive housing and assisted living programs, community mental health and addiction programs and other community services.

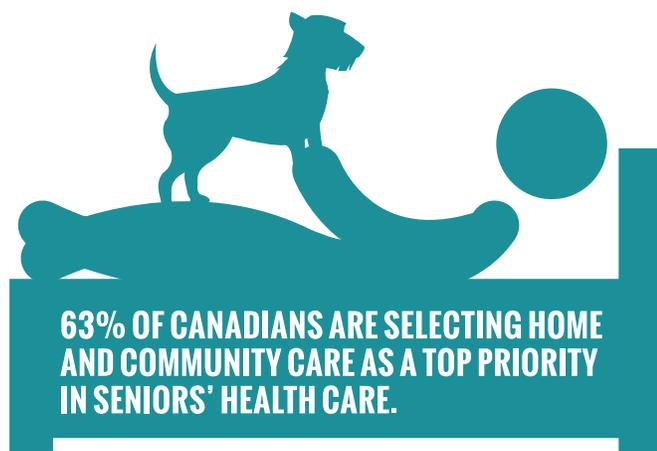
## These and other measures will help us come closer to answering the question:

*How will we come together to meet the needs of patients?*

### What should we expect from our health care system?

Medicare in Canada established funding arrangements between the Federal government and the provinces for the cost of diagnostic services, medical and hospital care services built around the fundamental principles of universality, comprehensiveness, accessibility, portability and public administration. Home and community care, including long-term care, and other important parts of the system, like pharmacare, are currently outside of this framework.<sup>10</sup>

Ontarians truly value their local hospitals and see them as a safety net for their community. While hospitals provide excellent care for patients in need of acute services, they are not ideal settings for people after their acute care needs are met. Staying in hospital longer than necessary can place patients at risk for hospital-acquired infections and for becoming deconditioned as the result of long periods in bed. It is also not a good use of acute care capacity.



Increasingly, the public is recognizing the value of a more robust home and community care system, with 63 per cent of Canadians selecting home and community care as a top priority in seniors' health care.<sup>11</sup> There is broad agreement on the need to

invest in a home and community care system that can handle the increased complexity and volume of patients. At the same time, given rising public expectations for flexibility and choice in the delivery of health care, we need to begin the difficult discussion about what services will be provided and funded by the public health system and what patients may be required to subsidize or pay for out-of-pocket—and how do we protect equity of access.

## As we prepare for the future we need to engage Ontarians to consider the question:

*What should we expect from our health care system?*

### How will we pay?

An ongoing area of focus for government and health care professionals is the way that money flows from government to health service providers to ensure that Ontarians get the health care they need—that is, how do we *fund* health care? Through health system funding reform we must continue to shape service delivery models and align incentives to ensure that appropriate care is provided in the right setting to achieve the best health outcomes at the lowest cost. This includes creating incentives to shift care from institutions to home and community settings, changing current reimbursement structures to encourage innovation and enable proactive outreach and wellness programs, and developing alternative ways to engage with patients, such as by telephone or email.<sup>12</sup>

A less frequently raised question is how we will continue to finance or pay for our health system? Today, approximately 30 per cent of health spending in Canada is funded privately or from supplemental and employer insurance for services that include private hospital rooms, dental care, prescription drugs, vision care and physiotherapy.<sup>13</sup> If we agree that the established norm of 30 per cent of health spending be paid for outside the public system, this will have important implications for society and individuals. As the population ages and is increasingly accessing services not traditionally paid for by the public sector, how will individuals make up the difference and how will we ensure equitable access?

<sup>10</sup> Simpson, Jeffrey. *Chronic Condition: Why Canada's Health Care System Needs to be Dragged into the 21st Century*. Toronto: Penguin Group, 2012.

<sup>11</sup> 2013 National Report Card. Ontario Medical Association and Ipsos Reid Public Affairs. August 2013.

<sup>12</sup> Ministry of Health and Long-Term Care, 2007.

<sup>13</sup> <http://www.oecd.org/els/health-systems/Briefing-Note-CANADA-2013.pdf>

According to a recent Canadian Medical Association poll, two-thirds of Canadians reported that they could not afford home care or institutional care.<sup>14</sup> Most reported that they would need to rely on the public system to provide nursing home, institutional and home care. Given rising expectations for choice and flexibility in their care options, Ontarians may well increasingly need to assume more financial responsibility for the cost of their care.

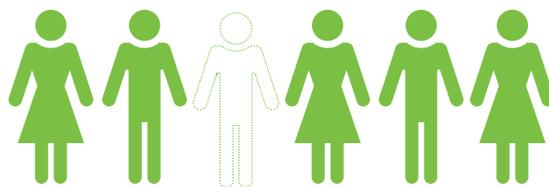
The implications of this go beyond the individual requiring care and have significant implications for the expectations of, and burden on, families or informal caregivers; who are already providing approximately 75 to 80 per cent of the care patients receive at home. This will also have economic consequences for workforce productivity and absenteeism of these informal caregivers.<sup>15</sup>

As a health system and society, we will need to clearly communicate the services provided by the public health system and initiate new approaches to encouraging individuals to plan and prepare for the cost of their care needs in the future. There is a need to raise the level of dialogue around the plans Ontarians will need to make for their health care future. In a recent report by Dr. Samir Sinha to the Ministry of Health and Long-Term Care, *Living Longer, Living Well*, Dr. Sinha recommended that Ontario “explore the implications of developing an income-based system towards the provision of home care and community support services” with the goal of creating a system that can “prioritize the principles of access, equity, choice, quality, and value.”

There is a range of options for Ontario to consider as to how we will pay for our health care system and, as part of that system, home and community care services. Below are five models from OECD countries with predominantly public health financing<sup>16</sup>:

1. *Public systems* funded through general tax revenues (e.g. Canada, Denmark, Finland, Ireland)
2. *Social insurance systems* funded through mandatory contributions; percentage of income often contributed by employers and employees (e.g. Germany, France, Netherlands)  
- These universal health care systems achieve a measure of income and risk distribution
3. *Private, not-for-profit* insurance funded through voluntary contributions in a competitive market, administered by private corporations that do not distribute profits
4. *Private, for-profit* “commercial insurance” funded through voluntary contributions in a competitive market, administered by private corporations that distribute profits to their owners (shareholders)
5. *Patient co-payments or “user pay” mechanisms and/or tax-sheltered health savings accounts.*

## ONE IN SIX ONTARIANS



AGED 45-64 REPORTED MANAGING  
ANOTHER PERSON'S CARE NEEDS OR  
ASSISTING WITH PERSONAL CARE,  
MEDICATION OR OTHER MEDICAL CARE.



<sup>14</sup> 2013 National Report Card. Ontario Medical Association and Ipsos Reid Public Affairs. August 2013

<sup>15</sup> <http://www.cbc.ca/news/health/story/2013/08/19/aging-doctors-poll.html?cmp=rss>

<sup>16</sup> Flood, Colleen. Exploring Social Insurance: Can a Dose of Europe Cure Canadian Health Care Finance? Montreal: McGill-Queen's University Press, 2008.



### HOME CARE IN GERMANY AND THE USE OF THE PRIVATE SECTOR FOR DELIVERY OF SERVICES

Germany's universal multi-player health care system has 90 per cent of the population covered by statutory health insurance, with the remaining citizens with higher income or who are self-employed using private health insurance. Health care spending as a percentage of GDP is the same as in Canada, even though Germany has a greater percentage of its population over 65 years old. For home care, Germany uses quasi-market mechanisms to increase competition with providers and to promote quality and choice and reduce costs. For example, if a person is eligible for long-term care insurance, he/she can choose to: receive a payment in cash, have a package of care services in-kind delivered by an agency, or combine the two options. Germany freezes benefit levels so that as costs rise, the increasing gap that develops is met by individual contributions.



Ontario is not alone in facing these challenges. Some examples of how other jurisdictions are developing approaches to paying for home and community care can be found in Germany, England and Quebec<sup>17</sup>:



### QUEBEC'S PROPOSED AUTONOMY INSURANCE

To address the fact that Quebec has the world's second fastest rate of population aging, the Government of Quebec proposed creating autonomy insurance, which would provide home care services through a protected funding mechanism that optimizes resource allocation. The insurance would be available to seniors with functional or cognitive loss of autonomy, adults with physical disabilities, and adults with intellectual disabilities. The insurance would be funded through the annual government amount available for long-term services, user fees, and fiscal expenditures equal to Quebec's Tax Credit for Home-Support Services for Seniors.

### INSURANCE SYSTEM FOR ELDERLY CARE IN ENGLAND

In light of the aging population in England (the number of people aged over 85 will double by 2030), plans are underway to create a universal state-backed insurance system for elderly care, which aims to cap costs for one in eight pensioners and cut bills for the wealthy. The social insurance scheme will have elderly people pay premiums, depending on their wealth and whether they receive care in the home or in a care facility. Costs per person will be capped at \$110,000 (US). The plan is geared towards supporting those with lower socioeconomic status and people who are qualified for care, but in the past were considered too wealthy to get social support.

Finally, private-sector organizations continue to view health care as an attractive area for innovation and investment. Public advertising is replete with examples of new products and services geared to supporting aging and care in the home and community, including home safety products and services, personal health technology and supported living environments, such as retirement homes. Thoughtful discussion should be devoted to the role that appropriate private investment can play in advancing our common health system aims.

### How can Ontario use private-sector interests and investment to complement the public health care system?

Building on the progress on funding reform in Ontario, the experience of other jurisdictions and the potential for broader private sector engagement, we must continue to focus on the question:

*How we will pay for our future health care system?*

<sup>17</sup> La Direction des communications du ministère de la Santé et des Services sociaux. "Autonomy for All: White Paper on the Creation of Autonomy Insurance." Gouvernement du Québec, 2013.

Ramesh, Randeep. "Elderly care revolution as state-backed insurance scheme announced." The Guardian. July 18, 2013.

Australian Government. "Report on the Operation of the Aged Care Act." <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-roaca-10-toc-~ch2>

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Tarricone, Rosanna, and Agis D. Tsouros. "The Solid Facts: Home Care in Europe." World Health Organization, 2008.

## How will we value and support caregivers?

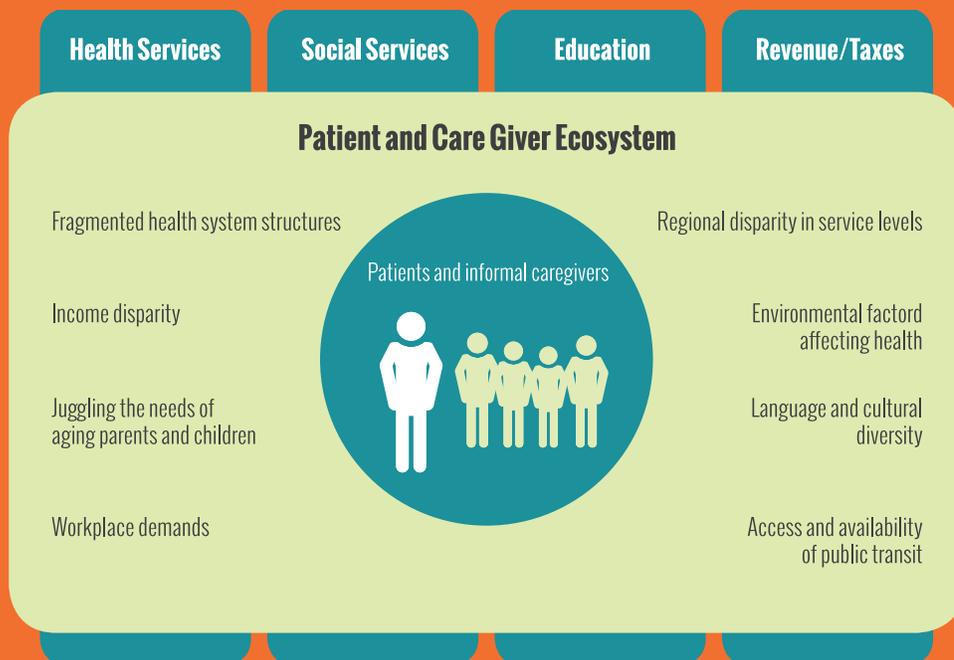
The home and community care system cannot function without the critical contribution of informal caregivers, such as family and friends. As our efforts to shift care out of hospitals into the home and community evolve, the home and community care sector is increasingly supporting more patients who have complex health needs. This shift also creates greater expectations for family members and other informal caregivers to absorb a higher burden of care and cost.

Often, these caregivers are not compensated and remove themselves, temporarily or permanently, from the workforce, thus negatively impacting their personal well-being as well as our economy. For example in 2007, Canadian businesses reportedly lost over \$1.28 billion in productivity as a result of caregiver absenteeism, quitting and/or job loss.<sup>18</sup> There are also considerable personal and societal costs in poorer health status and emotional well-being of caregivers.

As Ontario's informal caregivers age, their ability to provide the care and support to patients in the community will be reduced. Looking to the future we must also recognize that family structures and traditional support networks are changing. The 2006 Canadian census revealed that there were more unmarried than married Canadians, and nearly 43 per cent of households had no children. We will need new models of caregiving and increased volunteerism to ensure a vibrant home and community care system in the years to come.

In examining the role and complexities faced by our informal caregivers, we will need to continue to find ways to better support them and more effectively coordinate the home, community, health and social service supports around them. It will be important to look at opportunities beyond the traditional health and community support systems and engage new partners to consider innovative employment, housing and community planning models that support caregivers in their roles.

## Societal Tools/Lever



Nearly 3.1 million Canadians were estimated to have provided informal care to home care recipients in 2007. They provided over 1.5 billion hours of informal home care across Canada—more than 10 times the number of paid hours provided that same year.

*Canadian Alliance for Sustainable Health Care report on Home and Community Care.*

One in six Ontarians aged 45- 64 reported managing another person's care needs or assisting with personal care, medication or other medical care.

*Dr. Parminder Raina, "Why Not Now? A Bold, Five-Year Strategy for Innovating Ontario's System of Care for Older Adults." Long Term Care Innovation Expert Panel.*

As a society, we also need to start a conversation about what are reasonable expectations for families and friends, and consider how changing family and social structures will affect caregiving in the future. We must ask, What else can, should or must we do to support Ontario's caregivers?

<sup>18</sup> Leaders Collaborative, "Advancing High Quality, High Value Palliative Care in Ontario," 2011.

# MAKING OUR WAY FORWARD

The factors shaping the future of our health system represent a distinct call to action and opportunity to mobilize Ontario's talent, ingenuity and capabilities. In the face of the fundamental truths set out above, there is a growing imperative to explore new ways to address the obstacles to health system transformation.

The common challenges and common ground across health system stakeholders, including patients and families, must form the basis for ongoing discussion and healthy debate on what the future health system will look like, what changes are needed and how we will get there. Other jurisdictions, like Quebec, are rising to the challenge by creating forums to support deep, broad-based discussion on the future of our health care. The engagement of seniors, patients and families in these discussions is essential to test principles and ideas.

Ontario has begun to take steps towards health system transformation. There are several positive developments across multiple fronts including new and innovative structures in the form of Health Links, health system funding reform, and increased levels of funding for the home and community care sector.

As an important component of the overall health system, the home and community sector represents a significant lever in providing high-quality and integrated care for Ontarians at a reduced cost. To realize its potential to do so, investments of time, talent and capital will be required. More importantly, players across the health system and society will need to address important and unresolved questions. How will we come together to meet the needs of patients? What should we expect from our health system? How will we pay? How will we support our informal caregivers?

Our interviews with health system leaders uncovered a strong desire to address these questions and work together to find common solutions. In the papers to come we will explore pressing questions in the context of four representative home and community care patient groups: seniors with complex health needs, people with chronic health care needs, hospice and palliative care patients, and children and youth with complex and high needs.

Through these patient groups, the next papers will examine the ways in which our health system is performing well, ways in which the health and social systems are not adequately addressing the everyday needs of patients and their informal caregivers, and consider the implications and opportunities for the future. Through all of these papers, our goal is to begin an earnest dialogue about how we come together to create a high-performing health system and that optimizes home and community care.

