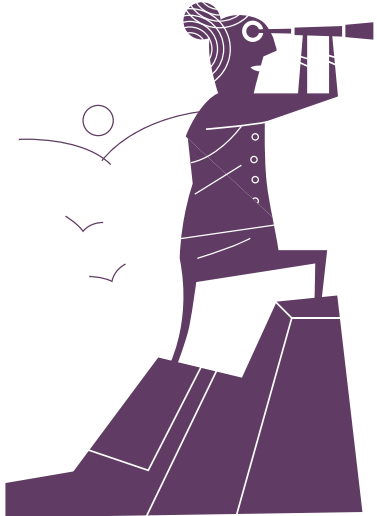
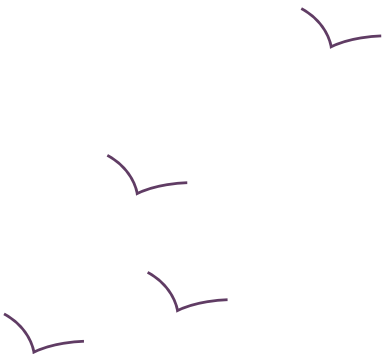


THE STORYBOARD
Implementing
The Change Foundation
strategic plan,
*Hearing the stories,
changing the story*

April 2011



Introduction

The Change Foundation's **vision** is *to be Ontario's trusted advisor advancing innovative health policy and practice.*

The Foundation's **mandate** is *to promote, support and improve health and the delivery of health care in Ontario.*

The Foundation's **mission** is:

- to make caregivers and individuals in need of health care part of the health-care discussion about how to find solutions to improve their experiences;
- to stimulate new ways of thinking, behaving, and interacting to foster improved health care for people, especially when they are in transitions;
- to generate robust and independent research and policy analysis of health-care issues related to improving the experience of individuals and caregivers as they navigate the health-care system; and
- to lead informed discussion and strategic engagement with the stewards, stakeholders and users of the health-care system.

The Change Foundation's Strategic Plan—*Hearing the stories, changing the story*—established a strategic priority: **to improve the experience of individuals and their caregivers as they move in, out of, and across Ontario's health-care system over time and as their health changes.** This priority flows from what we've learned from patients and caregivers, and also from practitioners and researchers. For Ontario's quality improvement agenda to advance, we need to learn how best to incorporate people's lived experience and their views directly into improvement methodologies.¹

The Foundation's Strategic Plan presents three strategic directions:

- Learn from the experience of individuals and caregivers at key transition points in the system and over time.
- Scout for, incubate and create innovative quality improvement solutions to address key problematic transitions in health-care delivery identified by those who use the services and those who care for them.
- Promote system-level adoption of innovations to improve the individual and caregiver experience through greater health system integration.

¹ The Change Foundation. June 2010. 2010-2013 Strategic Plan: *Hearing the stories, changing the story.*

This document is intended to guide the Foundation in achieving its strategic goal and strategic directions. The document will:

- i. present the Foundation's **logic model** to guide its work in achieving its strategic goal and strategic directions;
- ii. describe a **conceptual framework** for understanding the experience of individuals and caregivers as they navigate through the health system;
- iii. identify a **population of focus**; and
- iv. outline an **implementation plan** for achieving our strategic goal and strategic directions.

Logic Model to Guide our Work

The Change Foundation has developed a logic model to guide its work in achieving its strategic goal and strategic directions (see Figure 1). This logic model is a high-level depiction of the relationships between the Foundation's strategic directions and its inputs, outputs, short and long-term outcomes, and impact. This model will help the Foundation to strategically plan its activities and measure progress in achieving our goal of improving the experience of individuals and caregivers as they navigate through the health-care system in Ontario.

The Foundation has identified three **stakeholders** for its strategic plan: policy and decision makers, health-care service providers, and health-care users and informal caregivers.

In the next three years, the Foundation will engage in a variety of **outputs/activities**: research, policy analysis, care delivery redesign, and engagement. For example, we will:

- plan, host and partner on events to share information, evidence and analysis;
- engage with our stakeholders to question and validate our assumptions, elicit new ideas and solutions, and unearth perspectives;
- publish articles and synthesis reports; and
- sponsor research and community-level redesign initiatives.

The outputs from these activities will support the achievement of three short-term strategic **outcomes**:

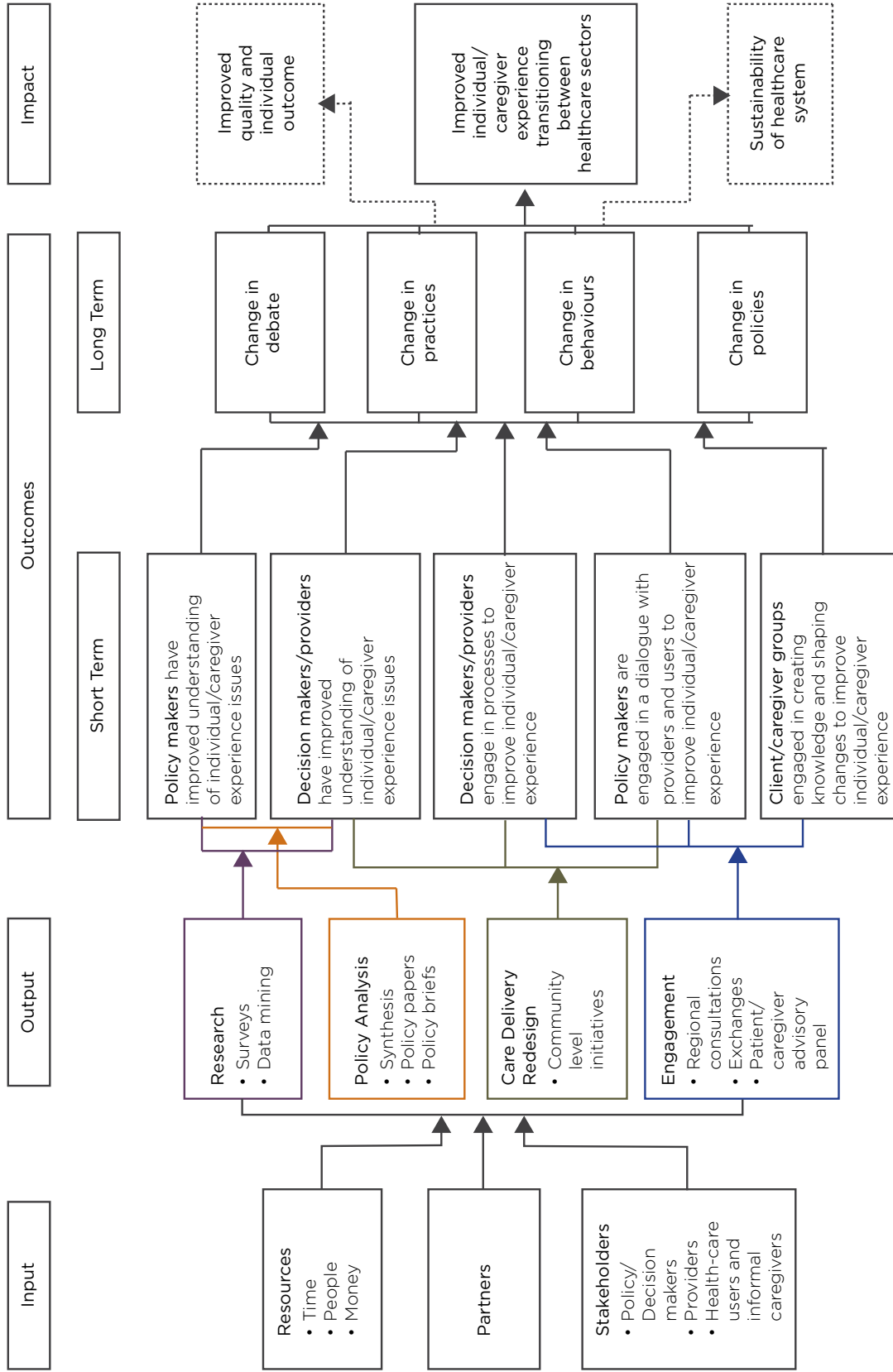
1. policy makers have improved understanding of the health-care experiences of individuals and care givers, and are engaged in a dialogue with them to improve it;
2. decision makers and providers have improved understanding of individual / caregiver experience and are engaged in improvement processes; and
3. individuals and caregivers are engaged in sharing and creating knowledge and shaping changes to improve experience.

In the long term, these improvements and adoption of new approaches / methodologies will lead to changes in health-care practices, behaviours and policy. A change in debate will be both a prerequisite to these improvements and a product of them, potentially heralding a more inclusive dialogue and a new dynamic of shared care and shared decision-making.

Ultimately, the **impact** of these efforts will be improved experiences of individuals and their informal caregivers in transitioning between health-care sectors. Our impact will be measured through the degree to which the Foundation has met these strategic outcomes. We plan to demonstrate that, taken together and over time, our work can prompt the improvement of people's health-care experiences. As well, given the increasing evidence of a positive association between the experience of individuals and clinical outcomes, and between quality and financial performance,² we expect our work will indirectly positively influence improved health outcomes and improved quality and sustainability of the health-care system.

² See:
Epstein, M. et al., (2010) Why the Nation Needs a Policy Push on Patient-Centered Health Care, *Health Affairs*, August, 29:8, pg. 1-7
Berwick, D. (2008) Connecting finance and quality, *Healthcare Financial Management* Oct.: 53-55.

Figure 1: The Change Foundation Logic Model



Conceptual Framework for Understanding the Individual and Caregiver Experience

The Change Foundation believes that a good patient experience is one where individuals and their family and friend caregivers:

- Are connected to the care that they need—if the goal is to stay at home longer or manage a chronic condition better, they will get the care they need to achieve those goals.
- Are provided with a range of appropriate services and supports.
- Are informed about how the people who provide them with various services or supports are connected to them and with each other.
- Understand who their key contact person is to help them coordinate care to meet their changing needs.
- Are provided with the information they need to help make decisions about their care.
- Are informed about all aspects of their care.
- Understand what comes next in their care—the process makes sense to them.
- Are confident that all the providers they interact with are complementing each other's efforts, are respectful of each other's contribution, and are working together in the individual's and caregiver's best interest.

Our conceptual framework for understanding the experience of individuals and caregivers as they interact with our health system includes two components: the elements of the experience, and the types of transitions between different parts of the health-care system. This conceptual framework—and refinements to this framework—will guide our activities over the course of our Strategic Plan.

i. What are the elements of the experience of individuals and their caregivers in their overall health system journey?

The Foundation views the following six thematic areas as important contributors to the experience of individuals and their caregivers as they navigate through our health-care system.³ These elements include the transactional aspects of the care experience—the “what” (i.e., elements 1 through 3) and the relational aspects of the experience—the “how” (i.e., elements 4 through 6). The elements are not distinct entities - rather there is a degree of overlap amongst the various elements.

1. Clear, consistent, reliable communication and exchange of information

Individuals and their caregivers receive clear communication from their providers. They feel that providers listen, and they understand the language and terminology used by providers. They are hearing consistent messages from all of their various providers. They have easy access to the information and records they need to stay informed about their health and the factors affecting it, to understand their treatment options, and to understand the next steps in their care plan (i.e., who? what? when? where? and why?). They are well informed to participate in decisions about their care and make decisions based on full disclosure—i.e., they are informed of the options and risks, and make a decision in the context of that information.

Individuals and their caregivers know who is aware of their full set of needs and can help them navigate through the system—i.e., they know who the “puzzle maker” is who is putting together all the pieces. Individuals are confident that there is clear, consistent and reliable communication between the various providers involved in their care, including timely communication across organizations and sectors of care—i.e., there is “informational continuity”.

Individuals and their caregivers have access to appropriate tools to help them self-manage and to enhance the patient-provider relationship. E-health and other technologies are used to expedite communication exchange and efficiency i.e., patients need to provide information which is then accessible to those who need it to deliver high quality care. Electronic health records are patient-accessible and patient-friendly—i.e., patients have ease of access to their health records and the opportunity to add relevant information.

³ Adapted from: U.S. Institute of Medicine (2001), Lewis (2009), Dagnone (2009) regarding definitions of patient-centred care; and Shaller's (2007) regarding review of influential frameworks for patient-centred care (including the Institute for Family-Centred Care and the Planetree Association).

2. Coordinated and Connected

Individuals and their caregivers are connected to appropriate providers, services, and supports—they have a clear understanding who all of their providers are, and sense that all of their providers are communicating with each other and working together as a team in their best interests. Our health-care system is highly complex with a proliferation of channels for service delivery and potential for service delivery problems. Ideally, individuals and their caregivers experience interactions with providers that are well-coordinated, integrated and value-added.

Individuals and their caregivers are confident that their physicians—general practitioners and specialists—are collaborating with other providers—nurses, pharmacists, midwives, counsellors, dieticians, etc. They feel that their providers are working together to meet their evolving health-care needs, and are helping them to navigate the health-care system. Individuals and their caregivers experience caring hand-offs between different providers and phases of care; their care appears to them to be logical and seamless. They recognize their providers and have the sense that their providers know them—i.e., an effort has been made, to the fullest extent possible, to ensure “relational continuity” between individuals and their providers.

3. Comprehensive

Individuals have a sense that all of their needs—not just some of their needs—are being addressed. Care needs are beyond the scope of medical care and include support services. Their living conditions are taken into consideration and incorporated into their care plans. They feel that their providers spend enough time with them to discuss their multiple needs and concerns. They feel that they are heard. Individuals and their caregivers are confident they will be provided with, or given access to, the people and resources to help them understand—and choose—their range of care options.

4. Engaged in Care

Individuals and their caregivers are active participants in decision-making about their care and are asked about their preferences, concerns, fears, and needs. There is a sense of shared responsibility around care decisions, with recognition that people will vary in their capacity and inclination to engage in their own decision-making about their care. For those who are able and interested, they feel encouraged by providers to be actively engaged in the management of their own health, as opposed to passive recipients of care.

Family and friends—often the informal caregivers—are treated as partners. They are made to feel welcome and respected by providers, and they are viewed as key players in decision-making. The involvement of family and friends is supported.

5. Respectful, empathetic and considerate

Individuals and their caregivers feel their time and their perspective are respected; they are given the time that they need to ask questions and express their concerns, fears, and hopes. Their stories, preferences, and questions are viewed as valid and are respected. They feel treated with empathy, fairness and consideration; their needs and situation are considered if changes in their care plan are required (e.g., cancellations or delays in appointments). They feel treated as equals and partners by their providers; the relationship between patients, their family and providers is a balanced, mutually respectful partnership. They feel respected for their feedback on quality and effectiveness. They feel they are treated with dignity and their privacy is respected.

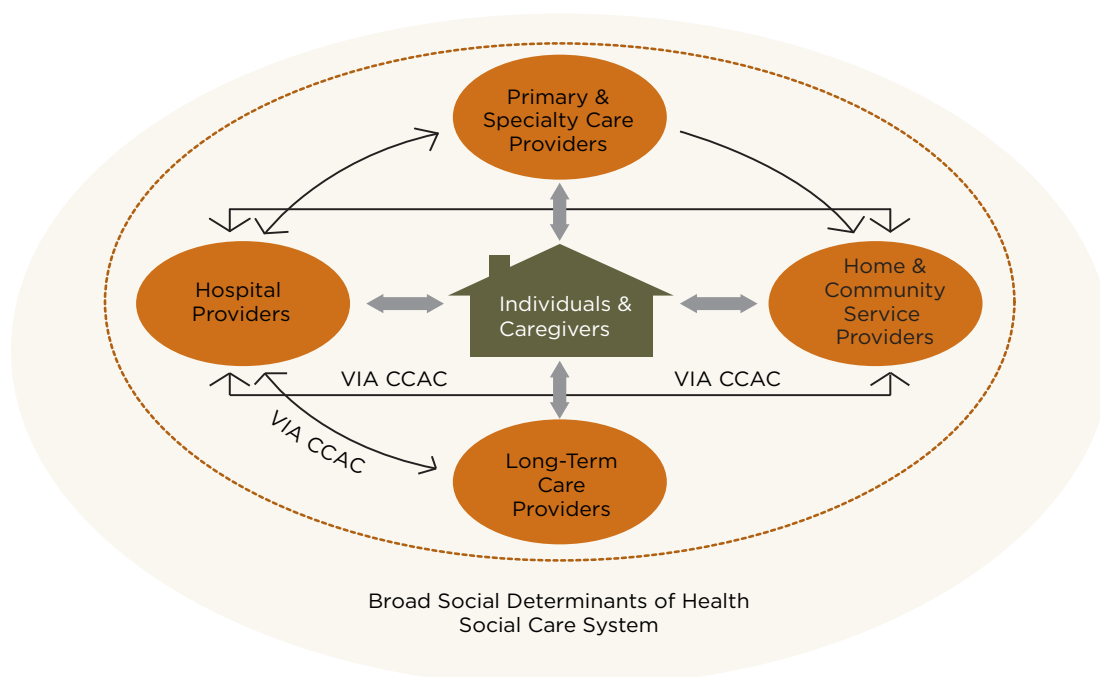
6. Timely and Convenient

Individuals receive support and care when they need it, without long waits that prolong pain or emotional turmoil, or contributes to unnecessary deterioration of their health status. Where a sequence of services is required, the intervals between services are short, and the need for individuals to go to different locations for services is minimized.

ii. What are the types of transitions that individuals and their caregivers experience in their overall health system journey?

The following visual (Figure 2)—as presented in The Change Foundation’s Strategic Plan - depicts the range of transitions that an individual may experience as they interact with the health system and as their health changes. The visual is not intended to depict the highly complex nature of our health system—i.e., there are highly complex systems within hospitals, satellite systems in the community care sector, alternative care providers outside of the publicly funded system. The visual is not intended to represent the granularity of multiple service interactions within complex systems—although we know that this granularity is critical to how individuals and their caregivers experience their interactions with the health-care system. Rather, the visual is intended to capture at a high-level view the range of transitions between health system sectors and providers. We intend to better understand the granularity of interactions and to address the problems of those interactions through care delivery co-design/re-design initiative(s).

Figure 2: Types of Transitions



The visual includes the following interactions:

- People interacting from home with:
 - primary care providers
 - home and community service providers
 - both primary care and community services sectors
 - tele-home-care program and supporting technology to link to multidisciplinary care team
 - one or more specialty care providers accessed through primary care providers
 - one or more specialty care providers
- People moving from home to:
 - hospital—acute, rehabilitation, etc.
 - long-term care facilities
- People moving from hospital to:
 - home with home and community supports, services
 - home with primary care follow-up and monitoring
 - long-term care facility

- People moving from long-term care facility to:
 - home with home and community supports, services
 - home with primary care follow-up and monitoring
 - home with both primary care and community services and supports
 - hospital—Emergency Department, acute, etc.

Population of Focus

To have meaningful impact within the limits of The Change Foundation's resources, the Foundation used the following criteria to select a population of focus:

- **Potential to have an impact**—Is this a group that has many interactions with different parts of the health-care system? If we understand the problematic transitions and aspects of their interactions, and work on solutions to those problems, is there potential for affecting system change that will positively impact the experience of a significant group of people?
- **Potential to make a value-added contribution**—Are other organizations currently focusing on this group? Is there potential for The Change Foundation to make unique contributions given its mission and mandate? Is there potential for the Foundation to augment or influence the efforts of other organizations without being duplicative?
- **Potential to access target group**—Is there potential for active engagement with this target group? Are there unique challenges to engaging this group in order to better understand their experience? Is there potential for gaining a more robust understanding of the experience of this group through innovative engagement?
- **Potential to leverage government investment in area of focus**—Is the government making investments that will impact this group? Is funding being committed? Is there a policy focus on this population?
- **Potential to benefit from existence of supportive legislative frameworks**—Will existing legislative frameworks that guide the provision of service to this group impede our efforts for positive change? Is there potential to improve the experience of this group within existing legislative frameworks?
- **Potential to transfer, spread solutions**—Is there potential to take what we learn from a focus on this population group and apply or adapt it to other target groups? Could there be key learnings that are universal and generalizable to other groups?

SENIORS WITH CHRONIC HEALTH CONDITIONS

After applying these criteria, The Change Foundation selected **seniors with chronic health conditions** as its population of focus. The following is the Foundation's rationale for focusing on this population group.

1. Potential to have an impact:

Seniors with chronic health conditions and their informal caregivers have multiple and frequent interactions with our health-care system, and arguably they have the most to benefit from a well-integrated, coordinated health-care system.

They represent a growing segment of our population who account for a high proportion of total health expenditures.

- Seniors aged 65 and over are high users of acute care—56% of Length-of-Stay patient days are attributed to patients 65 and over (CIHI, 2008)
- The rates of acute hospitalization of Canadians aged 85 and over is almost six times higher than those under 65 (Rotermann, 2005).

Recent data has concluded that the number of health-care services seniors use is determined more by the number of chronic conditions they have than by their age (CIHI, 2011):

- Older seniors (85 and older) with no chronic conditions made less than half the number of health-care visits as younger seniors (65 to 74) with three or more chronic conditions;
- Three out of four Canadians 65 and older reported having at least one chronic condition, while one in four seniors reported having three or more chronic conditions.

It is increasingly acknowledged that if we want to strengthen the quality and sustainability of our health-care system, we need to change the types of services and supports that are provided, by whom, and where.

A focus on seniors with chronic health conditions builds on the Foundation's previous investments in projects to enhance the continuity of seniors' care, and to better understand the needs of informal caregivers and trends in the use of home-care services. Given the Foundation's strategic focus—to improve the experience of individuals and caregivers—and our focus on looking at navigation across sectors and throughout the system (rather than an organization-specific focus), our work, taken together and over time, has the potential to support the redesign of more user-friendly and streamlined processes and services across the system, and improve people's experiences with it.

2. Potential to make a value-added contribution:

The Change Foundation is a think tank. We have networks and work with stakeholders across sectors. We are committed to understanding and advancing the individual and caregiver perspective as they navigate across the system. There is an opportunity for the Foundation to make a unique contribution without duplicating existing initiatives. The Foundation is interested in the transitions between—the “moving around” - between parts of the system and across the sectors of the system. Our focus is unique from other organizations who typically are interested in what happens within an organization, or what happens within a sector.

The Community Care Access Centres (CCACs) are in the business of care connections—they connect people with the care they need at home and in the community. Seniors with chronic health conditions are a key client group for the CCACs. They offer a range of supports and services to support clients to stay at home and in their communities for as long as possible. The CCACs typically address hand-offs and transitions with their own providers and key partner organizations, but not transitions beyond these organizations.

The Integrated Client Care (ICC) project has identified the frail elderly as a priority clinical grouping.⁴ The project plans to adopt an enhanced system navigation role to improve system linkages, communication and coordination; use Case Managers to provide support through the client's cycle of care in order to smooth transitions especially with primary care; and—a notable innovation—integrate across sectors of care—i.e., home care with primary care, acute care and community support services.

There may be opportunities for the Foundation to partner with other organizations or augment the initiatives of others with a Foundation-sponsored initiative - for example, CCACs may be an obvious partner given their focus on care connections, and innovative projects like the ICC are logical fits.

3. Potential to transfer, spread solutions:

Seniors with chronic health conditions have significant overlaps with other potential target groups:

- 89% of older (65 + years) home-care clients in Ontario live with two or more chronic conditions (The Change Foundation, 2010).
- Prevalence of mental health problems among the elderly (including age-related dementia) is estimated to be between 17% and 30% (CMHA); a high percentage—20% - of seniors living at home with home care had a diagnosis of Alzheimer's disease or dementia (CIHI, 2010).

A focus on seniors with chronic health conditions offers significant potential for applying learnings to other population groups, such as adults and children with chronic conditions, and people with mental health conditions. There are transitions between different parts of the health system that are common transitions regardless of the patient population. There is strong potential that care delivery redesign initiatives to address key problematic transitions for seniors will have cross-over benefit and adaptability to other population groups.

⁴ A joint initiative of the Ontario Association of Community Care Access Centres (OACCAC), the MOHLTC, and the Collaborative for Health Sector Strategy at Rotman School of Management.

4. Potential to access target group:

A focus on seniors with chronic health conditions and their caregivers will present unique challenges for engagement. An engagement strategy will need to ensure the input of seniors and their informal caregivers. The engagement tools and methodologies will need to be responsive to the challenges of both groups (i.e., health status, mobility, availability, computer literacy, etc).

The purpose of engagement with seniors with chronic conditions and their caregivers will vary over the course of the three phases of the Foundation's strategic plan (as described in "Plan for Achieving our Strategic Directions" below). It is anticipated that a combination of professionally supported initiatives and activities with patient / caregiver advocacy groups will be pursued. A number of patient and caregiver advocacy groups have indicated an interest in working with the Foundation.

5. Potential to leverage government investment in area of focus:

The Ontario government recently expanded its *Aging at Home Strategy*, investing \$1.1 billion over four years—\$330.6 million this year.⁵ The purpose of Aging at Home programs is to provide a continuum of community-based services and supports for seniors and their caregivers to support them to live independently and with dignity in their own homes. It is anticipated that this investment will help seniors avoid hospitalization, return home faster if they are admitted to hospital, reduce ER wait times and Ontario's Alternate Level of Care (ALC) rate. This government initiative is intended to strengthen community support services so that seniors get the care they need in settings other than hospitals and long-term care facilities. The provincial government has indicated that avoidable hospitalizations are a priority area of focus given emerging data.

A Foundation focus on seniors with chronic health conditions aligns with the government's investment in the Aging at Home strategy and the emerging focus on avoidable hospitalizations. Our plans for care delivery redesign initiatives should keep seniors at home with the necessary supports and services—avoiding hospitalization, returning home faster, reducing ER wait times and improving ALC rates.

6. Potential to benefit from existence of supportive legislative frameworks:

The recently announced *Excellent Care for All* legislation will ensure health-care providers are accountable for improving the quality of health care and enhancing the care experience of individuals and their caregivers. The legislation includes requirements for quality committees, annual quality improvement plans, executive compensation linked to achievement of improvement targets, patient/client/caregiver satisfaction surveys, staff satisfaction surveys, and patient relations processes to address patient experience issues. The focus of the legislation is initially on the hospital sector but there is explicit expectation that the requirements will be extended to other health sectors. The legislation expands the mandate of the Ontario Health Quality Council (OHQC) to support continuous quality improvement and promote health care that is supported by the best available evidence (including making recommendations on standards of care based on clinical practice guidelines and protocols, and on possible changes to health-care funding).

The Change Foundation's strategic priority and directions are clearly consistent with this legislative framework. There is alignment with the Foundation's interest in pursuing innovative, care delivery redesign initiatives to address problematic transitions for seniors with chronic health conditions. Our interest in working across sectors aligns with plans to extend the requirements of the legislation to other sectors through regulations. We anticipate that the care delivery redesign process will identify some policy and funding barriers. With the quality objectives of the legislation and the expanded mandate of the OHQC, there will be clearer avenues for the submission of policy recommendations and proposals for the spread of successful initiatives.

⁵ MOHLTC news release on August 31, 2010.

Plan for Achieving our Strategic Directions

To achieve our strategic directions, we will:

- Listen and Learn—we will continue to build on what we have learned to date, collecting and analyzing data and insight through literature reviews, surveys and engagement;
- Incubate and Innovate—we will support community-level care re-design initiatives that will involve patients and their informal caregivers as key partners to identify problematic transitions and innovative solutions to those problematic transitions;
- Advise and Advance—we will take what we learn from the small-scale innovation project and our engagement initiatives to inform the development of policy recommendations and promote system-wide adoption of innovations.

Our first year will focus on:

- collecting baseline data from the perspectives of our three stakeholder groups to capture their current understanding and experience of transitions;
- undertaking environmental scans and literature reviews to better understand the individual and caregiver experience and best practice initiatives;
- conducting regional engagement exercises with seniors and caregivers to capture and later compare qualitative information about how they experience transitions;
- sponsoring a competitive process to select a community of focus for a care delivery redesign investment; and
- building the Foundation's capacity to lead targeted engagement processes with key audiences / stakeholders.

The focus of the second year will be the launch of the care delivery redesign project, and the development and implementation of engagement initiatives including the launch of a provincial patient/caregiver advisory panel.

The third year will see the continuation and completion of the care delivery redesign project, and the various engagement initiatives.

In the fourth year, we will collect follow-up data from our community-level engagement and co-design participants—i.e., seniors and caregivers, and community-level providers—to assess if their experience and understanding has improved during the course of the care delivery redesign initiative. We will also collect follow-up data from policy and decision makers and from seniors and caregivers through regional consultations to see if their experience and understanding has shifted during the early years of the Excellent Care for All legislation. We will focus on the development of engagement, communications and knowledge transfer strategies to assist with the spread of care delivery redesign project learning to other communities. Our engagement initiatives will include a stakeholder summit following the completion of the care delivery redesign work to expand and refine the learning, support the uptake of learning, and develop and spread policy reform recommendations.

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Vision

To be Ontario's trusted advisor advancing innovative health policy and practice.

Goal

To improve the experience of caregivers and individuals as they move in, out of, and across the health-care system over time.

The Foundation will adopt a participatory approach to the following four methods: research, policy analysis, quality improvement, and engagement.

Mission

To make caregivers and individuals in need of health care part of the health-care discussion about how to find solutions to improve their experiences.

To stimulate new ways of thinking, behaving, and interacting to foster improved health care for people, especially when they are in transitions.

To generate robust and independent research and policy analysis of health-care issues related to improving the experience of individuals and caregivers as they navigate the health-care system.

To lead informed discussion and strategic engagement with the stewards, stakeholders and users of the health-care system.

Mandate

To promote, support and improve health and the delivery of health care in Ontario.

Values

Excellence. We strive for excellence in all we do. **Innovation.** We take innovative approaches in developing new ideas. **Collaboration.** We work in partnership with others to achieve success. **Inclusivity.** We strive to include all voices and views.

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THE CHANGE FOUNDATION

HEALTH CARE DESERVES
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