



*Care Renewal*    *Second souffle*  
*Reaching out to caregivers*    *L'élan vital d'un répit*

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**The policy implications of 13 caregiver respite projects**

June 2007

Prepared for The J.W. McConnell Family Foundation  
by Janet Dunbrack

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# Table of Contents

Summary.....	1
Definitions.....	3
Context: the Care Renewal Initiative .....	3
Themes emerging from the projects .....	4
Policy Implications .....	8
Policy Recommendations.....	11
Conclusion.....	12
Appendix 1 - Overview of Phase 2 projects .....	14
Resources.....	16

## Summary

This paper examines the experience of 13 organizations that carried out projects intended to help caregivers achieve respite. The paper identifies common themes emerging from the projects and makes policy recommendations to address the gaps they revealed.

The projects were funded by The J.W. McConnell Family Foundation under the initiative *Care Renewal: Reaching out to Family Caregivers*. The McConnell Foundation recognized a serious social policy gap in recognition and support for family caregivers and provided close to \$5 million in funding for the initiative from 1999-2007. The initiative focused on innovative ways to provide support for the nearly three million unpaid caregivers in Canada who are a largely invisible part of the health care system. The primary focus of the initiative was on helping caregivers to achieve respite. The key concept underlying the initiative was that respite is an outcome experienced by the caregiver, rather than a service input by the health care system. Reframing respite in this way opened up the possibility of discovering innovative ways to support caregivers in achieving respite and to give caregivers respite, choice, voice, recognition and empowerment.

The 13 projects involved a variety of organizations from across Canada working with communities of interest that included caregiver associations, health charities, cultural organizations, health care providers, and seniors' associations. Although each project approached respite in a unique way, common themes emerged as important and requiring policies to address gaps:

- self-identification as a caregiver and valuing by self and others
- ways of achieving respite vary
- breaking through social and emotional isolation
- the role of care providers in the health and social services system as well as in the non-profit sector

- partnerships are essential
- network and partnership building takes time
- knowledge leads to successful innovation
- employers can support caregivers
- age and gender
- needs of cultural communities
- volunteer recruitment and retention.

Policies to address these areas of concern can be philosophically consistent with current policy frameworks based on patient and person-centered care, self-management and self-care and network and partnership models of health care delivery. Reframing respite as outcome, rather than system input, allows for fresh ways of thinking about policy development and including caregivers at the policy table.

The following policy recommendations to all levels of government are intended to address gaps identified under the common themes:

- identify and value caregivers
- develop caregiver strategies
- recognize respite as an outcome for the caregiver
- create respite policies that allow for choice and flexibility
- provide training for care providers
- support community-based organizations
- support the creation of networks and partnerships
- facilitate knowledge exchange and translation
- integrate employment and human resource policies with caregiver policies
- recognize and respond to caregiver cultural diversity
- support volunteering.

## Introduction

This paper provides an overview of the main themes and policy implications emerging from a group of projects aimed at developing innovative ways for caregivers to achieve respite. The paper makes policy recommendations for consideration by federal, provincial and territorial governments.

Health care reform has had a significant impact on Canadian families. With the shift in health care away from hospitals and toward home and community care, family members are increasingly called upon to provide care for their loved ones. Nearly three million unpaid caregivers in Canada provide the equivalent of 750,000 full-time positions with an economic contribution to the health and social system of more than \$2 billion a year.<sup>1</sup> Caregivers provide a largely invisible support for the public health system whose needs are often overlooked by health care systems focused primarily on the needs of the care recipient.

A more holistic view of health care is needed which can encompass the whole care system, including the caregiver. The achievement of respite by the caregiver is essential in order for caregivers to maintain their physical and emotional health and to sustain their role as caregivers.



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<sup>1</sup> The J.W. McConnell Family Foundation



## Definitions

In order to ensure understanding of the key concepts of caregiver and respite, the following definitions are provided:

**Caregivers** are individuals who provide care and assistance for their family members and friends who are in need of support because of physical, cognitive or mental health conditions. The term family denotes both family members and friends; the caregiver, whether legally related or not, is considered to be part of the family. Caregivers play an integral role in supporting Canadians who require care, in all the possible settings in which care may be provided. An estimated three million Canadians are caregivers, spanning the age range from youth to old age.<sup>2</sup>

***Respite** refers to caregivers' experiences of relief or renewal. This relief or renewal can be physical, emotional, psychological, social, and/or spiritual. Respite results from any number of supports, activities and planning that may be in place to support caregivers in maintaining their own health and creating more balance in their lives. Respite allows caregivers to improve their quality of life and be more involved in their community. It may also help the family members or friends that the caregiver assists to improve their quality of life and integration within the community.<sup>3</sup>*

## Context: the Care Renewal Initiative

*Care Renewal: Reaching out to Family Caregivers* was an initiative launched by The J.W. McConnell Family Foundation in recognition of the vital role played by family caregivers and the serious social policy gap in recognition and support for caregivers. The McConnell Foundation granted nearly \$5 million to the overall initiative, which included funding to 13

community-based projects that explored the meaning of respite and enabled caregivers to experience physical, emotional, psychological, social and/or spiritual relief and renewal.

Phase 1 of the program, *Respite for Family Caregivers* (1999-2002), supported eight projects with an emphasis on providing family caregivers with an opportunity to make their voices heard, to have choices, and to experience relief from their day-to-day responsibilities. The projects were linked to one another and evaluated to ensure that the collective experiences could be effectively shared among interested institutions and policy makers.

Phase 2, *Care Renewal: Reaching out to Family Caregivers* (2003-2007) supported five new projects to continue exploration of respite as outcome and three continuing projects from Phase 1. VON Canada acted as the secretariat for Phase 2.

These organizations were funded under Phase 1:

- Family Caregivers' Association of Nova Scotia
- Hamilton CaReS Project
- The Lighthouse / Le Phare
- Providence Centre – Tamil Caregiver Project (Toronto)
- Family Caregivers' Network Society (Victoria)
- Seniors Resource Centre Association of Newfoundland and Labrador
- Multiple Sclerosis Society of Canada
- VON Canada

Funding under Phase 2<sup>4</sup> was given to:

- Alberta Caregivers Association
- Canadian Association for Community Living
- CSSS Cavendish (Montreal)

<sup>2</sup> Adapted from Framework for a Canadian Caregiving Strategy, 2005. Canadian Caregiver Coalition

<sup>3</sup> Care Renewal Initiative, November 2004

<sup>4</sup> More detailed Phase 2 project descriptions can be found in Appendix 1



- The Lighthouse / Le Phare (Montreal)
- Multiple Sclerosis Society of Canada
- Pauktuutit Inuit Women of Canada
- Schizophrenia Society of Canada
- Seniors Resource Centre Association of Newfoundland and Labrador

This paper is concerned primarily with the themes emerging from Phase 2. In addition to project evaluation reports, two earlier papers resulted from Phase 1: *This Day is for Me - Caring for the caregivers* by Silver Donald Cameron; and *Towards a National Caregiver Agenda: A Focus on Building Community Capacity – A Call to Action*.

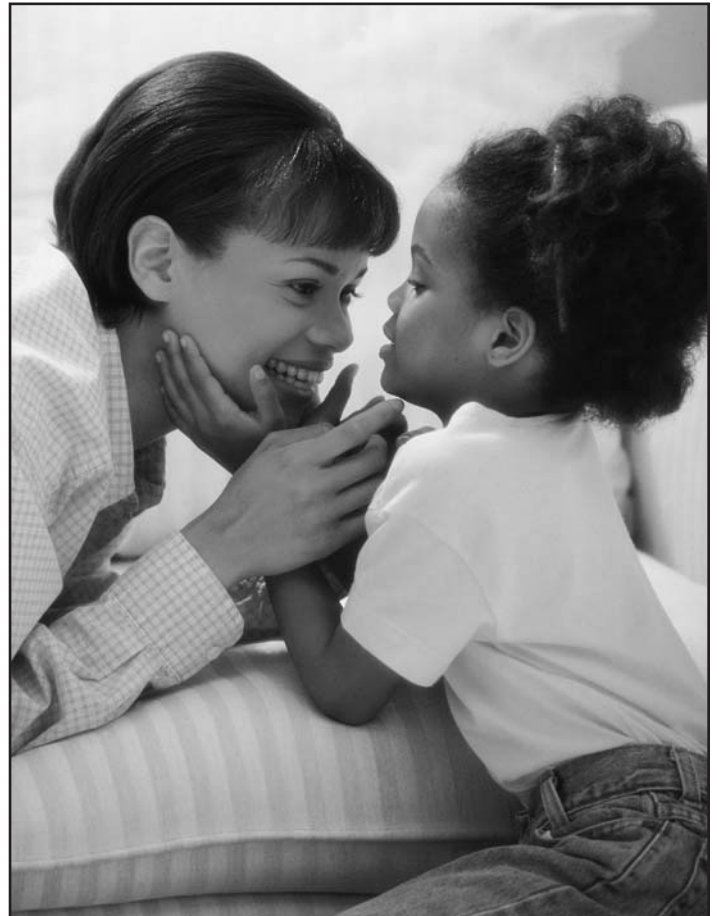
## Themes emerging from the projects

Although each of the eight projects took a unique approach to helping caregivers achieve respite, the following common themes emerged which incorporated the themes emerging from Phase 1 projects.<sup>5</sup>

### Self-identification and valuing by self and others

Several organizations discovered that caregivers may not identify themselves as such and therefore have limited awareness of their needs. In many cultures and families, the caregiving role is assumed as a duty with little awareness of the consequences for the caregiver. Only after caregivers realize that they are caregivers can they begin to perceive their contribution and develop an awareness of the impact of caregiving on their lives. This awareness can lead to recognition of their needs and their right to have these needs met. If caregivers do not have this awareness, they are at risk of isolation, emotional distress, burnout and illness.

Recognition and valuing by others of the caregiver and their contribution are also important. The caregiver must have a response from others if they are to feel valued, legitimized in their needs and able to receive support and services from families, communities and a society that recognize their value and the need to support them.



<sup>5</sup> Phase 1 themes were respite, choice, voice, empowerment, recognition and sustainability.

## Ways of achieving respite vary

The projects revealed a myriad of ways in which caregivers can achieve respite.

These included:

- feeling recognized and valued as a caregiver
- time off without worry or guilt
- letting go and letting someone else provide care
- sharing the caregiving load with the family
- sleep
- having someone to talk to
- providing emotional and social support for other caregivers
- empowerment through information and access to knowledge and tools
- developing new strategies for caregiving and self-care
- having an open, respectful relationship with professional care providers
- education
- opportunities for work, career and personal learning – a life outside caregiving
- getting back a sense of control over one's life
- time and ability to enjoy a relationship with the care recipient without being a caregiver

Because the projects focused on respite as outcome, rather than as a service input such as paid care worker or volunteer hours, they were able to recognize the diverse ways in which caregivers may achieve respite. Some projects re-defined their approach to enabling respite as their projects progressed, in order to make their volunteers or services more adapted to actual caregiver needs.

Ways of achieving respite are diverse, and therefore service options to allow caregivers to achieve respite must be diverse and flexible. A caregiver may need information at one time, sleep at another and social interaction outside caregiving at another time. Simply providing “respite hours” in the home

will not meet all needs. Caregivers may need time, but they may also need support in connecting with available resources in order to achieve respite.

Options for achieving respite do not need to be expensive. Access to knowledge can be provided through online resources or teleconferencing and caregiver help lines that can serve caregivers living with geographic or social isolation.

### Breaking through social and emotional isolation

*One of the most striking caregiver statements to emerge from many of the projects was*  
*Now I know that I'm normal – I'm not the only one experiencing this.*

Once caregivers had connected through social events, teleconferencing or workshops, they expressed relief at learning that there were others like them, experiencing and feeling the same things. Sometimes this knowledge in itself allowed them to feel recharged. Even caregivers who had a social or work life outside caregiving expressed this relief because there were few or no opportunities in their daily lives to share with empathetic others the truth of what they were living as caregivers.

### The role of care providers

Caregivers have significant interactions with care providers such as physicians, nurses, social workers and home care workers. Most of the organizations participating in the Care Renewal initiative learned that the attitudes and behaviour of care providers affect caregiver wellbeing and ability to achieve respite. Caregivers often spoke of feeling invisible when their needs were not taken into account by care providers or when care providers assumed that the caregiver would just have to accept the care plan and services as defined by care providers for the care recipient alone. Caregivers in some projects placed

high value on respectful and open relationships with care providers, which they did not always experience.

Some projects focused on educating care providers to be aware of the caregiver's needs and to incorporate these into the care plan. One result of this was that care providers came to see caregivers and their needs not as just another problem for an overloaded system, but as opportunities to establish relationships where dialogue could lead to innovative approaches that improved outcomes for all those involved in the care plan. Being recognized, valued and treated as a respected partner were rated highly by caregivers and were a focus of care provider training in these projects. Caregivers and care providers involved in other projects also stressed the need for care provider training in this respect.

### **Partnerships are essential**

Many of the projects enhanced their outreach to caregivers through partnering with disease-specific, cultural or service organizations that had existing links to caregivers or to government-supported home care programs. As some project reports noted, no single organization can “go it alone” in supporting caregivers to achieve respite. Partnerships enabled the projects to reach caregivers, facilitate caregiver participation in project activities and enhance sustainability after the projects ended. In many cases, partner organizations increased their understanding of caregiver issues and chose to give caregiver needs a more central place in their policies and programs. The support of communities through community-based organizations, whether at the local, regional or national level, was important in helping caregivers to achieve recognition and support. Partnership activities also raised community awareness of caregiver issues and built community capacity to respond to them.

### **Network and partnership building takes time**

Most projects included building partnerships and some focused on creating caregiver networks. The projects that invested significant time and resources in building networks and

partnerships reported that this took much longer than they had expected. Although the multiplier effect of partnerships and networks can bring enormous benefits, a substantial amount of time must be devoted to building them. Once they are built, they require work to sustain, but usually less intensively than during the initial building period.

### **Knowledge leads to successful innovation**

The *Care Renewal* initiative included several all-project meetings where information and knowledge were exchanged. Participants in the projects reported that this helped them to learn and innovate. Knowledge was also exchanged between the projects and other organizations they were involved with as partners. In addition, the projects discovered that support and guidance from others can enhance the effectiveness of innovations. One organization, for example, was approached by a community group to collaborate in sponsoring a “knowledge cafe” for caregivers. Another organization was able to link researchers with caregivers and to help partner organizations improve their training for volunteers working with caregivers.

### **Employers can support caregivers**

A project that included working with employers to support employee caregivers helped company decision makers and human resources staff to learn that support is more than giving staff time off from work. Information, education and workshops can help caregivers to feel less isolated and to benefit from resources and social support from their co-workers.

### **Age and gender**

Although many caregivers are caring for seniors or may be seniors themselves and although women outnumber men as caregivers, many of the projects learned that caregiving is not just a seniors' issue or a women's issue. A significant number of caregivers and care recipients are relatively young. Men may have different ways of achieving respite than women.

## Cultural communities

Organizations that provided outreach to cultural communities discovered that self-identification and valuing of the caregiver's role by self, family and community were important first steps in working toward respite for caregivers. Culturally appropriate outreach and resources were essential in working with communities. Many projects that did not target specific cultural communities emphasized the need for culturally-appropriate approaches in our diverse society.

## Volunteers

All of the projects involved some degree of volunteer participation and found that volunteers played an essential role in helping caregivers to achieve respite. The volunteer role varied according to the project and included spending time with the care recipient to allow the caregiver time off, organizing support groups and other enriching activities for caregivers, or doing research and administrative work related to the projects. Several of the projects had difficulty in recruiting and retaining volunteers or in matching them with appropriate caregiving situations. One project expressed gratitude at the requirement in some jurisdictions that high school students must serve a number of volunteer hours in order to graduate. Without this source of volunteers, some of the projects would have had trouble recruiting enough volunteers. Other projects supplemented volunteers with university students doing work or study placements.

## Policy Implications

Policy gaps exist in all of the theme areas emerging from the projects. Most of these gaps could be addressed by re-framing the role of caregivers as full participants in health care who have a voice at the policy table and whose legitimate needs are taken into account in developing health care programs. This is consistent with the assumptions underlying patient- and person-centered care and with the movement toward self-management and self-care in public health.

*Caregiver policies can fit into existing policies on chronic disease-management, long-term care, home and community care, seniors, disability, mental health, hospice/palliative and end-of-life care, and outreach to cultural communities, but it is important to identify caregivers as a distinct group with legitimate needs that can be met and to recognize that caregiving cuts across all categories of health conditions and age.*

The Call to Action from Phase 1 of this initiative and the Canadian Caregiver Coalition's Framework for a Canadian Caregiving Strategy focus on a comprehensive approach to caregiver support. This paper is concerned primarily with policies to help caregivers achieve respite while recognizing that respite is one element of a broader policy framework for caregiving.

The current policy climate in Canada presents opportunities to put caregiver issues on the political and social agenda. The present federal government has identified seniors as a priority issue, especially in the areas of housing and elder abuse. A policy link can be made between elder abuse and caregiving since burnt-out caregivers without respite may be at risk of elder abuse and elderly caregivers themselves may suffer from abuse.

An all-party Senate of Canada committee is conducting an in-depth study of aging in Canada and has issued an interim report focusing on the contribution that seniors can make to Canadian society and on the challenges they face. Earlier Senate reports on health care, palliative care and mental health (the Kirby commission reports) highlighted the need for

caregiver support and respite. The federal Employment Insurance (EI) Compassionate Care Benefits program has recently been extended to include family care leave for a wider range of family members living with terminal illness. Most Canadian provinces and territories have modified their labour legislation to be consistent with this EI benefit by allowing leaves of absence with job protection. There is a possibility that a federal election may be called within the next year or two, which presents opportunities now to dialogue with elected representatives of all parties about caregiver issues.

At the provincial and territorial level, several Canadian jurisdictions have taken steps that can lead to enhanced support for caregivers and their achievement of respite. Conversations with federal, provincial and territorial officials at the working level show that many officials understand and embrace the concept of respite as outcome. This understanding has not yet percolated up to the level of official policy and is not evident in policy documents provided to the public on provincial and territorial websites.

There are encouraging policy developments concerning caregiving at the provincial/territorial level. Alberta, British Columbia, Newfoundland and Labrador, Nova Scotia, Ontario and Quebec have declared caregiver weeks. Ontario has declared June to be Seniors' Month and has linked this to increased funding for home care support. Several provinces or territories have disease-specific strategies for cancer, Alzheimer's and other conditions that acknowledge the existence of caregivers and their need for support. In its home care and palliative care strategies, Quebec recognizes that caregivers are service recipients in addition to being partners in care.

These are important developments that provide levers for putting caregiver issues on federal, provincial and territorial policy agendas. While these policy levers open doors to further discussion, many of them focus on a single aspect of caregiving or the dynamics of a specific condition or age group. Since caregivers can be of almost any age and deal with a wide range of health conditions in a variety of contexts, caregiving strategies focused specifically on caregivers may

provide a more effective way to recognize and address caregivers and caregiving in all its dimensions.

A caregiver strategy can achieve many things. It can recognize and value the caregiver as a person making a social contribution who has legitimate needs that can be met. It can provide the opportunity for partnership among caregivers, care providers and policy makers and create mechanisms for ongoing dialogue. This can lead to innovative, collaborative approaches that have a good chance of success. In fact, any initiative that is focused on caregivers as important in their own right rather than as secondary elements in the care plan, has a chance of providing better support to caregivers, resulting in better outcomes for the care recipient and the caregiver.

Nova Scotia is the first jurisdiction to undertake the development of a caregiver strategy. The strategy is being developed with the participation of caregivers and caregiver organizations who report that provincial policy makers have heard and understood that respite is an outcome for the caregiver. Other jurisdictions have not announced formal plans for caregiver support and respite initiatives.

Canada can look to the example of other countries such as the United Kingdom and Australia which have recognized caregivers as requiring specific strategies.

All Canadian jurisdictions recognize the need for caregiver respite and all, at present, define respite in terms of a service provided rather than an outcome experienced by the caregiver. Respite services are typically defined as service inputs such as in-home hours for a paid homemaker, day programs that take the care recipient out of the home, and "respite beds" in long-term care facilities, hospices or hospitals where the care recipient may receive care while the caregiver takes a break or holiday. Some jurisdictions provide in-home stimulation programs for care recipients which are intended to improve alertness and well-being, which may result in an improved situation for the caregiver. Other jurisdictions provide information services, training and education, counselling and support groups for caregivers.



Since respite is an outcome for the caregiver rather than a service input, policies based on this understanding are more likely to be responsive to caregivers and to be flexible and diverse. The enormous demand for the caregiver respite allowance provided by the Multiple Sclerosis Society of Canada project and the resultant caregiver satisfaction show that this may be a model worth considering. Building in choice and flexibility in achieving respite can give the caregiver back a sense of greater control over their life. This can help reduce stress, depression and burnout.

Policies that favour social and emotional connection for caregivers will combat caregiver isolation and lead to reduced stress, emotional relief, information exchange and a sense of being recognized and valued. Breaking out of isolation can be a form of respite for some caregivers. Appropriate policies would support caregiver networks and communication systems, support groups, social and information events, and so on.

Professional care providers need education and training in order to become sensitized to the role of the caregiver as a person with needs that must be taken into account in the care plan. Policies can favour education and training that help care providers to shift their way of seeing caregivers in order to recognize the importance of respite and the reality that achieving respite varies with the individual caregiver. Education can be incorporated into existing policy frameworks for health, human resources and interdisciplinary professional education and development.

Support for caregivers involves support for the communities in which they live and work. This most often means support for community-based organizations and agencies that provide direct and indirect supports to caregivers. Policies that support community-based organizations at the local, regional and national level will help to support caregivers, build social capital and enhance the resilience of communities. These broad concerns should be built into health and social policies.

Policies that support the creation of networks and partnerships must recognize that the process takes time. This is an

important consideration for the current policy emphasis in health care reform on coordination of networks and partnerships as exemplified by Ontario's new Local Health Integration Networks. Networks of caregivers and partnerships with relevant organizations can benefit caregivers and ultimately impact on their recognition and ability to take their place at the policy table. Policies must allow adequate time for the building phase and also for maintenance once the networks and partnerships are established.

Knowledge exchange and translation provide a foundation for innovation in helping caregivers to achieve respite. This is consistent with the current policy emphasis in all jurisdictions on knowledge translation in research and programs. In the context of caregiver respite, policies can recognize and support the exchange of information on successful innovations and strategies.

Employers can be partners in creating caregiver policies,. At the government level, policies can include support for employer policies and programs that recognize and support employee caregivers and that give employee caregivers a voice at the policy table. Governments can work with employer networks and individual employers and employer human resources associations. This may require intra-governmental partnership between labour/employment policy makers and health care/caregiver policy makers. Some of the Care Renewal projects provide models. We can also look to the United Kingdom, where British Telecom, which employs more than 120,000 people worldwide, has implemented a carers<sup>6</sup> policy and works with other employers to develop human resources policies to support caregivers.

Caregivers can be any age, as can care recipients, and policies need to take this into account.

*Caregiver policies will be most effective if they are targeted to caregivers as a distinct group, rather than as add-ons to policies for seniors or chronic disease management.*

Cultural diversity is a fact of Canadian life. The need for cultural competence and culturally-appropriate approaches and resources has been recognized by most governments. The Care Renewal projects have confirmed these needs and shown that cultural competence goes far beyond providing translated print materials and includes a variety of ways of engaging in communication and relationship. The policy challenge is to include caregivers as well as care recipients in culturally-appropriate approaches to health and social services.

Policies that support existing volunteers and volunteerism should be sustained. Volunteer recruitment and retention will continue to be challenges in all areas of Canadian life because of demographic and economic realities that will result in fewer potential volunteers and fewer who can afford to devote significant time to volunteering. Older volunteers will retire, baby boomers will age and the younger population that can provide volunteers will form a smaller proportion of the population than in the past. Volunteers are important partners in caregiver respite. Policies that favour volunteering, such as the requirement for volunteer hours in high schools, may help to increase the number of Canadians who are willing to volunteer throughout their lives.

## Policy Recommendations

The following recommendations are intended to address policy gaps and increase the ability of caregivers to achieve respite.

### Identify and value caregivers

Effective policies will help caregivers to self-identify and receive societal recognition by supporting awareness-raising initiatives. Policies can also provide for programs that enable caregivers to connect with each other and with service providers. Caregivers must have a voice at the tables where policies and programs are developed.

### Develop caregiver strategies

Caregivers need targeted strategies rather than small program

components of strategies aimed at service delivery to care recipients. Recognizing caregivers as needing their own policies and strategies is a major step toward helping them achieve recognition, support and respite. Caregiver participation, voice and mechanisms for ongoing dialogue are essential components of the policy framework. Existing and emerging initiatives for aging, chronic disease management and other concerns can include caregiver components while recognizing that caregiving cuts across all ages and health conditions.

### Recognize respite as an outcome for the caregiver

Recognizing respite as an outcome for the caregiver is a paradigm shift away from seeing the caregiver as a secondary player in the provision of care. When respite is re-conceived as an outcome for the caregiver rather than a service input (e.g. number of respite hours or respite beds), then the caregiver can be seen as a person with legitimate needs who has a right to choice and voice as to how they will achieve respite. This encourages a partnership model that is participatory, responsive and likely to be effective in helping caregivers to achieve respite. Although a number of government officials at all levels of government embrace the concept of respite as outcome for the caregiver, this should be incorporated into official policies.

### Create respite policies that allow for choice and flexibility

When respite is seen as outcome that varies with the individual caregiver, the need for policies that allow for choice and flexibility is clear. Policy development needs to include the caregiver voice. It may be more challenging to develop policy in this way, rather than assigning hours or beds as inputs, but in the long run, this approach will be more effective in ensuring that caregivers achieve respite.

### Provide training for care providers

Policies must ensure that care providers reframe their way of seeing caregivers so that they are seen as receivers of care services as well as partners in care. It is vital to incorporate



the crucial concept of respite as outcome into care provider education and training and into care planning. This will encourage care providers to engage in dialogue with caregivers and to work with them to find innovative and individual ways to achieve respite.

### **Support community-based organizations**

Community-based organizations at the local, provincial/territorial and national levels are well worth supporting because they provide essential programs for caregivers and, more broadly, for the health care system and society. Support for the voluntary sector results in a healthy, resilient society and deserves to be maintained, if not increased.

### **Support the creation of networks and partnerships**

Policies should support the creation of networks and partnerships involving caregivers and relevant stakeholders such as disease-specific and seniors' associations and public health care organizations. Networks will give caregivers a voice and break isolation, and partnerships will lead to knowledge exchange and the creation of innovative approaches to achieving respite. Policies and programs should be built on the understanding that these processes take time and need to be sustained.

### **Facilitate knowledge exchange and translation**

It is essential to build knowledge exchange and translation into caregiver and respite policies because these favour successful innovation and improving quality. This can be achieved through a variety of means, some of which are relatively low-cost. Examples include web-based information,

webcasts, teleconferencing, print resources, workshops, and social/educational events. Here again, caregiver voice is important in developing policies and programs that are likely to meet needs.

### **Integrate employment and human resource policies with caregiver policies**

Policies dealing with employment and human resources can be linked to policies on health care and caregiving. Integrated policies will create dialogue about the employee as caregiver and can lead to caregiver recognition, support and enhanced respite. Participants in the dialogue should include governments, employer associations and individual employers, human resources associations and caregivers.

### **Recognize and respond to caregiver cultural diversity**

Caregivers are as culturally diverse as Canadian society and must be recognized and supported in culturally-appropriate ways. Including caregivers in policy and program development will result in more responsive and effective approaches.

### **Support volunteering**

As part of broader social policies, continued support for volunteering is essential. Extensive research has been done on the dwindling number of volunteers and on incentives to volunteering for younger Canadians. This research can inform policies. Caregivers can contribute to policy development in this area.

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<sup>6</sup> Caregivers are referred to as carers in the United Kingdom, Australia, New Zealand and some other countries.

## Conclusion

A great deal has been learned from the experience of 13 organizations that participated in the Care Renewal – Reaching out to Family Caregivers initiative. A crucial discovery is that understanding respite as outcome opens up the possibility of caregiver recognition, valuing, voice, choice and achievement of rest and renewal. Each of the projects made discoveries that contributed to building a fund of knowledge that was enhanced through exchange. The diversity of challenges and solutions reflected the diversity of caregiver situations and needs. Many of the projects resulted in sustained programs or new approaches that will continue to benefit caregivers.

These projects provide compelling evidence that respite can be achieved in diverse ways that are sometimes surprising and may not be expensive. The trends emerging from the projects invite policy responses from governments and other stakeholders. The policy responses may be diverse but all must recognize that caregivers should have a voice at the policy table.

## Appendix 1 - Overview of Phase 2 projects

### Alberta Caregivers Association



**Alberta  
Caregivers  
Association**  
*Caring for Caregivers*

This project worked with volunteers who were matched with caregivers

in order to provide support that would result in the achievement of respite. An important finding from the project was the variety of ways in which caregivers could achieve respite, including relief from financial stress, help in meal preparation and household chores, companionship and social contact, affordable transportation and mental and physical stimulation. Recognition of the variety of ways in which caregivers achieve respite has led to new ways of looking at the volunteer role so that it is adaptable to the caregiver's definition of respite. The responses of caregivers also led to a shift in focus for the organization from friendly visiting towards developing a 'Certified Caregiver Advisor' program.

### Canadian Association for Community Living



**Canadian  
Association for  
Community Living**

The project focused on building effective respite strategies for caregivers caring for family members

with disabilities through the development of a national resource guide, training, information and workshops with the involvement of hundreds of caregivers. The resource guide and workshops were adapted to fit local conditions.



## CSSS Cavendish, Caregiver Support Centre and the Foundation for Vital Aging (Montreal)

The Caregiver Support Centre of  
Centre de santé et service sociaux  
Cavendish

Centre affilié universitaire

This project developed the Care-ring Voice Network which provided information and social support for caregivers through teleconferences, an info-line and internet-based tools. Caregivers reported that they acquired knowledge that they planned to use in applying new strategies. The teleconference network helped to reduce social isolation and affirm caregivers in their right to support and respite. A number of continuing partnerships were formed with community organizations in Montreal and elsewhere.

This project developed the Care-ring Voice Network which provided information and social support for caregivers through teleconferences, an

## The Lighthouse / Le Phare (Montreal)

LE PHARE  
Enfants et Familles



THE LIGHTHOUSE  
Children and Families

The Lighthouse is a hospice organization offering support to families with children living with life-threatening illness. The project provided an in-home support program that allowed parents time off while a trained volunteer was with their child. Parents reported that they benefited from guilt-free time off and that their child enjoyed time with the volunteer.

## Multiple Sclerosis Society of Canada

MS Multiple Sclerosis  
Society of Canada

The MS Society supported a pilot project that provided caregivers with minimal funding for a variety of individualized services, activities or items that they identified as achieving respite. The Society developed a national strategy on caregiving, including a set of guidelines for supporting caregivers in all operational areas and across each level of governance.

The MS Society supported a pilot project that provided caregivers with minimal funding for a

## Pauktuutit Inuit Women of Canada



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PAUKTUUTIT  
INUIT WOMEN OF CANADA

The project focused on identifying the respite needs of Inuit caregivers and awareness activities to contact caregivers.

Partnerships were developed with home and community care services to determine how caregivers could be supported. A significant finding was that a first step in supporting caregivers is to help them self-identify as caregivers. Following this, caregivers can be recognized, valued and affirmed in their right to respite and support. The challenges faced by caregivers who must spend time in the south (of Canada) while the care recipient is undergoing treatment were highlighted.

## Schizophrenia Society of Canada



A REASON TO HOPE. THE MEANS TO COPE.  
SCHIZOPHRENIA SOCIETY OF CANADA  
SOCIÉTÉ CANADIENNE DE LA SCHIZOPHRÉNIE  
UNE SOURCE D'ESPOIR, DE SOUTIEN ET D'ENTRAÏDE.

The Schizophrenia Society conducted a national survey of caregivers and care recipients to determine their

characteristics, needs and the impact of caregiving on their health and quality of life, as well as the meaning of respite. Caregivers often defined respite as rest and renewal without fear or worry that would result in peace of mind for them. The survey results will provide a basis for policy and program development by the Schizophrenia Society.

## Seniors Resource Centre Association of Newfoundland and Labrador



This project provided direct support to caregivers according to their self-identified needs, enhanced awareness of issues identified by caregivers and promoted policy development. Project resources included a caregiver telephone line, local events throughout the province, support for local caregiver networks, and local initiatives such as telephone buddy systems. Partnerships were formed with other provincial and local organizations in order to reach more communities and caregivers.

## Resources

### Care Renewal project reports

- Alberta Caregivers Association. 2006. *Care Renewal: Reaching Out to Caregivers, the Freedom and Friendship Project*.
- Canadian Association for Community Living. 2007. *Securing Respite: building Effective Strategies for Caregivers Year End Report – 2006*.
- CSSS Cavendish/CAU, Caregiver Support Centre and the Foundation for Vital Aging. 2007. *Care Renewal: Reaching Out to Caregivers, Final Reporting Template – February 2007*.
- Family Caregivers' Association of Nova Scotia. 2003. *Community Caregiver's Project Evaluation Report 2000-2003*.
- Family Caregivers' Network Society, Victoria BC. 2003. *Supporting Family Caregivers, Final Project Report*.
- Hamilton CaReS Project. 2003. *Final Report on Respite Project*.
- The Lighthouse. 2005. *Respite for Family Caregivers Program Report December 2005*.
- Multiple Sclerosis Society of Canada. 2005. *The Caring Balance Pilot Project: Supporting Caregivers and People with MS on Their Journey Together, Final Report December 2005*.
- Pauktuutit Inuit Women of Canada. 2006. *Inuit Family Caregivers Respite Strategy. Final Activity Report June 2006*.
- Providence Centre. 2003. *Final Report: Tamil Caregiver Project, August 2000-July 2003*.
- Schizophrenia Society of Canada. 2005. *People Living With Schizophrenia: Results of a National Survey of Schizophrenia Society Members*.
- Seniors Resource Centre Association of Newfoundland and Labrador. 2004. *Caregivers "Out of Isolation" Phase II Final Report*.
- Victorian Order of Nurses Canada. 2004. *Learning to Listen – Listening to Learn: A New Way of Caring for Caregivers*.

### Other resources related to the initiative

- Alliance of Family, Seniors, Disability and Caregiver Organizations. 2005. *Towards a National Caregiver Agenda:*

*A Focus on Building Community Capacity – A Call to Action.*

- Anderson M and Parent K. 2006. *National Evaluation Interim Report II on the Care Renewal: Reaching out to Caregivers Initiative. Executive Summary. Kingston, Ontario.*
- Cameron, Silver Donald. 2003. *This Day Is For Me: Caring for the caregivers.* The J.W. McConnell Family Foundation, Montreal.
- Torjman S. 2003. *What Are Policy-Makers Saying About Respite?* Caledon Institute of Social Policy, Ottawa.

### Other resources

- All federal/provincial/territorial departmental websites containing information about caregiver policies and programs. Of particular interest is the Nova Scotia Health site link that refers to the development of a caregiver strategy: Continuing Care Strategy for Nova Scotia – Shaping the Future of Continuing Care.  
[http://gov.ns.ca/health/ccs/Continuing\\_Care\\_Strategy06.pdf](http://gov.ns.ca/health/ccs/Continuing_Care_Strategy06.pdf)
- Canadian Association for Community Care. 2002. *Give Me a Break!: Helping Family Caregivers of Seniors Overcome Barriers to Respite.*
- Canadian Caregiver Coalition. 2005. *Framework for a Canadian Caregiving Strategy.*
- Canadian Home Care Association and Canadian Hospice Palliative Care Association. 2006. *The Pan-Canadian Gold Standard for Palliative Home Care.*
- Dunbrack J. 2003. *Respite for Family Caregivers: An Environmental Scan of Publicly-funded Programs in Canada.* Health Canada.
- Senate of Canada. 2007. *Embracing the Challenge of Aging.* Special Senate Committee on Aging, First Interim Report.
- Senate of Canada. 2006. *Out of the Shadows At Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada.* The Standing Senate Committee on Social Affairs, Science and Technology.
- Torjman S. 2006. *Shared Space: The Communities Agenda.* Caledon Institute of Social Policy and the Metcalf Foundation.



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