

Ontario Caregiver Coalition

Initial Advocacy Strategy and Plan

The Issue

“Family caregivers” care for spouses, children, parents, extended family members and friends in need of support due to age, debilitating medical conditions, chronic injury, long term illness or disability. Family caregivers are an integral part of the Ontario health care system. While the Government of Ontario supports family caregivers with several programs and services, a broader range of policies and programs are needed to support caregivers in Ontario and reduce their “burden” of care.

Background

There are approximately 3 million caregivers in Canada (1) who provide care to spouses, children, parents, extended family members and friends. While caregiving tasks include cleaning, home maintenance, meal preparation, transportation and providing personal care (dressing and bathing), caregivers are frequently called upon to deliver skilled care such as dressing wounds, giving injections, suctioning, and muscle stimulation (as designated by a health care professional). Canadian caregivers contribute an estimated \$5 billion in unpaid labour per year (2); saving Canada’s formal health care system as much as \$2 billion per year (3). Caregivers provide more than 80 % of care needed by individuals with long term conditions

Current Status

Care At Home

Frail seniors and people with chronic illness or disabilities prefer to stay at home and in their communities rather than reside in a care facility or institution. In order to stay at home, they often require assistance and supervision on an ongoing basis. While some of this assistance is provided by the publicly funded and/or privately funded home care services, it is usually supplemented – sometimes largely - with care provided by family members and friends.

Demographics

Ontario’s population is aging. Between 2006 and 2031 it is projected that the population 65 and over will more than double from 1.6 million (12.9 % of the population) to 3.5 million (21.4 % of the population). (4) With aging comes increased risk of developing a disability, dementia and/or other serious illness of the mind and body. 15.5% of Ontarians live with a disability. At age 65, one in three Canadians has a mobility-related disability and by age 75 that rate jumps to 45 %. (5) About 90 % of people with Alzheimer’s disease or a related dementia are over 65, with the prevalence of the disease increasing with age. About 40 % of those over 85 have dementia. (6)

Chronic diseases like multiple sclerosis, arthritis and cancer affect people of all ages, requiring care from family on an ongoing and episodic basis.

Burden of Care

Over the past decade there has been considerable research on “informal” caregiving and recognition that family caregivers are experiencing unprecedented stresses. Despite enjoying the inherent satisfaction of caring for their loved ones, studies have demonstrated that caregiving often has a negative effect on the caregiver’s health. Also there are direct costs (like the cost of nursing services or medical supplies not covered through public or private sources) and indirect costs (such as the loss of income from work time lost) which are a significant concern to caregivers. Caregiving places enormous pressure on caregivers and can cause them to become patients themselves; at risk of illness, social isolation, stress, depression and death.

Caregiver Supports

Despite the reliance on family caregivers as essential partners in care for the frail, the elderly and the vulnerable of all ages, there is limited training, compensation or support infrastructure for caregivers in Ontario.

Some caregiver support and respite care programs exist in Ontario, with more coming on stream through initiatives such as the Aging At Home Strategy. But their accessibility is often limited and insufficient. For example:

- Respite care and caregiver support programs can provide a few hours per week for caregivers to catch up on errands or recharge their batteries
- Caregiver education programs provide information and counselling on an as-needed basis
- Financial support may be available to adapt the home for persons with a disability
- Tax credits may be available for in home care
- Compassionate Care Leave benefits are restricted, short term and available only to people in the work force

Caregiver issues and the need for caregiver supports have been recognized across the world. The United Kingdom and Australia have developed special strategies to address the needs of caregivers. The province of Nova Scotia is in the process of developing such a strategy. And the Canadian Caregiver Coalition has developed a Framework for a Canadian Caregiver Strategy demonstrating the need to engage in achieving the vision for family caregiving in Canada.

In Ontario recent developments point to this being a good time to undertake advocacy to advance the public policy agenda relating to caregiving, including the “Caring About Caregivers” Long Range Scenario

Planning of the Ministry of Health and Long Term Care and the recognition of the importance of informal caregiving by Local Health Integration Networks.

Strategic Inquiry

In the fall of 2008, the newly-formed Ontario Caregiver Coalition undertook a “Strategic Inquiry” process to help determine how best to position the issues relating to caregiver support on the public policy agenda in Ontario. Eleven key informants in the Ontario bureaucracy and government were identified to be interviewed to inform the inquiry process. Two important developments at the political level affected the timing and scope of the Strategic Inquiry.

First, unbeknownst to the Coalition, the Ministry of Health and Long Term Care was launching around the same time a consultation process “Caring About Caregivers” to identify and prioritize long term strategies to support caregivers in Ontario. As a result, the scope of the OCC Strategic Inquiry changed so that some of the original key informants identified would not be consulted due to their involvement in the Caring About Caregivers consultation.

And secondly, the public consultation period in advance of the Ontario Budget was pushed forward by numerous weeks to the November-December period, giving the OCC the opportunity to provide input into budget priorities, but several months earlier than anticipated and in a much more scaled back approach due to a perceived lack of appetite at the political level for “big ticket” spending items.

The input acquired during the Strategic Inquiry key informant interviews helped to influence the content and direction of the OCC’s pre-budget submission presented to Finance Minister Dwight Duncan and the Standing Committee on Finance and Economic Affairs.

Seven individuals were interviewed for the Strategic Inquiry, providing rich and creative input. As well, research was undertaken on new caregiver supports being funded by LHINs,

Current Political and Public Policy Environment

Economic Crisis

The global economic crisis is having tremendous ramifications on the Province of Ontario including a return to deficit budgets. The Minister of Finance recently predicted a deficit of close to \$18 billion in the 2009-2010 fiscal year. As a result of the downturn in the economy spending in the Ontario budget due to be released March 26th, is expected to focus on infrastructure and job creation stimulus and restrict new spending in other areas.

Health System Restructuring

Over the past several years, restructuring of the health care system has resulted in decision-making on planning, funding and accountability for hospitals, community care access centres, community support services, mental health and addictions services, community health centres and long term care homes

being mandated to 14 Local Health Integration Networks established by the Province across Ontario. While the Ministry of Health and Long Term Care continues to provide the money, the decision-making on allocation rests primarily at the local level with the LHINs through Service Accountability Agreements. MOHLTC has responsibility for strategic direction and LHIN accountability. While resulting in more community engagement at the local level, the transition to the LHINs has added a layer of complexity to groups working at a provincial level to influence local direction-setting and has the potential to result in inconsistent levels of service from one LHIN to the other.

Caring About Caregivers

As noted above, the MOHLTC has embarked on a Long Range Scenario Planning exercise aimed at identifying and prioritizing long term (30 years into the future) strategies to support the informal caregiving role. The Caring About Caregivers project is being led by the Health System Strategy Division of the Ministry.

Population Health

There is increasing focus on the “population health” model of health care which looks to evidence-based directions with measurable outcomes to improve health outcomes for groups of individuals. Examples of this are the Aging At Home Strategy and the Chronic Disease Prevention and Management Strategy with the current priority focus on diabetes.

Government Health Care Priorities

In addition to Chronic Disease Prevention and Management Framework and Aging At Home, identified government priorities include Mental Health & Addictions, Acute Care diversion (emergency department wait times and alternate levels of care), and Family Health Care (access to primary care). Groups wanting to affect change and move their respective causes forward are advised to find ways to fit within the priorities.

(The following strategy is presented to the OCC for consideration and refinement.)

Advocacy Strategy

Goal :

To bring caregiving issues to the policy table in Ontario

Objectives:

Short Term

March/April 2009

- Dissemination of the pre budget submission to Members of Provincial Parliament and Local Health Integration Networks as an introduction to the Ontario Caregiver Coalition work on caregiver public policy
- Provide input to the draft “Caring About Caregivers” report outlining policy directions and strategy options

June 2009

- Engage key stakeholders in “think tank” format to assist in identification of priorities relating to caregiver support
- Identify potential new members to broaden reach of OCC
- Identify ongoing opportunities for OCC collaboration with and participation in government initiatives which impact on family caregivers, including the “Caring About Caregivers” initiative

Medium to Long Term

September to December 2009

- Utilize the input from the June “think tank” and the “Policy Options for Inclusion in the Pre-Budget Submission” November 18, 2008 document as the basis for development of a Framework for an Ontario Caregiving Strategy
- Prepare an implementation plan to guide the work of the OCC in securing commitment to the priorities outlined in the framework by: Identifying action needed to move the agenda forward; identifying champions among provincial politicians and the bureaucracy (across relevant Ministries) to influence change; developing a communication strategy with succinct messages; and identifying partners for strategic alignment whose work complements that of the OCC;

- Prepare pre-budget submission to the Minister of Finance and Standing Committee on Finance and Economic Affairs for the 2010 Ontario budget

The Initial “ASK” of the Provincial Government

(Based on pre-budget submission November 2008)

1. Prioritize Caregiving Issues to support caregivers today and into the future by:
 - Recognizing the importance of family caregivers
 - Championing caregiver issues
2. Expand Financial Incentives to help defray the cost of caregiving by:
 - Working with the Ontario Caregiver Coalition to examine a range of options that will provide financial support to family caregivers in Ontario
3. Continue emphasis on enhanced health and social services for care recipients and care givers by:
 - Continuing implementation and funding of the Aging at Home Strategy
 - Maintaining and enhancing a community-based programs and services for all Ontarians who require them, including those who are not seniors
 - Developing a consistent message around caregiver support to the LHIN, health care providers and policy makers
4. Facilitate access to information for caregivers by:
 - Establishing an expert panel to examine how family caregivers receive and use information, and provide recommendations to government about how to meet the information needs of family caregivers
 - Encouraging existing information access initiatives to consider how to deliver information to family caregivers

Strategy Tactics

- Media strategy e.g. media releases on framework, pre-budget submission
- Preparation of articles for inclusion in member newsletters/websites
- Use of web page on Canadian Caregiver Coalition website
- Meetings with politicians and bureaucrats
- Preparation and dissemination of briefing notes

Highlights of Strategic Inquiry

(The following input was given by two or more of the key informants interviewed)

- Understand the fiscal reality the government is currently working in
- Government is definitely thinking about caregiver needs
- Be specific and focus on evidence-based measurable outcomes
- Link recommendations to big platform commitments (key priorities)
- Ministry of Health and Long Term Care role has changed significantly to one of stewardship, focusing on outcomes
- Engage with the Local Health Integration Networks

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- (3) Ibid.
- (4) Ontario Ministry of Finance. Ontario Population Projections Update 2006-2031. <http://www.fin.gov.on.ca/english/economy/demographics/projections/w002/>
- (5) Statistics Canada, Participation and Activity Limitation Survey 2006. <http://www.statcan.ca/english/freepub/89-628-XIE/2007002/profileadults-en.htm#a5>
- (6) Caring for the Caregivers. Alzheimer Society of Ontario. January 31, 2008