

Consultation on Family Caregiving

.... From the 2008 Home Care Summit

The Power of People

October 23-25, 2008



Production of this report has been made possible by through the financial support of Human Resources and Skills Development Canada. The views expressed in this paper are the authors' and do not necessarily reflect the opinions of Human Resources and Skills Development Canada or of the federal government.

Introduction

The Canada Health Act recognizes home care as an element in the category of “extended health services”, and, as such, it is not an insured health service to which the principles of the Act apply. Currently nine provinces have legislation related to public home care through various acts and policies. Other provinces and territories have orders-in-council or guidelines that direct the delivery of their home care services. Despite this lack of legislative framework, all provincial and territorial governments have clearly signaled a shift in policy focus from provision of care in an acute care setting to provision of care “closer to home”. Home care has emerged as an essential element of the health care system. The CHCA estimates that one million clients receive home care annually across the country.

Integral to the delivery of home care services are family caregivers – individuals who provide 24 care to families in their homes. Care at home is the unfunded support that is needed to help those with frailties to remain independent for as long as possible in their homes.

Family caregivers are individuals who provide care and assistance for spouses, children, parents and other extended family members who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability. Increasingly, family caregivers are working Canadians trying to juggle employment responsibilities, child care and elder care. Women most often fulfill the caregiving role for their families and as a consequence are particularly vulnerable to illness, stress and lost time at work.

The aging population in Canada translates to more individuals requiring some form of support from family in order to maintain independent lifestyles in their homes and communities. Additionally, the demographic shift to an older population will compound the current health human resource shortage and directly impact the nature and amount of caregiving responsibilities assigned to families.

The issue of family caregiving is of particular interest to the home care sector as this component of health care is heavily reliant on family support and participation in care. In many jurisdictions, the availability of family is an essential criterion for admission to home care. To support this key area, the Canadian Home Care Association (CHCA) has identified 'human resources' as one of its strategic priorities; and is a signatory to the Canadian Caregiver Coalition (CCC). The interplay and balance between employed home care workers and family caregivers needs to be understood. The CHCA Home Care Summit afforded an excellent opportunity to explore the issues related to family caregiving and share knowledge about the challenge and approaches across the country.

An interactive workshop and series of concurrent educational sessions were included in the program agenda at the 2008 CHCA Home Care Summit, which was attended by over 400 stakeholders from across Canada. The special 2.5 hour workshop, *Social Innovation and Family Caregiving*, sponsored by HRSDC was held on the first day of the Summit (Oct 24th). Additionally, there were three concurrent sessions that specifically addressed family caregiving issues within home care. The findings of the workshop form the basis for this report. An overview of the concurrent sessions are appended to this report (Appendix 2).

The Workshop – Social Innovation and Family Caregiving

An estimated 60 participants in the workshop included home care administrators, policy makers, researchers and providers. The workshop was held on October 24, 2008 for 2.5 hours.

Purpose

The purpose of the workshop was to share information and engage in a dialogue on family caregiving and the formal home care system.

Format

Participants were provided with a workbook (Appendix 1) that included the background and context of family caregiving; outlined the work of the Canadian Caregiver Coalition; and presented the questions for discussion.

In order to stimulate discussion presentations by a panel of speakers was provided.

The panelists included:

- Wendy Theis, Signatory with the Canadian Caregiver Coalition and Vice President Government Client Relations, Comcare Health Services
- Faye Porter, National Project Coordinator, Care Renewal: Reaching Out to Caregivers, Phase III funded by J. W. McConnell Family Foundation
- Nora Spinks, President, Work-Life Harmony Enterprises

The discussion was facilitated by Marg McAlister, an experienced facilitator frequently retained by the CHCA to develop policy papers and manage multi-stakeholder projects including consulting support to the Canadian Caregiver Coalition.

The focus of the session was to address the following questions:

- What are the gaps between what family caregivers require in order to support a loved one at home and the support they receive?
- What is the impact of the supply of formal home care services on family caregivers?
- What are the barriers to engaging and supporting family caregivers?
- What kinds of support can home care provide that would be most effective for family caregivers?
- Are there regional variations or differences based on age, gender or disease to the issues facing family caregiving?

Outcome

In addition to addressing the questions, participants left the workshop with:

- A greater understanding of the scope and magnitude of family caregiving in Canada and of the work of the Canadian Caregiver Coalition
- An understanding of the framework for social change that is used by the J. W. McConnell Family Foundation
- Increased knowledge about the kinds of support that are, or should be available to family caregivers
- Recommendations as to how to support people who need to balance caregiving and work

Discussion

Family caregiving is a vital component of home care and was threaded through many of the presentations at the 2008 Summit. Summit delegates shared information about their respective practices and discussed the issues and possible ways to best blend home care and family caregiving. This discussion serves to capture the key messages arising specifically from the afternoon session and from a number of the concurrent sessions. Notes specific to the sessions are found in the appendix to this report.

Health systems across the country are realizing the potential of home care and are responding to increasing demand by health consumers to receive care at home. The growth in home care necessitates available and active participation in care by family caregivers. Families undertake caregiving responsibilities for a number of reasons. According to the Home Care Human Resource Sector Study (2003), the most frequent reason that family caregivers provide care is because their loved one is elderly or frail, but wishes to remain in his/her home. Other reasons, in order of priority, are that the care recipient:

- is not elderly but is physically or mentally ill, disabled or frail in some way
- is receiving rehabilitation services at home after an accident or illness
- has been discharged from hospital and needs short-term care
- is terminally ill and wants to live in the home as long as possible.

Family caregivers carry out a wide range of tasks from housekeeping support to health care interventions. Survey data provides an overview of the types of tasks that family caregivers undertake. These include:

	Respondents
	N=774
Clinical Care	
Cleaning and bandaging pressure or bed sores, infections or wounds	8%
Giving needles or taking care of intravenous therapy	6%
Helping with oxygen, suctioning or other respiratory therapy	5%
Helping with bladder catheterization or bowel routines	4%
Helping with tube feeding	1%
Helping with home dialysis	1%
Instrumental Activities of Daily Living (IADL)	
Making sure care recipient takes medication as required	56%
Getting person to doctors' and other appointments or to visit friends	76%
Helping by communicating with others, reading and writing	33%
Helping clean house, doing housekeeping	61%
Helping with eating or preparing meals	44%
Activities of Daily Living (ADL)	
Helping with dressing, undressing, washing, bathing, helping in the bath-	20%
Helping with mobility problems such as positioning in bed, or moving from bed to chair	18%

The final report from the Continuing Care Research Project for Veterans Affairs Canada and the Government of Ontario released in April 2008 was not able to identify specific home care services that are instrumental in keeping people out of facility care. However, the study findings clearly identified the vital role of family caregivers in enabling people to remain at home. Over 70% of caregivers identified meal preparation, shopping, laundry, housework and managing finances as key activities they perform for their loved one. 83% of clients indicated that they receive emotional support from their family caregiver.

What are the gaps between what family caregivers require in order to support a loved one at home and the support they receive?

Family Caregiver Requirements

Considering the nature and scope of tasks that family caregivers assume, their support requirements are relatively simple. Essentially, caregivers report that they want to be acknowledged and supported personally based on their specific needs; and they want information so they can do a better job providing care to their loved one. While it is important to recognize that each caregiving situation is unique, there are key gaps that have been identified by family caregivers. These include:

- Respite care - “somebody to do their duties to give them a break”
- Emotional or mental health support
- Financial assistance
- Information on community services available for the care recipients
- Information, advice or training on how to provide care
- Information on legal issues.

For many, the support from the formal system is limited. Norah Keating describes four categories of care that individuals experience:

Care from family members only - About one third of care recipients report that their only source of support is from their families who are providing about eight hours of care a week on average.

Care from family and formal providers – About one quarter of older adults, frail older adults receiving care, receive formal care, but only when the level of family caregiving is significant, suggesting that the formal system holds off until families reach the breaking point.

Care from the formal system only – Care recipients are actually less frail and receiving fairly low levels of support. This level of support is often important to enable people to stay in the community, but they report no family help.

No care - 25 percent of frail older Canadians report that they receive no care. It is vital to understand more about this group as they are often invisible, particularly to formal care providers.

If a care recipient doesn't have a family advocate who can broker with the formal system they are virtually "invisible" and it has been shown that it is harder for them to get formal care.

Services through the Formal Home Care System

Formal home care services help people with a frailty or with acute, chronic, palliative or rehabilitative health care needs to independently live in their community and to ensure co-ordination and management of admission to facility care when living in the community is not a viable alternative. These services are designed to **complement and supplement**, but not replace, the efforts of individuals to care for themselves with the assistance of family, friends and community.

Home care programs encourage and support the care provided by the family and/or community. Programs typically arrange for support and relief for family caregivers and provide individuals with information about, and make referrals to community-based services, long-term care homes, and other services. **Increasingly there is recognition that family caregivers must be considered as clients** who may require services of their own, as well as being partners able to provide services within their abilities.

Gaps in Respite

In recognition of the aging population and the need to provide alternative care strategies to support independent seniors as they age, Aging at Home/in Place programs have been initiated in many jurisdictions across Canada. These programs are designed to provide small amounts of home based care in order to support frail seniors and extend the time that people can stay at home. Service models in these programs rely heavily on family caregivers to provide support to the client and meet their ongoing requirements of activities of daily living and instrumental activities of daily living. This program is generally well received by clients as most want to remain at home for as long as possible and research has shown that small amounts of home care service is cost effective and can delay admission to a facility. With the health human resource shortage it is hoped that small levels of formal support can extend the contribution of family caregivers.

Home care eligibility criteria and service delivery guidelines vary across the provincial/territorial jurisdictions. Most set limits on the amount and nature of home care service (including what the care provider is allowed to do) and many have limited hours of operation, not offering service on weekends or evenings. This limitation often results in inflexible respite for family caregivers and minimal time for emotional and/or mental support.

Gaps in Emotional Support

Family caregivers absorb non-economic costs such as physical and mental health and social well-being as part of their caregiving reality. The health team, including home care providers, do a poor job proactively addressing caregiver issues. Interventions are typically provided in response to a crisis.

Gaps in Financial Support

While home care programs strive to meet the needs of the client and the family caregiver, family caregivers absorb out-of-pocket expenses. Many jurisdictions have limits to the amount of financial support for equipment, supplies and medications for individuals outside of acute care. Compounding the additional expenses to provide care are the employment related costs - loss of promotion, reduced hours etc, as a result of undertaking the responsibility of keeping a loved one at home.

Gaps in Access to Information

More so than any other area of health care, home care programs rely on client and family participation in treatment plans. With increased client and family involvement come increased expectations for services and information to facilitate care provision.

For the past decade, Canadians have experienced a revolution in communication and access to information through the explosive growth of the internet. Family caregivers want access to current, relevant, user-friendly information on community resources and care provision. A rise in consumerism in the future and/or the prevalence of older boomers will impact family caregiving as individuals will expect to get health care when and where they want it. In the absence of policy, market solutions such as personal health records that are targeted to patients and their caregivers, will emerge. The future delivery of health care must embrace innovation in order to effectively utilize resources and meet growing demands.

Individuals are admitted to facilities primarily because their health needs increase and/or because their family caregivers are unable to provide the requisite care.

What is the impact of the supply of formal home care services on family caregivers?

The supply of health human resources is a pressing issue across the country. Workshop participants acknowledged the reality that too often family caregivers are left to manage on their own so that those with more acute and urgent needs can be addressed. The most frequent cause of dissatisfaction expressed by caregivers relates to staff shortages and lack of continuity of staff. Home care differs significantly from hospital care in that patients are distributed geographically amongst private residences designed as homes rather than being concentrated in a centralized institutions equipped specifically for the delivery of health care. Patients provide self-care and family and friends provide informal caregiving as part of the planned care (health care management) to a greater extent in home care.

Safety

Dr. Nancy Sears presented findings from her doctoral research showing a statistically relevant number of adverse events while on home care (see Appendix). These statistics prompt reflection as to the expectations placed on families at home and the amount of education, training, and support that is provided to patients and their family caregivers in the home care setting.

The research linked critical indicators to probability and predictability of adverse events. While the work prompts numerous questions and points to the need for more research, there is clearly a need to ensure that clients and family caregivers along with providers need to be part of the safety equation.

Stress

Families generally cope and, when asked, typically indicate that they are “doing okay”. However the stress is cumulative resulting from being overloaded and exhausted; trying to do it all; not asking for help and being isolated. Caregivers have a marked decrease in the amount of time they spend on social and leisure activities. “Caregiver syndrome” is now recognized as a “debilitating condition brought on by unrelieved constant caring for a person with a chronic illness or dementia.” The chronic stress of caring for someone can lead to high blood pressure, diabetes and a compromised immune system. It can also result in inappropriate behavior, such as verbal or physical abuse or neglect in the worst cases, by the caregiver to the care recipient. The stress is not only related to the daunting work of caregiving, but also the grief associated with the decline in the health of their loved ones. Many caregivers are also elderly and may have health problems or functional limitations which impact their ability to provide care. It is suspected that their limitations may worsen more quickly when assuming caregiving responsibilities without support.

What are the barriers to engaging and supporting family caregivers?

There are huge differences in families’ capacity to care. Families do not, or cannot, always attend to the care recipient’s best interests. Families in which all the caregivers are in the labour force are only able to provide a few hours of care. Families are not always available to engage in providing care. Families are smaller, more dispersed; reflect new structures through high rates of divorce and remarriage; have more women in the formal workforce; and experience marriage, childbearing and retirement later in life.

Given these dynamics, a number of barriers to engaging and supporting family caregivers were identified:

Lack of Recognition of the Need

Many family caregivers don't see themselves as caregivers. They see themselves as good daughters, good wives, spouses, sons, but not as caregivers. And they don't reach out for support until they get to a crisis state. A challenge we face is how to provide education to help people understand that they are, in fact, caregivers and that they are eligible, or they have the right to ask for some kind of help?

Additionally, often it is not recognized that family caregivers continue to provide significant amounts of care even after the family member is admitted into a facility (acute care or long-term care). Where families are providing care, many exhausted caregivers do not seek help because they don't recognize their need.

Family caregivers should be viewed from a broad perspective which considers “families that care” not just an individual “family caregiver”. When a person considers their “family”, it is important to look at “the people in one’s network, if on the receiving end of care?” “Who is the group that provides care?” Typically the type of family / friend care networks includes:

- Children at home (primarily adult children who live with the person they're caring for, mostly likely in the labour force)
- Friends, as well as close relatives (often friends are nearby and may be doing some of those kind of episodic things like shovelling the snow and so on)
- Spouses

Distance

95 to 99.8 percent of Canada’s land mass is considered “rural” and communities with less than 10,000 residents account for 22.2 percent of the population or 6.4 million Canadians.’ The senior population within rural areas represents almost 23 percent of this population. However, the notion of rural and remote is not only an issue of quantification (distance and population). Remoteness can be defined by the individual’s connectedness to a social support network of any kind, and to the health care system, both in terms of access and contact. Time and effort to access or provide care are key elements of the rural and remote context. The ability to provide formal or family care is challenging where individuals are isolated.

In some communities, out of necessity, the paid staff may be a family member who also assumes the informal caregiving role. The burden placed on these individuals can become excessive and impact their family relationships.

Lack of Program Flexibility

Also working against the family caregiver is the lack of program flexibility. While changes are being made, the nature, amount and conditions under which service may be provided are restrictive and typically designed to address crises of need. Some programs offer respite care, but typically it is delivered as part of a service package and is subject to a number of restrictions. Participants discussed the concept of respite as an outcome. In other words anything that contributes to a caregiver's emotional, spiritual, physical and/or social rejuvenation enabling them to have the reserves and resources they need to care. This concept of respite as rest and relief, versus a service, is still foreign to many. A temporary move of the care recipient can affect the condition negatively and increase the load on the caregiver. Flexibility would support the caregiver having 24-hour home support for a few days or a week so he or she can actually go away without the guilt of having forced the loved one into a facility for the duration of the respite.

Caregiving – Worklife Balance

Family caregivers must continually balance between providing care and support for their loved one and managing their time, their professional workload and their emotional stress. Results from the 2003 Home Care Human Resource Sector Study were discussed as they impact family caregiver needs for employment flexibility and security. Of the 774 caregivers surveyed, the majority of respondents who indicated that they were employed felt that their employer was very likely or somewhat likely to allow them to leave on short notice to respond to an urgent situation. Between half and two-thirds of this group felt that their employer would allow them to reschedule their work, use holiday time, take unpaid leave or have flexibility work hours to accommodate caregiving needs. Only one-quarter felt they would be allowed to take extended paid leave and only one quarter felt they could work at home instead of at the office.

All employers must respond to the flexibility that their employees require in order to fulfill their caregiving responsibilities. Innovative solutions and collaboration across organizations will need to happen in order to be successful. For example, small employers cannot individually offer senior care programs, but might be able to achieve effective support through associations. Employers could introduce benefits that accrue respite care for their employees who are caregivers.

There is research to support that productivity can improve within a flexible work environment and where employers address family needs. It is vital to think big and differently! An interesting model in Denmark is graduated reduction of paid to volunteer hours creating a culture of volunteerism and caregiving.

Contribution of Seniors

Seniors are often portrayed as a demographic with a single profile and a common set of needs. The continuum within the 'senior period of life' is as varied as in any other period. Neglecting the potential caregiving contribution of seniors compromises access to individuals with a wealth of knowledge and experience.

Seniors caring for seniors as a form of employment in exchange for monetary reimbursement or future service for themselves was discussed. The model should be transportable so that seniors who spend time in more than one community can contribute.

What kinds of support can home care provide that would be most effective for family caregivers?

Caregivers often do not see a need for assistance for themselves. However, the most common form of support requested is: 1) respite to address their need for socialization; 2) assistance with supportive services in the home; and 3) additional home care service to attend to the care needs of the care recipient. Transportation is also frequently identified as a support need.

Many home care programs direct care to the patient / client. It is important to recognize the family caregiver as distinct from the care recipient and having unique care needs. Suggestions on the kind of supports that home care programs can provide included:

Caregiver Assessment - An assessment of caregiver needs independent of the care recipient is vital to providing effective support and could be undertaken by case managers who typically conduct detailed assessments of clients. In addition to determining service needs and resources, the assessments could serve as the appropriate validation for government subsidies.

Flexible Services - Flexibility within home care programs as to the nature, amount and timing of services would allow the staff to be involved in helping the caregiver, not just the care recipient. Providing respite as more than a service, but rather an outcome can have a significant impact on families' abilities to cope. Additionally, providing adequate resources (equipment and supplies) and home care services for clients supports caregivers who otherwise must cope on their own.

Access to Information & Support - Caregivers need access to information and education about how to provide care. The establishment of networks as described in Manitoba (see Appendix) is a promising initiative that provides more structured support and engagement of family caregivers.

Clear Public Policy - Identification of where government should intervene within the family unit and the family's responsibility to care for its own is not consistent amongst Canadians as a whole or home care providers as a subset. This led to interesting discussion about the extent to which the health care system should provide support and relief to families caring for an individual and reinforced the need for leadership on this important social issue.

Are there regional variations or differences based on age, gender or disease to the issues facing family caregiving?

The regional variations relate to how health care, and specifically home care, is delivered across the country. In addition to the variation in home care, the concept of family respite ranges from a service to an outcome. Some jurisdictions provide respite to family caregivers in response to their needs, even to continue to work outside of the home, as in Manitoba. Others, such as Ontario, offer respite as service hours only with a fixed monthly maximum. In Ontario, respite cannot be used to allow the caregiver to go to work. Most jurisdictions offer respite in long-term care facilities; however waiting lists to access a respite bed are lengthy.

An example provided was of a 92 year old caregiver to her 96 year old spouse on an eight month waiting list for respite. Respite in a long-term care facility is not ideal for many, especially those with dementias, as it is too disruptive to the routine.

The delegates struggled with the idea of respite as an outcome and with the concept of fewer restrictions on what could be provided to families. There are a variety of parameters that are assessed before allowing access to limited resources.

Caregivers are not typically compensated and there was a wide range of opinion to the idea of compensating families to arrange care for their loved one or for themselves.

Conclusion and Recommendations

The issue of family caregiving and home care is inextricably linked. Delegates engaged in lively discussion sharing their current practices, the issues that they are addressing and debating where the right amount of formal support should exist when caring for those in need. The premise to which all agreed is that Canadians want to remain independent at home as long as possible and that a mix of home care and family support will make this possible. However, there was a sense that family caregiving as a social value in Canada needs to be declared so that it can be integrated into all aspects of our society.

There were two overarching themes arising from the discussion: 1) investment in home care needs to be targeted to those with chronic long term needs so they can remain in their homes for as long as possible; and 2) a national caregiving framework that articulates the key elements of a Canadian caregiving strategy needs to be adopted as a means of achieving a consistency, and importantly of demonstrating the value placed on this component of our social expectations.

Within these two themes participants agreed that the following priorities and actions need to be addressed. These recommendations do not lie exclusively within the purview of one jurisdiction or authority, but rather require the active engagement of many. As the issue transcends all aspects of society, so does the implementation of strategies.

It is envisioned that the federal government should lead in:

- Minimizing excessive financial burden placed on family caregivers
 1. Broaden the eligibility for income support to a wider group of people with significant caring responsibilities
 2. Enrich the existing caregiver tax credits
 3. Develop ways to improve the assessment process for determining eligibility to income support for family caregivers
- Investing in research on family caregiving as a foundation for evidence-informed decision making
 1. Launch a series of briefing papers that highlight “promising policy” in the area of family caregiving in Canada.

The provincial/territorial governments should be responsible for:

- Safeguarding the health and wellbeing of family caregivers and increasing the flexibility and availability of respite
 1. Develop accessible programs to teach family caregivers about maintaining their wellbeing and about how to provide care
 2. Improve mechanisms for providing support to family caregivers of people with mental illness or addiction both locally and in collaboration with the Canadian Mental Health Commission
 3. Develop health care policy to recognize and address the needs of the family caregiver as separate and distinct to the care recipient so that caregivers can be better informed and supported to provide care
 4. Adopt caregiver assessment as a distinct component of the health care process
 5. Introduce flexibility into respite programs

- Enabling access to user friendly information and education
 1. Develop user-friendly caregiver information packages to support family caregivers through transition points in the health system. This could be modeled after a web-based tool developed in the US.
 2. Incorporate caregiver awareness to all health care professionals' curriculum.

Governments and private employers should work together to develop policy and practice to enable:

- The creation of flexible workplace environments that respect caregiving obligations
 1. Extend the EI training programs to support the reintegration of caregivers into the labour market at the end of a prolonged caregiving episode through the provision of financially supported training, education and labour force re-entry programs.
 2. Host a roundtable to encourage employers from all sectors (public, private and voluntary) to work with caregivers to address their respective needs in order to develop strategies on retention.

Two of the recommended actions could be easily initiated and would be of benefit. These include:

4 a. - Develop user-friendly caregiver information packages to support family caregivers through transition points in the health system.

2 a. - Launch a series of briefing papers that highlight “promising policy” in the area of family caregiving in Canada.

Appendix 1- Session Workbook

INTERACTIVE WORKSHOP: SESSION FRI-12 **Social Innovation and Family Caregiving**



2008

Home Care Summit
Sommet des soins à domicile

The Power of People / Le Pouvoir des Gens

Workshop Agenda

Purpose

The purpose of the workshop is to share information and engage in a dialogue on family caregiving and the formal home care system.

Format

Short presentation by a panel of speakers followed by a facilitated discussion with the workshop participants. The panel will consist of:

- Wendy Theis, Signatory with the Canadian Caregiver Coalition and Vice President Government Client Relations, Comcare Health Services
- Faye Porter, National Project Coordinator, Care Renewal: Reaching Out to Caregivers, Phase III funded by J. W. McConnell Family Foundation
- Nora Spinks, President, Work-Life Harmony Enterprises

The discussion questions:

- What are the gaps between what family caregivers require in order to support a loved one at home and the support they receive?
- Are there regional variations or differences based on age, gender or disease to the issues facing family caregiving?
- To what extent should the formal home care system support family caregivers?
- What are the barriers to engaging and supporting family caregivers?
- Should there be policy or legislation directing employers in Canada to support people who need to balance caregiving and work?
- What would be the appropriate components of such legislation?

Outcome

The intended outcomes of the workshop are that participants will:

- Have a greater understanding of the scope and magnitude of family caregiving in Canada and of the work of the Canadian Caregiver Coalition
- Understand the framework for social change that is used by the J. W. McConnell Family Foundation
- Share their knowledge about the kinds of support that are, or should be available to family caregivers
- Develop recommendations as to how to support people who need to balance caregiving and work
- **Family Caregiving – The Issue**

Background & Context

“Family caregivers” provide care and assistance for spouses, children, parents and other extended family members who are in need of support because of age, debilitating medical conditions, chronic injury, long term illness or disability. Canadians recognize that they will be called upon to play a caregiving role for a loved one who is ill; and that, for many, likely that role will be of lengthy duration. More and more Canadians are experiencing firsthand the financial, emotional, physical and mental burden that accompanies caregiving responsibilities, especially when coupling caregiving with paid employment in the regular workforce.

The aging population is a significant driver to the need for family caregiving and the necessary changes in Canada’s health and social policies. The changing demographic compounds caregiving issues as it heralds greater shortages of health human resources and increased numbers of people with chronic conditions that compromise health and necessitate support from family caregivers.

There has been, over the past several of years, a gradual increase in awareness of the family caregiver by governments. In summary:

- The health reform reports of Commissioner Roy Romanow and Senator Michael Kirby in 2002 both recognized the significant role of caregivers in Canadian society
- In January 2004 the Employment Insurance Compassionate Care Benefits (EICCB) was introduced to provide up to six weeks of income support and job protection for workers caring for gravely ill family members
- In July 2004 a new federal Cabinet position, Minister of State for Families and Caregivers was created
- The federal Speech from the Throne in October 2004 promised further tax based support for caregivers
- In 2005 the federal government through Tony Ianno, Secretary of State for Families and Caregivers hosted regional consultations and a national conference on caregiving
- May 2007 a National Seniors Council with a mandate to provide advice on issues of national importance to seniors was established; the Council has recognized the role of caregivers for seniors

The interest of the federal government on the impact of caregiving to the economic prosperity of the nation was a key pillar to the throne speech in 2007. Stephen Harper re-affirmed his party's support to family caregivers during the 2008 election campaign.

"...a re-elected Conservative Government will introduce important financial changes to benefit families that care for family members with disabilities."

A re-elected Conservative Government will:

Allow families to split their income between spouses to reduce their taxes in situations where one spouse is not working full-time in order to care for one or more family members with disabilities – whether children or adults.

Improve the Registered Disability Savings Program by making it easier for a person with disabilities to access money that has been transferred from the unused retirement savings of a deceased family member."

There have been several announcements by provinces for 'aging in place' / 'aging at home' strategies in the past couple of years which implicitly require family caregiver support

Specific recognition of the family caregiver has been evidenced in some provinces:

British Columbia, 2008 Throne Speech:

"New tools and support services will be created to help home caregivers and family members who are providing in-home care."

Ontario – November 2007 Throne Speech

"Your government believes we need to do more to help seniors who want to stay in their own homes. It will broaden the services available to seniors through home care and provide a caregiver grant to those caring for elderly family members."

Quebec – Assembly Declaration

That the first week of November will be dedicated to Caregivers' Week.

Through the Health and Social Service Ministry, developing services for caregivers has been part of the homecare policy.

New Brunswick – February 2008 Long Term Care Strategy

"The long-term care strategy also calls for studying the idea of compensating family members for helping their loved ones, reducing the property tax burden for people who convert part of their home into an apartment for a senior and helping pay for those renovations."

Nova Scotia – November 2007 Throne Speech

“Strategies relating to labour force development, caregivers, improvements to health-care delivery, and educational achievement will follow.”

Current Status

There are at least 2.85 million Canadians providing care for a family member with long-term health problems. As this statistic is derived from 1997 data, it is believed that 4 - 5 million would more accurately reflect the number of caregivers today.

Caregivers provide more than 80 percent of care needed by individuals with ‘long-term conditions’ and it is estimated contribute more than \$5 billion of unpaid labour annually to the health care system. The changing demographics and aging population are expected to place further burdens on caregivers.

Currently an estimated 1.4 million caregivers over the age of 45 combine caregiving and paid work and another 589,000 combine child care, eldercare, and paid work. Women most often fulfill the caregiving responsibilities, however ten percent of all men in Canada (approximately 1.5 million) are family caregivers and their numbers are increasing.

In 2002, more than 1.7 million adults aged 45 to 64 provided informal care to almost 2.3 million seniors with long-term disabilities or physical limitations. Most of these caregivers were also in the work force, with 7 out of every 10 caregivers in this age range were employed, and many were women.

All employers can expect to have employees who will assume caregiving responsibilities which will have an impact on the employment relationship. These may include lost productivity, increased absenteeism and/or the loss of excellent human capital to the organization. Individuals providing four hours or more of care per week were more likely to reduce their work hours, change their work patterns or turn down a job offer or promotion. Among this group, 65% of women and 47% of men who were working over 40 hours were substantially affected.

Caregivers can be found across all income strata, however, it has been reported that they have household incomes below the national average. Only 35% of households with caregivers report income over \$45 000.

25% of caregivers report their employment situation has been affected by their caregiving responsibilities.

Employed female caregivers are more likely to make workplace adjustments than male caregivers. Changing work patterns and reducing hours were reported by employed caregivers more than declining a promotion or quitting a job.

While many caregivers report difficulties balancing work and caregiving, many caregivers report benefiting from flexibility from their employer (66%).

42% of caregivers believe flexible work hours and provisions for short term job and income protection from employers would be helpful.

More than one third of caregivers report extra expenses due to their caregiving responsibilities. It is estimated that two-thirds of these caregivers are spending more than \$100 per month on caregiving. This is conservatively translated to an annual cost to Canadians of \$80 million.

The economic value of caregivers' unpaid eldercare to the Canadian economy is estimated to be over \$5 billion and between \$6-9 billion for all caregivers (chronic and palliative care) unpaid work.

Caregivers of persons with chronic conditions spent more than 15.6 million hours per week collectively at their caring work.

Canada has the opportunity to build on its global reputation of supporting people with disabilities by developing public policy that specifically addresses the caregiver support for family caregivers.

About the Canadian Caregiver Coalition

Overview

The Canadian Caregiver Coalition (CCC) is a diverse group of organizations from across Canada that join with caregivers, service providers, policy makers and other stakeholders to identify and respond to the needs of caregivers in Canada. The vision of the Coalition is - ***a Canada that recognizes and respects the integral role of family caregivers in society, and supports this role with the understanding that it is not a substitute for public responsibility in health and social care.***

The CCC provides leadership in identifying and responding to the needs of caregivers in Canada. Coalition members recognize and respect the integral role of family caregivers in society, and through the CCC work to have government and the public understand that caregiving is not a substitute for public responsibility in health and social care. The work of the CCC involves: advocacy, research, education, resource development and communication.

History

The CCC was established in 2000 through a Founding Meeting, funded by a donation from Pfizer Canada Inc., of over 50 participants from across Canada, including caregivers, professionals, researchers, government officials, and organizations with interest in and commitment to caregivers. The new Coalition built upon previous national work in caregiving undertaken by VON Canada and Health Canada. In 2002 the CCC was incorporated as a non-profit organization and through the collaborative efforts of the membership the CCC has built a solid record of accomplishments, including the development of a series of policy/briefing papers, support of the 2005 National Conference on Caregiving and the hosting of a National Symposium on 'Tools for Transition: Becoming Partners in Care'. In June 2007, the CCC hosted an International Conference on Caregiving as part of FICCDAT (Festival of International Conferences on Caregiving, Disabilities, Aging and Technology). At the same time the Coalition renewed its commitment to the vision and mission and undertook to restructure itself. Four sustaining partners (signatories) – VON Canada, CSSS Cavendish Installation CLSC Rene-Cassin, Comcare Health Services and the Canadian Home Care Association, committed to building a virtual network of partners who will support the Coalition in an expanded effort to extend influence across the country. The priorities for CCC include: building partnerships and expanding influence with federal, provincial, territorial and local caregiving networks; embracing a grass roots approach; and informing policy and direction.

The Ask: The CCC would like to see the adoption of a comprehensive Canadian Caregiving Strategy which includes:

- Recognition of the importance of family caregiving in policy, practice and legislation
- Provision of comprehensive caregiver support which includes financial measures, services for caregivers based on their assessed needs, and flexible work environments for those caregivers who are also employed
- Research to enable evidence based decision making.

A HIGHLIGHT OF ACTIVITIES BY MEMBERS OF THE CANADIAN CAREGIVER COALITION

(August 2008)

Members of the Canadian Caregiver Coalition work together, and independently, to achieve positive change for caregivers at the federal and provincial levels of government. The momentum for family caregivers is building and this update describes just a few of the many initiatives underway across the country.

ARTICULATING ISSUES & OPTIONS:

A concise briefing paper, outlining the situation and challenges of family caregivers and options available to the federal government to support caregivers across Canada has been submitted to Federal cabinet.

ENGAGING STAKEHOLDERS:

A stakeholder roundtable on Social Innovation and Family Caregiving .

A Caregivers Coalition has been formed in Ontario. The goal is to have the family caregiver recognized in the 2009 provincial budget.

The Nova Scotia Caregivers Coalition has initiated discussions with health and non-health organizations to advance the issues of family caregiving as a vital human resource issue in the province.

FEDERAL / PROVINCIAL ADVOCACY:

In person meeting with the Minister of Human Resources and Social Development, the Honourable Monty Solberg to discuss family caregiving and possible federal initiatives.

Submission by the BC Caregivers Association to the National Seniors Council.

Submission to the Federal Standing Committee on Finance, available on the CCC website www.ccc-can.ca under the “News and Updates” section on the right-hand side of the home page.

The Canadian Cancer Society is advancing the need to support family caregivers as a priority and is calling on organizations to support an ad in the Hill Times.

INCREASING AWARENESS:

CCC is being represented on a panel discussion on family caregiving being held at the International Federation on Ageing's conference in Montreal on September 5th (www.ageingdesignmontreal.ca/en/intro.php).

CCC is hosting a special workshop on caregiving at the Canadian Home Care Association's annual conference from October 23rd-25th in New Brunswick (www.cdnhomecare.ca).

As members of the CCC we all commit to putting our voice behind the message that family caregivers need to be effectively supported in every province and territory. As we work together to build on the momentum, please share your activities and successes.

DISCUSSION QUESTIONS

Consider the following questions from an individual and system perspective.

1. What are the gaps between what family caregivers require in order to support a loved one at home and the support they receive?
2. Are there regional variations or differences based on age, gender or disease to the issues facing family caregiving?
3. To what extent should the formal home care system support family caregivers?
4. What are the barriers to engaging and supporting family caregivers?
5. Should there be policy or legislation directing employers in Canada to support people who need to balance caregiving and work?
6. What would be the appropriate components of such legislation?

Contact Information

If you are interested in additional information about family caregiving, please leave your name and address.

Name _____

Title _____ Organization _____

Address _____

Address _____

Phone _____ Email _____

- Would like to become a partner of the CCC
- Would like to receive reports and information about family caregiving
- Would like to be contacted by CCC personnel to discuss the issue of family caregiving further

Appendix 2 - Overview of Sessions

Harm from Home Care: A Patient Safety Study

Presented by Nancy A. Sears, PhD, University of Toronto, Faculty of Medicine, Department of Health Policy Management and Evaluation, Ontario

This study builds on the limited work on patient safety in home care by understanding the nature of patient safety and expanding the evidence to provide an estimate of the incidence of adverse events in home care. It also describes the relationship between home care patient factors and adverse events. Patient safety is the freedom from accidental or unintended injury. An adverse event is an important subset of patient safety and is described as:

An unintended injury or complication AND which results in disability, death or increased use of health care resources (e.g. Additional attendance by health care professionals, prolonged home care stay, hospitalization), AND is caused by health care management.

Home care differs significantly from hospital care in that patients are distributed geographically amongst private residences designed as homes rather than being concentrated in a centralized institutions equipped specifically for the delivery of health care. Patients provide self-care and family and friends provide informal caregiving as part of the planned care (health care management) to a greater extent in home care. The findings are drawn from a statistically relevant patient population from three sites was that at least 13.2% patients experience an adverse event while on home care and that 10.9% of patients with adverse events died (1.4% of all patients). In this sample the contributing sources for the adverse events were

Self care - 52.6%

Health care staff - 29.5%

Informal caregivers - 27.9%.

Of these adverse events, six resulted in death.

These statistics prompt reflection as to the expectations placed on families at home and the amount of education, training, and support that is provided to patients and their family caregivers in the home care setting. The research linked critical indicators to probability and predictability of adverse events. While the work prompts numerous questions and points to the need for more research, there is clearly a need to ensure that clients and family caregivers along with providers need to be part of the safety equation.

A Model for Development of Caregiver Networks

Presented by Antoinette Zloty, Consultant, Manitoba Health and Healthy Living, Manitoba

Ms. Zloty presented a model for the development of Caregiver Networks, which is being implemented in Manitoba reflecting the importance that is placed in the province on the well being of the care receiver.

The model permits caregivers to access opportunities to gain education information, socialize and discuss common issues and needs, while receiving respite services. The model requires a system's approach taking into consideration the ramifications and/or impact a specific action will have on the entire system. The caregiver social network is one in which caregivers, partners, social workers, stakeholders and interested parties meet and communicate at regular intervals, while receiving care.

Caregivers are defined as individuals who provide the ongoing care and assistance, without pay, to family members and friends in need of support due to physical, cognitive, or mental health conditions. - Canadian Caregiver Coalition, www.ccc-ccan.ca.

Respite is viewed as an outcome, defined as anything that contributes to a caregiver's emotional, spiritual, physical and/or social rejuvenation, enabling them to have the reserves and resources they need to care. It was acknowledged that this concept of respite as rest and relief, versus a service, was adopted from the J.W. McConnell Family Foundation Program.

The rationale for the caregiver network model is to:

1. provide transferability and portability across communities,
2. familiarize partners with the relevant literature and research and how they can benefit from the information, and
3. provide consistent information for relevant staff and caregivers, using common terms and common focus.

The model requires the responsible authority to provide a caregiver network coordinator and to implement a regional caregiver network overview team.

T

he Caregiver Network Coordinator is expected to:

- Review existing and keep current on caregiver needs and support options/services in the community
- Provide leadership /to support and promote the network including scheduling and booking meeting times
- Foster partnerships between responsible authority, government departments, churches, community organizations, businesses, universities or other partners
- Complete assessments of caregivers' stress/risks and care recipients' needs prior to the network being established and at regular intervals throughout the length of time the network exists
- Determine respite care hours required (evenings or days) for congregate respite care during caregiver gatherings
- Conduct satisfaction surveys

Screening both the receiver and the provider of care is an important part of this model and accordingly care receiver and caregiver assessments are conducted prior to participation in the network and at regular intervals thereafter.

Caregivers of all ages and who care for all ages cope differently as they bring to care giving their own internal and external resources including coping abilities, perceptions, values and beliefs, but whether or not they are coping well there is still room for participating in a network since they can provide support to others and they can prevent some health risks by hearing earlier on about information which can become a threat later. Also, there is an opportunity for the care recipient to feel less of a burden on the caregiver when respite care is given.

Participants sought for the networks include caring family members who are unable to help themselves in some areas of daily living and independent activity and who were stressed by the responsibilities of being a caregiver. It is important that the participants do not feel alone in their care-giving journey, that they have support.

The benefits from the network include:

- Caregivers:
- Group respite care in close proximity to home and where the caregivers meet
- Relaxation techniques and opportunities for relaxation
- Passive exercise techniques
- Healthy eating/ cooking classes
- Movies/video watching/discussion
- Hobby development or support for existing hobbies
- Presentations on best practices and research
- Counseling /information on services
- Individual and collective issue identification and possible strategies to address them

Partner/stakeholder:

- Decreased reliance on one to one staffing
- Techniques that help caregivers cope with the stress of caregiving will lengthen the caregiver's ability to continue caregiving for a longer period of time
- Healthy living can be promoted in a supportive group setting
- Knowledge transfer regarding research and best practices can be done more readily in a designated time slot rather than relying on caregivers accessing this information independently
- Decreased waiting time for respite care
- Useful information pertaining to day to day care e.g. nutrition, medications, behavior management and communication can be provided
- Counseling /information on services will be provided through the network
- Caregivers would feel that their individual and collective issues are being addressed

Empowering Interventions – Clients and their Families

Presented by Francis Gallagher and Denise St-Cry Tribble, School of Nursing, University of Sherbrooke with support from Pierre Godgout, School of Nursing, University of Moncton

The presentation focused on empowering interventions as they unfold in home care services with clients and family caregivers. The study was funded by the Canadian Institute of Health Research. The study was based on clients with chronic diseases recognizing the importance of addressing health problems, the long-term activity limitations that are experienced in chronic disease, and the burden that is placed on caregivers. The objectives were to:

1. Describe the modes of actualization of empowerment interventions in home care settings
2. Obtain the caregivers views on empowerment interventions and the process of individual empowerment
3. Examine the relationship between empowerment interventions

The empowerment intervention is recognized as a social process of recognizing, promoting and enhancing people's ability to meet their own needs, to solve their problems, and to mobilize the necessary resources in order to feel in control of their situation. Interventions that promote empowerment enhance a person's potential to learn; to use the tools they need to live as independently as possible and to maintain or improve their own or family's quality of life.

Several individual case examples were presented showing the outcome for clients and caregivers from the empowerment interventions. The preliminary findings of the study suggest that clients benefit from an empowerment strategy during their care delivery. From the client perspective, there is an increase in client autonomy and social integration and a decrease in burden placed on the caregiver. However, the results for caregivers were mixed and there appears to be an absence of empowerment interventions for family caregivers.

Social Innovation and Family Caregiving

This was a special three hour session which began with presentations by a panel of speakers and was followed by a facilitated discussion with the workshop participants. The panel consisted of:

Wendy Theis, Signatory with the Canadian Caregiver Coalition and Vice President Government Client Relations, Comcare Health Services

Wendy Theis is a Registered Nurse with over thirty years experience, the last fifteen with Comcare Health Services. In her current role as Vice President of Government Client Relations Wendy's primary accountability is to support and influence public policy affecting the home care sector. Wendy is a past Director for the Canadian Home Care Association, and is currently Vice President of the Ontario Home Care Association (OHCA). Wendy represents Comcare Health Services on the Canadian Caregiver Coalition as one of four signatories. In her capacity with the coalition she is responsible for the Anglophone partnership portfolio.

Faye Porter, National Project Coordinator, Care Renewal: Reaching Out to Caregivers, Phase III funded by J. W. McConnell Family Foundation

Faye Porter is a Registered Nurse and has a Bachelor of Science Degree in Nursing from the University of Alberta and a Masters' Degree in Health Services Administration from Dalhousie University. Faye is the National Coordinator for Care Renewal: Reaching Out to Caregivers, Phase III, funded by the J.W. McConnell Family Foundation. She has held senior management positions in acute care, public health, and home and community care. In 2002, Faye was awarded the Queen's Jubilee Medal for her commitment to caregiving and volunteerism in Canada and in 2005 she received the Lady Isobel Aberdeen Award, VON Canada's highest award for "service of the greatest distinction" to VON Canada.

Nora Spinks, President, WorkLife Harmony

Nora Spinks is the President of Work-Life Harmony Enterprises, an international research and consulting firm based in Toronto, Canada. For more than 20 years, Nora has worked with progressive organizations, helping business, labour, government and community leaders to create effective, productive and supportive work environments; strengthen families; and build healthy communities. A renowned speaker, author and recognized thought leader, Nora has provided strong leadership in the work-life field across Canada and around the world. Building on experience, staying current and analyzing trends, Nora has added tremendous value to work-life and wellness committees, executive teams, human resource professionals and practitioners, board of directors and research organizations.

The presenters provided an overview of family caregiving and the implications to our social framework as the basis for discussion. The interest and approach of the Canadian Caregiver Coalition (CCC) to achieve announcements by the Federal Government and provinces of specific changes in public policy that manifest support and acknowledgement of family caregivers was discussed. Specifically, the CCC is working to:

- Secure a dedicated champion or sponsor for family caregiving at the senior political level within the federal and provincial/territorial governments
- Strengthen and build a network of national and provincial organizations to support the CCC advocacy strategy
- Link the issues of labour shortage, economic prosperity, health, and investment in family caregiver support
- Work with various mediums to generate awareness and support for the family caregiver

Working with the support of the J.W. McConnell Family Foundation, the CCC is applying a framework for social change that is comprised of:

- Knowledge brokering – to assist and enable improved use of information, particularly between the academic and practitioner communities
- Convening - to overcome ‘silo’ mentalities and increase cohesion
- Leadership development – in order to strengthen the capabilities of representatives participating in social innovation
- Systems transformation - support to bolster implementation of promising initiatives.

Employment culture has gone through a number of phases. In the 1960s and 70s it was ‘work centric’. Employees did not bring their family issues to work and the needs of the job took precedence. In the 1980s and 90s work shifted to being ‘family centric’. Maternity and paternity leaves of absence were introduced and increased; daycares at work were developed and employees who made family a priority were applauded. Currently work is ‘dual centric’ and employers who may have three generations within their workforce are attempting to balance and respond to a variety of needs. The youngest employee sector is largely the product of intergenerational care and is more likely to be engaged in family caregiving responsibilities feeling a commitment to grandparents who may have been actively involved in their upbringing while their parents worked.

Boomers are transitioning to retirement. Currently a baby boomer in North America is turning 60 years of age every seven seconds. One third of women retire within one month of their spouse and another third within a year. The evolution of employer interest in accommodating family caregiving responsibilities is increasing as organizations seek to find innovative ways to recruit and retain their workforce. Family caregivers want recognition and flexibility and accordingly customization is the only practical way for employers to respond to the issue. Innovative practices to support family caregiving include:

- Future leave programs whereby employees can set aside a percentage of their earnings in order to fund a leave of absence. In the past programs typically involved working for four years in order to acquire a 12 month leave. Increasingly, the demand is shifting to two and half years for six months leave or ten months work for a two month leave.
- Meals to go purchased from the employer’s cafeteria
- On site day care services – for elders
- Savings plans, care options are key to the overall compensation package
- EAP coordinated counselling that includes employee’s siblings
- Top up the compassionate care benefit



About the Canadian Home Care Association

The Canadian Home Care Association (CHCA) is a not-for-profit membership association dedicated to ensuring the availability of accessible, responsive home care and community supports to enable people to stay in their homes with safety, dignity and quality of life. Members of the Association include organizations and individuals from publicly funded home care programs, not-for-profit and proprietary service agencies, consumers, researchers, educators and others with an interest in home care. Through the support of the Association members who share a commitment to excellence, knowledge transfer and continuous improvement, CHCA serves as the national voice of home care and the access point for information and knowledge for home care across Canada.

For more information, visit our website at www.cdnhomecare.ca

© The Canadian Home Care Association, February 2009
www.cdnhomecare.ca

The use of any part of this publication reproduced, stored in a retrieval system, or transmitted in any other form or by any means, electronic, mechanical, photocopying, recording or otherwise, without proper written permission of the publisher and editors is an infringement of the copyright law.