

# CAREGIVER SUPPORT FRAMEWORK

A PLANNING TOOL FOR HEALTHCARE PROVIDERS • MAY 2018



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## Definition of a caregiver

Family Caregivers are people – family, friends and neighbours – who provide essential and often ongoing personal, financial, social, psychological and physical support, assistance and care, without pay, for family members and friends in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability, or end-of-life. (Source, adapted from: *Change Foundation Report: A Profile of Family Caregivers in Ontario, 2016*).

## Definition of a person who receives care

In a healthcare context, the person who receives care is often referred to as a “patient”. Whereas in a social service context, he/she is referred to as a “client”. For the purposes of this document, the terms “client” and “patient” are used interchangeably to ease readability.

# WELCOME

Welcome to this revised framework for use by healthcare organizations working with patients and families to improve the culture and practices for supporting caregivers.

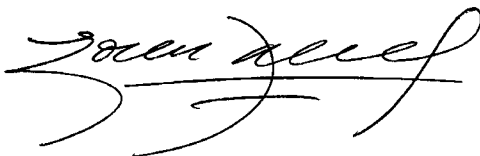
We are pleased to provide this “second edition” of the Caregiver Support Framework, resulting from recent consultations with caregivers and healthcare providers across the Central Local Health Integration Network (LHIN) region. The consultation feedback confirmed the value of the Program Logic Model format to drive a more systematic approach for identifying gaps and planning improvements. Examples of such improvements are:

- better communication practices between caregivers and healthcare providers, (e.g. asking caregivers how they are doing, or having supportive conversations about topics such as serious illness or end-of-life care)
- simpler and more flexible ways of helping caregivers find the right supports for themselves (including peer coaching, counselling, and reliable disease-based information)
- providing a plan of care for the caregiver to meet their own health needs (if their circumstances requires this level of support)

The Caregiver Support Framework is a resource document for healthcare providers to use in leading collaborative improvement plans with clients and caregivers (e.g. families and friends). The Logic Model’s Vision, Objectives, and the Five Main Elements can be used to guide, plan and measure the impact of specific caregiver support activities such as, peer education, caregiver training, and respite programs.

We hope these efforts will lead to changing conversations with caregivers, improving service delivery practices, and more proactively supporting caregivers within our health system.

Sincerely,



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# ACKNOWLEDGMENTS

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*The Members of the Caregiver Collaborative in the Central LHIN gratefully acknowledge the contributions of the consultation participants for generously sharing their perspectives and experiences to inform this work.*

## **List of Consultation Sites and Key Informant Interviews**

Thank you to the following organizations that helped to distribute surveys and organize focus groups:

- Alzheimer Society of York Region (Caregivers)
- Better Living Health and Community Care – Margaret Bahen Hospice (Healthcare Provider Staff)
- Behavioural Support Services and Behavioural Support Transition Resource Team (Healthcare Provider Staff)
- Central LHIN Patient and Family Advisory Group (Caregivers)
- Community Living York South (Caregivers)
- LHIN/Home and Community Care (Healthcare Providers)
- Villa Colombo (Caregivers)
- Langstaff Square – Long-Term Care (Caregivers and Healthcare Provider Staff)
- Lumicare (Healthcare Provider Staff)
- Matthews House Hospice (Caregivers – Telephone Interviews)
- North York General Hospital, “Pop-Up” Survey Site (Caregivers and Healthcare Provider Staff)
- Yee Hong Centre – Markham (Healthcare Provider Staff)
- Yee Hong Centre – Finch Centre (Healthcare Provider Staff)
- Social Services Network (Seniors and Caregivers)
- Southlake Regional Health Centre, “Pop-Up” Survey Site (Caregivers and Healthcare Provider Staff)
- Home on the Hill - Family Support Group (Caregivers)

## **Key Informant Interviews:**

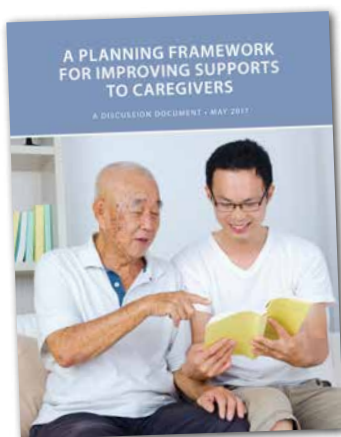
- Ontario Dementia Advisory Group
- Family Services York Region – York Rainbow Support Network

With financial support from:



# BACKGROUND

In the Fall of 2016, the Alzheimer Society of York Region was invited by the Central LHIN to lead and facilitate a process of developing a caregiver framework. A Caregiver Collaborative committee was established, and co-design methods were used to involve family caregivers and health care professionals in the planning process.



The members of this collaborative group were primarily located in one part of York Region and, in May 2017 they produced a caregiver framework outlining a model of care called, “**A Planning Framework for Improving Supports to Caregivers: A Discussion Document**”.

**Why a Second Edition?** In the fall of 2017, a broader consultation process was launched to reach both healthcare providers and caregivers from across the Central LHIN. The consultations aimed to gather more information about caregivers’ experiences when interacting with the health system, and to test the applicability of the caregiver support framework elements with people in a diverse range of caregiving circumstances (e.g. ages, health conditions, cultures, languages, living situations, and locations).

The consultation feedback confirmed the value and applicability of a simplified version of the Caregiver Support Framework – mainly for use by healthcare providers – as they develop and evaluate specific care process improvements, or design new caregiver supports such as peer education, caregiver training, and respite programs. The consultations also yielded recommendations on priority areas for further health system improvements to support caregivers. This included strengthening the way that healthcare providers communicate with caregivers about their own needs and concerns, and expanding the availability of caregiver peer supports, counselling and educational offerings, and other home care and community services (e.g. day programs and respite) and supported housing/ residential models.

The following sections of this document present a snapshot of the consultation findings, from both the perspectives of the caregivers and healthcare providers. These findings offer key insights to guide planning of improved communication, service delivery practices and care processes for better supporting caregivers within the healthcare system.

## The Nature of Caregiving

The term caregiver as a title or position, is not always recognized or understood. There can be external barriers to recognizing caregivers (e.g. the social stigma of caring for a person who resists a diagnosis such as with a mental health diagnosis or dementia) or internal barriers to the person (e.g. the individual might not view themselves as a caregiver). Caregiving is a voluntary and unpaid role, yet not all caregivers feel that they have a choice. The caregiving process is dynamic and is affected by both fluctuations in the conditions and circumstances of both the client and caregiver. Caregiving is not a linear path, nor is the patient experience. There can be cycles where things are more certain and manageable (or a “steady state”), or times when things are unpredictable and feel overwhelming for the caregiver.

## Importance of Communicating with Caregivers to Identify their Need for Support

Respectful and compassionate communication throughout the care process (between healthcare providers, patients and caregivers) is widely known to affect and improve the quality of the patient and caregiver’s experiences and outcomes of care. When the roles are clear and communication is effective, a partnership is formed called “the triad of care” between the formal provider, patient and caregiver. Typically, the communication and partnership is focussed on communicating about the patient’s care plan and treatment. Yet, the caregivers consulted in the Central LHIN have identified an important additional dimension of this communication. Healthcare providers can be asking the caregiver how they are doing, feeling and managing, with the goal of ensuring timely access to their own supports to maintain their health and sustain their caregiving role.

# CONSULTATIONS WITH CAREGIVERS AND HEALTHCARE PROVIDERS

## Overview of the Consultation Process

**Methods:** Three channels were used to consult with both caregivers and healthcare providers during March and April 2018:

- Surveys
- Focus groups
- Key informant Interviews

The consultation process gathered input from almost 850 people. Surveys reached a range of caregivers who help people of various ages and health conditions, and healthcare providers who work in a range of roles and practice settings.

- 327 Caregiver Responses (260 of which reported they care for someone living in the Central LHIN and 67 Caregivers in other LHIN areas)
- 192 Healthcare Staff/Provider responses
- 39 Primary Care and Allied Health Professionals responses

In addition, focus groups were held in several locations to reach over 100 Informal Caregivers and 300 Healthcare Providers. For a list of the Focus Group sites and Key Informant Interviews, see Acknowledgments on page 4.

## Healthcare Provider Survey Demographics

(192 Responses)

### Practice Settings

Community Support Sector (27%)  
LHIN/Home and Community Care (19%)  
Long-Term Care, Hospital (14%)  
Home Care Service Providers (14%)  
Primary Care (11%)  
Specialized Geriatric Services (5%)

### Roles

Nurse (19%)  
Supervisors/Managers (19%)  
Social Workers (12%)  
Physicians (9%)  
Personal Support Workers (9%)  
Educators (3%)

## Caregiver Survey Demographics

(260 Responses)

### Where Care Recipients Live

At home in the community (78%)  
Long-term care home (12%)  
Other settings (5%)  
Retirement home (3%)  
Not specified (2%)

### Age and Health Conditions of Care Recipients

Care recipients over the age of 65 (82%)  
Aging and/or frailty (60%)  
Dementia or cognitive impairment (36%)  
Chronic or ongoing illness (38%)  
Mental health disorder or illness (28%)  
Physical disability or illness (26%)  
Health condition that will worsen over time (22%)  
Developmental disability or illness (9%)

### Age Range of Caregivers

55-64 years old (32%)  
35-54 years old (29%)  
65-74 years old (21%)  
75 years and over (15%)  
16-34 years old (3%)

### Relationship of Care Recipients to Caregivers

(note: some caregivers help more than 1 care recipient)  
Parent or in-law (53% and 5%)  
Partner or spouse (30%)  
Daughter/son (11%)  
Sibling (5%)  
Other (5%)  
Friend (3%)

### Health Status of Caregivers

Half reported that they are in good health, with the other half reporting health challenges, including:  
Aging and frailty (17%)  
Chronic health conditions (17%)  
Mental health disorders/illness (13%)  
Health conditions that will worsen over time (11%)

### Length of time Caregiver has been providing care

More than 5 years (51%)  
Between 1-5 years (35%)  
Less than 1 year (11%)  
Care recipient deceased (2%)

### Main Regions of Central LHIN Where Caregivers Live

(note: 45% of caregivers live in same dwelling as care recipient)  
York Region (73%)  
Toronto (19%)  
Simcoe (8%)

## Highlights of the Survey Results

### Communication, Relationships, and Caregivers as Part of the Team

#### Caregiver Perspective

Overall 68% of caregivers are satisfied or very satisfied with how timely healthcare providers can be with following up on caregivers requests for information.

65% of Caregivers report that they are always asked for input into the assessment/care plan for the patient, **yet only 37% of caregivers report that they are asked about how they are doing, feeling, managing, or if they have any questions.**

Caregivers reported on the key things that Healthcare Providers can do to improve how they are supported:

- 60% Listen to my concerns
- 49% Provide me with a contact person if I need help
- 49% Respond better to the needs of the person I am caring for
- 41% Value my role/contribution
- 35% Communicate with other healthcare providers to save me time
- 25% Provide clinical information and directions at the right time

#### Healthcare Provider Perspective

- 67% healthcare providers report that they always seek input from caregivers on the care/treatment plan for patients/clients
- **Healthcare providers indicate an interest in improving the quality of conversations with patients and caregivers. The topic of interest for further training include:**
  - 58% Supportive conversations with patients and caregivers about a serious illness
  - 55% Conversations about end-of-life
  - 54% Conversations about healthcare navigation and planning
  - 50% Conversations about capacity issues and Power of Attorney
  - 37% Interviewing/enquiry techniques

### Access to Services for the Person they Care For

- 28% of Caregivers report that the person they care for is not receiving formal support services
- Of those accessing formal support services, the top ranking services in place are:
  - 53% Personal Care
  - 23% Medication Reminders and Support
  - 23% Respite (Caregiver break)
  - 19% Meal Preparation
- **34% of Caregivers report that they do not have one person or more to step in as a back-up**
- 59% of Caregivers report they experience barriers or challenges in accessing community based services. The types of services are:
  - 27% Getting care needed at home
  - 24% Personal care and grooming
  - 17% Community-based day or evening program respite care
  - 15% Social Companionship/supports,
  - 10% Nursing/Rehab care
  - 9% Medication reminders/support
  - 8% Cognitive Assessment
  - 8% Counselling

### Top Challenges that Caregivers Report they Experience

- 56% Challenges with balancing caregiving duties with other responsibilities
- 56% Challenges with finding time and space to take care of themselves (self-care)
- 34% Challenges getting care at home
- 26% Logistical challenges getting to care e.g. transportation, weather, time of day or night
- 25% Challenging with covering the cost of care
- 24% Getting into a residential setting or LTC home
- 24% Scheduling of care/appointments when caregiver is available
- 22% The person they are caring for resists the help of healthcare providers

## Highlights of the Focus Group Results

### Navigation and Supports

#### Caregiver Perspective – What works well

- Connectedness of the team members (including the caregivers and healthcare providers within healthcare organization, or across organizations).
- Partnership models between organizations work well, when co-ordinated.
- Caregivers find peer supports a very valuable source of information, emotional support, orientation and a feeling of being understood.
- Day/Community programs offering meaningful client activities and a break for caregiver.
- Staff/clinicians not rushing /having time to provide care and communicate.
- Caregivers being informed about disease trajectory – and ways to support the person comprehensively (e.g. nutrition, exercise).
- Caregivers feeling literate about patient's condition/ care provision along with maintaining their own health /self-care.
- Caregivers find reliable and consistent in-home care (personal care, medications, and nursing/ rehab care) to be very supportive.

#### Healthcare Provider Perspectives – What Works Well

- More societal awareness and normalized conversations about aging and end-of-life reduce social stigma.
- Conversations with clients about importance of advanced care planning strategies including clear family/team roles.
- Faith-based and culture based organizations that provide supports to clients/caregivers.
- Educating clients/caregivers on what to expect with a disease trajectory – and how visualize and plan for the possible later stages of the disease.
- Offering caregivers talk therapy and navigation supports, along with arts therapy/creative expression.
- Identifying “at risk” caregivers during the intake or assessment process to ensure the right resources are made available.

- Developing a care plan for the caregiver (e.g. build upon the Hospice Palliative Model, and AS York Region approach).
- Trained volunteers can play a stronger role in supporting caregivers and clients (e.g. Community Support Services and Hospice Models).

#### Barriers Experienced by Healthcare Providers

- Navigational challenges also apply to healthcare providers – they are seeking better information and supports re: referral options.
- Lack of electronic tools to support information exchange and collaboration between staff of different agencies and organizations.
- Funding criteria (e.g. eligibility) often encourages more reactive responses versus proactive planning and services for clients/caregivers.
- Need for more integrated inter-professional teams – including behavioural and mental health experts on teams.
- Different boundaries or regions can make collaboration and communication difficult for the caregiver and the system. There is a lack of cross-LHIN Regional Networks (formal) to enable smooth flow of information.
- Some clients resist attempts to address their health issue or need – e.g. they refuse assessments or are not interested in receiving a service/program, which presents challenges for the caregiver.
- Language barriers between generations (e.g. senior client and younger caregiver ) can present challenges when interacting with healthcare staff.



# SUMMARY OF KEY THEMES FROM THE CONSULTATION

## Better Communication

Communication between patients, caregivers and healthcare providers remains a top priority in two ways. Firstly, **caregivers want to be recognized and asked how they are doing**. This simple question, asked in the right moment or way (e.g. during or after an appointment, when visiting in hospital, or when picking up a client after a program) presents a **key opportunity to establish a new standard of practice** for healthcare providers. This subtle change in communication will “start the process” of valuing their role, listening to their concerns, and guiding them to supportive resources and services. This practice will also help to identify the caregivers who need a formal assessment and a care plan to address their own needs.

Secondly, healthcare providers are confident in their ability to gather input from caregivers on a patient care plan, but they are seeking more **skills training on communicating about complex or sensitive topics** such as, serious illnesses or end-of-life, navigating the healthcare system, and patient capacity issues and Power of Attorney. Improving the quality of conversations between clinicians, patients and caregivers on these important topics enables meaningful decision-making.

## Stronger Supports for Caregiver Navigation and Education

Navigation remains a significant challenge that is shared by patients, caregivers and healthcare professionals. Caregivers identified that having a caregiver resource and a contact person is very important to them. Caregivers also noted that **peer-based models are very helpful for self-navigation either on an individual or group basis** – via in-person group sessions, skype meetings, one-to-one visits, chat rooms, webinars, and more. In addition, some caregivers identified the need for **professional counselling** (e.g. social worker, psychologist) to foster greater self-awareness and emotional supports to increase resiliency and self navigation.

Healthcare providers are seeking more **training on referral options** for patients/caregivers and **modern methods of making referrals**. They also want stronger networks across organizations and LHINs, to ensure co-ordinated communication and **electronic information sharing between healthcare organizations**, to strengthen patient/caregiver navigation.

## Increased Access to Services and Expanded Supports

Accessing the right types services including, respite services and residential settings continues to be major challenges that caregivers face. The top stated concern of caregivers is having the health system *“respond better to the person I am caring for”*. Bundled into this statement is a mix of having the right levels and types of services available, and having front-line workers that are well trained and familiar with the care routine.

Caregivers and healthcare providers recommend more customized or specialized **Community-Based Day, Evening, Overnight and Short-Stay Respite Programs** that address the unique healthcare, social, mental health, and/or cultural/linguistic needs of clients living in the community. Ideally, these models are comprehensive and offer dimensions that support both the client and caregiver (e.g. wellness, exercise, nourishing food, arts, learning/skill building activities and social activities).

Caregivers also are seeking more care at home through **high quality, in-home Personal Support Worker (PSW) Services, Nursing and Respite**, and **financial assistance to caregivers** to cover the costs of care. Some caregivers are seeking the option of self-directed funding for those caring for individuals with long-term disabilities and/or mental health conditions. In situations when a caregiver can no longer sustain the care at home, more **Supportive Housing/Residential care options are needed**.

## Streamlined Logic Model for Improvement Planning

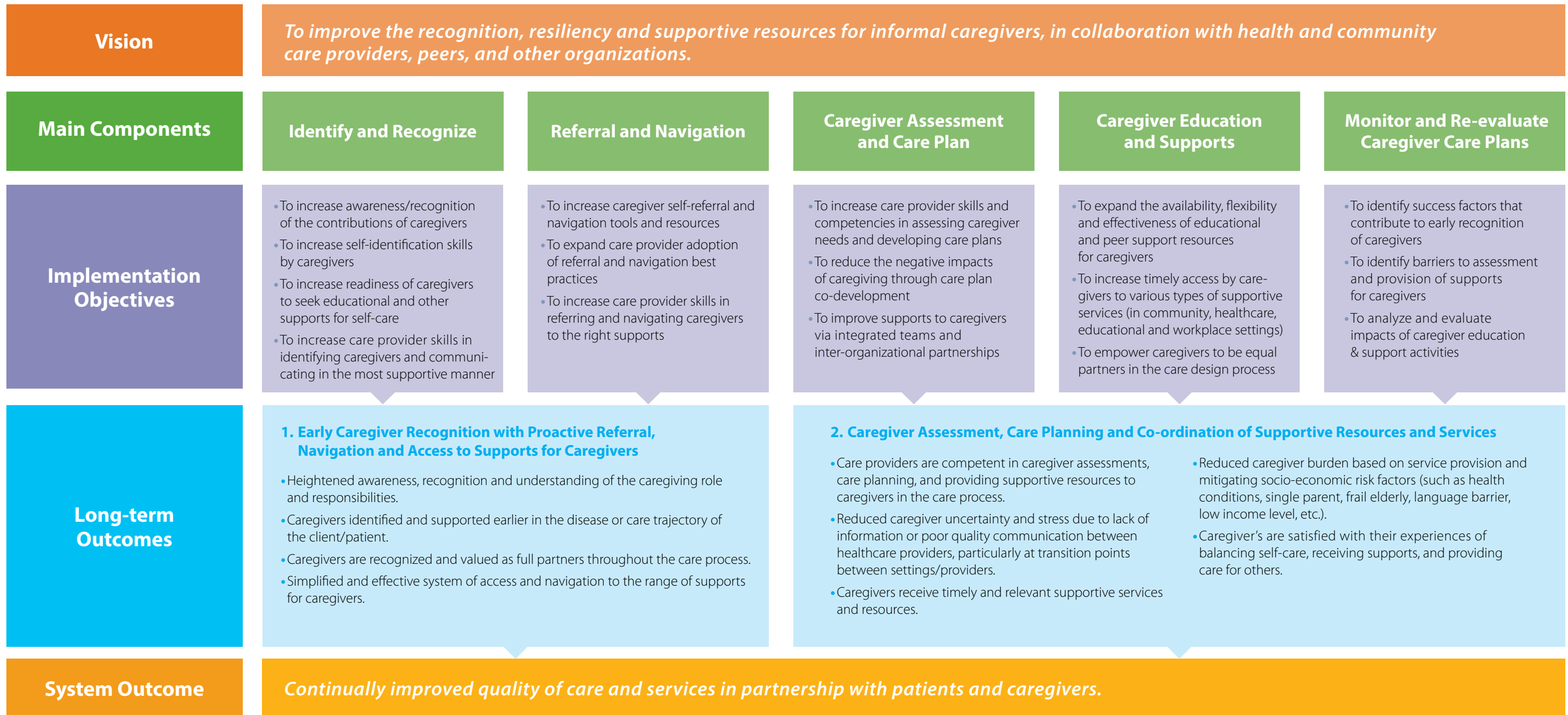
A more simplified version of the Caregiver Support Framework (originally presented in the May 2017 *“A Planning Framework for Improving Supports to Caregivers: A Discussion Document”*) was recommended. The **revised version on page 10** reflects consultation feedback and is intended to guide the development and measurement of improved practices that recognize and support caregivers through stronger communication, care processes, and resources for navigation.

# CAREGIVER SUPPORT FRAMEWORK (Click here for the printable version of the Logic Model)

## Purpose of the Logic Model Framework

The visual representation of the Caregiver Support Framework in the Logic Model format provides a tool for healthcare providers to plan specific activities for achieving the desired outcomes. This format brings together all of the aspects of the framework on one page, to enable healthcare providers to visualize the key elements of the approach, identify gaps, plan and set priorities for implementing specific activities, and measure progress over a period of time.

## Logic Model: An Outcome-Oriented Approach to Health Service Delivery Planning



**For more information about this initiative, or to participate  
in the consultations, you can visit:**

**[www.alzheimer.ca/en/york/We-can-help/  
Support/Caregiver-Framework](http://www.alzheimer.ca/en/york/We-can-help/Support/Caregiver-Framework)**