

Respite Care in Canada



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Tel. (613) 241-8005; Fax (613) 241-5055

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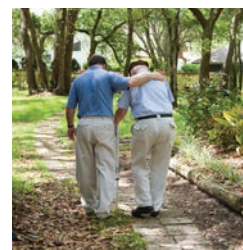
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The Canadian Healthcare Association (CHA) is Canada's only federation of provincial and territorial health associations and organizations, which represents all aspects along the continuum of health, from health promotion through acute care to continuing care. CHA is the recognized champion for a sustainable and accountable quality health system that provides access to a continuum of comparable services throughout Canada, while upholding a strong, publicly-funded system as an essential, foundational component of this system.

Learn about our solutions to health system challenges at <http://www.cha.ca>. Follow us on Twitter: @CHA_ACS.

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Executive Summary

Respite care and services are not insured services under the *Canada Health Act*. Respite is considered part of home care services and depending on the jurisdiction may be partially publicly-funded. Most families pay out of pocket for respite services. Other families may go without respite services due to cost constraints.

An aging population and an aging family support system have major implications for respite services. There is variability in access to and provision of respite services and differences in the application of co-payments and user fees. Over the past decade, Canada's health system has undergone considerable change. Care once delivered in the acute care sector is now delivered in the home or community; however, required hours of home and respite care may not be accessible.

The delivery of appropriate community, home, and facility-based respite services will continue to be a challenge until policy-makers realize its importance to the changing health system and focus on making access to these services more equitable across the country.

With this brief, the Canadian Healthcare Association, whose members span the country and the health continuum, urges governments to give the respite care sector and its caregivers the long-overdue policy recognition that they so deserve.

Respite care is the provision of short-term and/or temporary relief to those who are caring for family members or loved ones who might otherwise require permanent placement in a facility outside the home.



Introduction

Respice care is an increasingly important need in our health care system with the potential to affect all Canadians. At some point in their lives, many Canadians will find themselves in need of respite from caregiving responsibilities. Respite care is a pan-Canadian challenge requiring immediate attention given the amount of care provided by family/friend caregivers and its importance in Canadian society.

For the purposes of this brief the term “disabled” is used to refer to persons who suffer from physical, mental, or cognitive impairment.

Respite Care in Canada explores the respite care landscape in Canada with the purpose of:

- broadening awareness of the current respite experience among key stakeholders, including family/friend caregivers, care and service providers, health planners, policy makers, and the Federal government;
- analyzing major issues associated with respite;
- stimulating debate and promoting action; and
- offering recommendations to all governments and stakeholders to help address the challenges Canada faces.

Canada's health system has recently undergone considerable change. Care once delivered in hospitals and other institutions is now delivered in the home or in communities, whenever resources are available. Health reform, coupled with an aging population, has led to an increase in the demand for home care. Often the responsibilities of caring in the home rest with a family/friend caregiver. As most will need periodic respite, it is essential to develop a pan-Canadian approach to support these caregivers.

Other factors contribute to the changing landscape of health care services in Canada:

- the evolution of medical science has added to the complexity of care;
- the closing of hospitals, regional health care centres and health care institutions;
- the upcoming impact of an aging population; and
- a shortage of health human resources, including family physicians, nurses and other health professionals.

Respite services in Canada, emerged in the late 1960s in response to the de-institutionalization movement and was based on the belief that the best place to care for a person with a disability is in the family home and community, rather than in a facility setting. Respite care is the provision of short-term and/or temporary relief to those who are caring for family members or loved ones who might otherwise require permanent placement in a facility outside the home. Respite can be provided in-home, where an alternative caregiver, paid or volunteer, comes to the home of the disabled person, giving the permanent caregiver a break. Respite can be provided out-of-home, where the disabled person attends an organized program for a few hours up to a few times a week. Respite can also be provided out-of-home in a health care environment for a period of weeks while the caregiver goes away on vacation or attends to personal health issues which may require hospitalization.

Originally, the primary users of respite services were the parents and other family caregivers of children or adults with physical or mental disabilities. Over time, respite care has evolved to become an essential component in the overall support services that families need in order to care for their disabled family members at home. The fastest growing group of potential respite services consumers is the elderly.

What is the appropriate balance between familial and social responsibility for respite care?

- Canadians are living longer. According to Statistics Canada, "between 1921 and 2005, the average life expectancy at birth rose substantially in Canada from 58.8 to 78.0 years for males and from 60.6 to 82.7 years for females" (2010, Publication 82-229-X).
- Extended family networks are decreasing.

- Families no longer live in the same geographical area and there are fewer two-parent families.
- The number of in-home medical needs is increasing, including the use of ventilators and feeding tubes.

Does the responsibility of caring for the disabled rest at the individual/family level or should that responsibility be assumed by society as a whole? Does the primary responsibility for care belong with individuals and their families with government acting as the payer of last resort for those unable to provide for their own needs? Or, rather, is respite care a societal responsibility requiring a corresponding level of public support? These issues will have to be resolved to determine the level and means of reasonable assistance.

Families are diverse: big, small, nuclear, extended, multi generational, living under one roof or many. A family can be as temporary as a few weeks or as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. Most importantly, there is often a strong commitment and attachment among family unit members that includes future obligations.

Statistics Canada. (2010). *Healthy People Healthy Places: Life Expectancy*. Publication 82-229-X. Available online at: <http://www.statcan.gc.ca/pub/82-229-x/2009001/demo/lif-eng.htm>.

Respite care is the term used to denote the act of leaving a loved one with special needs in the temporary care of another party. This provides caregivers with temporary relief from the physical and emotional demands involved in caring for their loved ones, and time to attend to other responsibilities.



What is Respite Care in Canada?

Respite can be defined as a reprieve, a short interval of rest, temporary relief, and as an interruption in the intensity of a caregiving activity. In the literature respite is referred to as care, as a service and as an outcome. It can be a crisis intervention; but, ideally, respite is part of a network of services to support the caregiver(s) and the care recipient. Respite care usually refers to the provision of a break for caregivers, but can also refer to a break for the care recipients.

Case Example

A 13-year-old with a chronic condition goes to summer camp to have a break from his/her regular caregivers and environment, to meet other children with similar conditions, and to learn new skills and coping mechanisms.

Respite care is the term used to denote the act of leaving a loved one with special needs in the temporary care of another party. This provides caregivers with temporary relief from the physical and emotional demands involved in caring for their loved ones, and time to attend to other responsibilities. Golder (2008) finds respite to be a combination of medical and/or social care, that is, care that helps people with daily living, personal care and independence.

Respite care serves a double purpose in that “respite” is a service primarily offered to family/friend caregivers and “care” is provided to the disabled family member. Initially, the focus of respite care

was on the main caregiver's need for a break from care-giving duties. Today, a broader view is emerging that takes into consideration the needs of the care recipient and other family members. In addition to providing a break from caregiving, respite care services can be designed to:

- meet the therapeutic needs of the care recipient;
- offer opportunities to develop the care recipient's social, recreational and life skills;
- strengthen families by reducing stress and ultimately improving long-term functioning of both caregivers and care recipients; and
- maintain or enhance the quality of life for families whose members have disabilities or chronic conditions.

The spectrum of respite ranges from being able to get away from caregiver responsibilities for an hour or two, to taking longer intervals of time away from the caregiving role. A key element of success is the accessibility of resources that enable caregivers "to feel safe, confident and comfortable," (Rajan, 2008, p. 1) leaving their loved ones for any period of time. In short, this is not about letting go of the relationship, but rather the responsibilities.

Case Example

A retired professional hockey player returned to Atlantic Canada to care for his elderly mother who has early-stage Alzheimer's disease. A special team reunion in California necessitated his leaving the small community for several days. Being single and without family support, he investigated respite care options for his mother. Fortunately, a long term care home twenty kilometres away had two respite care beds. While he successfully completed his trip and his mother managed well in the home, the Administrator cautioned the man to plan his future trips well in advance as the respite care program is often booked several months ahead.

The literature presents several emerging perspectives on respite care. For the purposes of this brief:

- care recipient refers to the child or adult living with a chronic condition, be it physical, mental, emotional or psychological, who requires assistance because of their long-term health problem or disability; and
- caregiver refers to either paid workers, or volunteers, friends and neighbours or relatives providing unpaid, in-home care to a child, sibling, spouse, parent or other relative with disabilities.

Respite care is most effectively provided within a family-focused framework, meaning that services are offered to support the entire family not just the care recipient and primary caregiver. Optimally, respite care services need to be flexible and responsive to the individual needs of all families, honouring the ethnic, cultural, religious and geographical differences of families and are individualized to respond to each family's changing needs. Strong family involvement in respite care development ensures the relevance of the program by:

- allowing family/friend caregivers to direct the care needed and help determine if it was successful;
- preventing crisis situations from developing; and
- providing a natural and essential advocate.

The importance of treating caregivers as partners in providing care was reflected in the Alberta government's *5-Year Health Action Plan* released in November 2010 (Government of Alberta, 2010).

Respite as an outcome occurs when respite care provides experiences of relief or renewal. Some literature asserts that the needs and aspirations of the primary caregiver are paramount. That may be so. But we must also acknowledge the needs of the care recipient and those of other family members. Services and care should be conceived and offered accordingly and aim to meet all of those needs.

The outcome of respite should be the result of attending to all family members' well-being from a holistic perspective: emotional, spiritual, physical, psychological, social and financial. Respite as outcome not only enables caregivers and their families to sustain their vital role as caregivers but also can improve their quality of life. The experience of respite will not occur for caregivers if the needs of the care recipient are not met through meaningful and appropriate levels of support and services.

The needs of caregivers are dynamic and may change over time; therefore supports must be both flexible and diverse. A revealing 2007 study joined the ample evidence in the literature that a one-size-fits-all approach will not work. *Care Renewal: Reaching Out to Caregivers* examined 13 organizations across Canada that carried out projects intended to help caregivers achieve respite. The report disclosed numerous ways in which caregivers may achieve respite. These included:

- feeling recognized and valued as a caregiver;
- time off without worry or guilt;
- sharing the caregiving load with the family;
- providing emotional and social support for other caregivers;
- empowerment through information and access to knowledge and tools;

- 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; and
- time and ability to enjoy a relationship with the care recipient without being a caregiver (Dunbrack, 2007).

Respite care can occur in-home or outside the home of the care recipient. It can be offered as a crisis intervention or as part of a network of services that supports both caregivers and care recipients. The availability and variety of respite services vary greatly from one community to another.

Out-of-Home Respite

This type of respite can be provided in a setting where the care recipient receives around the clock care. Giving the caregiver a sustained break of one to two weeks is often a way of maintaining family care in the long term. A common venue for this form of caregiver respite is a long term care home where the disabled person is welcomed as a short-stay resident.

Day programs provide out-of-home respite. Disabled persons may attend day programs, including vocational day programs, specifically designed to accommodate their conditions and abilities. These programs free up family members from one to several days a week to do errands, participate in outside the home activities, or relax at home.

In-Home Respite

Respite is provided in the disabled person’s home. This can be a therapeutic visit from a health care provider, a sitting service, or help from another family member or friend who frees up the caregiver for an hour or more to attend to other activities. The main users of in-home respite services include spouses of seniors, their middle-aged children and families who provide care; and, parents of children with a disability.

Respite Care for Children

In cases of disabled or chronically ill children, respite can prove invaluable for both the caregivers and the children. In addition to the continuum of supports that parents need to enable their children to live at home, there is also a need for “access to trained support workers and financial assistance to allow their children and themselves to enjoy an inclusive community life” (Canadian Association for Community Care, 1996).

Examples of respite services for children and their caregivers may include:

- **Matching and Brokerage Programs:** The objective is to develop long-term, lasting relationships between the family and the caregiver. Care and support is offered in the family home or the home of the respite worker or volunteer.
- **Parent Respite Cooperatives:** Organized by families with a professional coordinator, this type of program serves as a respite care exchange program. Families provide emotional support to each other and exchange direct care. The professional coordinator helps to organize the cooperative and provides ongoing support and guidance to parents.
- **Volunteer Families (Extend-a-Family):** This program matches families of children with disabilities or chronic conditions with host families in their community. Respite is provided in the host family's home. An 'agreement for service' is arranged between the two families, with the host family outlining their commitment and the natural family orienting the host family to the child's needs. Care is systematically reviewed by both families three to four times a year.
- **Buddy Programs:** The objective of this program is to match a teen or grandparent volunteer to provide companionship to a child or youth with disabilities, providing respite to both the parents and the child.
- **Summer Camps:** These offer full recreational and medical support, providing disabled children with opportunities to experience social, emotional, and physical growth while providing a break to the other family members.
- **Group Day Care:** These programs offer daytime care to pre-school children with disabilities. This type of service is licensed and usually provided at a facility or a family day-care home.
- **Group Respite Facilities:** These offer *only* respite care, providing both long- and short-term services. These programs offer the child the opportunity to socialize and develop peer relationships.
- **One-Day Drop-in/Parents' Day-Out Programs:** These programs involve both professionals and volunteers and are recreational in nature.
- **Community Residences:** These residences may reserve one or two spaces for respite care, or admit children for short periods of time in emergency situations.
- **Residential Treatment Facilities:** These may reserve one or two spaces for respite care.
- **Paediatric Nursing Homes/Hospitals/Rehab/Extended Care:** Functioning primarily as long term care environments, these providers offer respite to children who have medical needs.

- **Hospice/Palliative Care Placements:** These programs offer short and long term care respite for families. Comprehensive care programs are provided to address the medical and psychological needs of the child, along with play activities. Counselling and training for families learning specialized medical and care techniques are provided. In some hospices entire families including pets can move in for a number of days at a set number of times per year (Canadian Association for Community Care, 1996).

In 2003 Health Canada produced an updated report *Respite for Family Caregivers – An Environmental Scan of Publicly-funded Programs in Canada*. The report includes data from all provinces, territories; as well as services provided to Canadian veterans through Veterans Affairs Canada and programs offered through the First Nations and the Inuit Health Branch of Health Canada.

Details in the report include the types of respite programs available, user profiles, eligibility criteria, cost to the user, level of demand, and special features. All provinces and territories offer a range of in-home and facility-based respite services based on availability within specific communities or regions. The range of respite services available across Canada includes:

- in-home services for seniors;
- facility-based services;
- day programs;
- rural and remote services;
- services to First Nations and Inuit peoples offered by First Nations and Inuit Health Branch, Health Canada;
- palliative care;
- care for adults with disabilities;
- care for children (under age 18 or 19 depending on the jurisdiction) with disabilities;
- mental health (not all jurisdictions offer specific mental health respite programs); and
- in some provinces, support groups and services for caregivers.

The report concludes that all jurisdictions acknowledge that family caregiver respite is a vital issue for large numbers of their constituents. Some jurisdictions, due to limited financial or human resources, are limited in the provision of respite care. For more information, see <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2003-respite-releve/index-eng.php>.

There are pockets of excellence in the provision of respite care. The following represents an illustrative sampling of innovations in respite care in different parts of Canada.

Quebec

One Centre Local de Services Communautaires (CLSC) in Montreal offers a Caregiver Support Centre for families caring for seniors or disabled adults. The Centre offers a three-pronged approach to respite: a drop-in program for care recipients, education and counselling for caregivers, and in-home “stimulation” programs. To qualify, the caregiver must be a non-remunerated family member or friend who cares for a senior with physical or cognitive impairment or mental health condition. The Centre offers direct and easy access to services, a flexible and varied type of response, and encourages the active participation of caregivers in a variety of activities.

The on-site services program (drop-in) for care recipients includes: a short period of advance booking (from 24 hours in advance), flexibility in start and stop times of respite throughout the day, and the number of hours provided. Seniors participate in group activities that are tailored to their needs. The activities are conducted by trained staff, students, and volunteers. This unique program provides caregivers with free time according to their schedule and their need for respite.

The Foyer Program provides caregivers with information, education and support from trained volunteers who themselves are caregivers. Daily and weekly programs such as: support groups, workshops, conferences, information sessions and access to information on disease, coping strategies, and resources, are offered.

The In-Home Stimulation Program involves students or volunteers visiting with the care recipients in their homes to spend time pursuing physical and recreational activities that are tailored to the individual’s interests and levels of functioning. The program also offers training to caregivers to help them interact with the care recipient in new and creative ways. Caregivers are equipped to provide ongoing stimulation on a long-term basis.

An offshoot of this program is the In-Home Stimulation Program Building Project. This is a group stimulation program organized for residents in buildings that are highly populated with seniors. The groups focus on enhancing individual socialization, promoting neighbourly contact and encouraging stimulating activities.

The Short-Term Counselling Program provides a 6-10 week counselling program for caregivers. The focus of these sessions is on coping skills, stress mediation, limit setting, and linkage with respite/support programs. The program is staffed by a professional social worker trained in caregiving issues. In addition to leading the sessions, the social worker evaluates caregivers, assesses individual needs for services and refers caregivers to other services as appropriate.

Ontario

In 2007 the Ministries of Finance, Community and Social Services and Children and Youth Services, facilitated by the Geneva Centre for Autism, launched a province-wide website, <http://respiteservices.com>, to provide families, individuals and professionals with information and links to local respite services for people with disabilities and their families across 38 Ontario communities.

The objectives of respiteservices.com are:

- to develop a comprehensive respite system across Ontario;
- to provide a central point for information on respite services and the access process for families of children and adults requiring respite options;
- to facilitate the connection to various respite options for individuals, which match their identified needs;
- to connect families to workers who are interested in providing respite care; and
- to work collaboratively with host agency providers and other service providers to enhance the respite services available.

Information and links include:

- respite service providers and respite options;
- information about accessing respite services in local communities for children or adults with physical, mental, or cognitive disabilities;
- events and training opportunities;
- funding sources; and
- information about connecting with workers and families through the Worker Bank and Community Helpers for Active Participation (CHAP) programs.

In addition to providing caregivers with better coordinated local respite resources and information, the goal of centralizing information on respiteservices.com is to be more responsive to their needs. This service provides an opportunity for respite agencies and organizations to work collaboratively to improve the quality and delivery of services, maximizing the most efficient use of resources.

British Columbia

The British Columbia Schizophrenia Society (BCSS) offers a Family Respite Program for primary caregivers of individuals with a serious mental illness, “providing family-centred respite enables the person with a serious mental illness to remain in their own home while the regular caregiver is away” (British Columbia Schizophrenia Society, 2003). Using contracted services of trained and experienced mental health workers, e.g., personal care aides and registered psychiatric nurses, the BCSS Respite Program is flexible to the needs of the whole family. The services range from a few hours per day, week or month, to a period of days or weeks. Funding for this respite service is provided by the Regional Health Authority, up to a fixed maximum per year per family, with all costs being administered by the BCSS. To date these respite services are provided in the Lower Mainland and in Victoria.

BCSS provides an online respite forum operated by the coordinators of the respite program to support other parts of the province. Here family members have access to creative ideas on how to arrange restful breaks from caring for ill relatives.

Golder, S., Mason, A., & Spilsbury, K. (2008). Systematic searches for the effectiveness of respite care. *Journal of the Medical Library Association*, 96(2), 147-52.

Rajan, Doris. (2008). *Real respite for the whole family: a resource guide for organizing and delivering a family workshop on respite for individuals with an intellectual disability and their families*. Toronto: Canadian Association for Community Living.

Government of Alberta (2010). *Becoming the Best: Alberta's 5-Year Health Action Plan 2010-2015*. Retrieved from <http://www.health.alberta.ca/documents/Becoming-the-Best-2010.pdf>

Dunbrack, Janet. (2007). *Care Renewal: Reaching Out to Caregivers. The policy implications of 13 caregiver respite projects prepared for the J.W. McConnell Family Foundation*. Retrieved from <http://www.von.ca/carer renewal/eng/pdfs/Care%20Renewal%20Policy%20Paper%20FINAL%202007.pdf>

Canadian Association for Community Care. (1996). *Best practices in respite for families: A handbook for parents*, Ottawa: Author.

British Columbia Schizophrenia Society. (2003). The (BCSS) Respite Program. Retrieved from: http://www.idplus.ca/clients/bcss/webs/Get_Information/Resource_Materials/respite.htm

The study found that children who received respite services demonstrated higher scores on academic measures than non-recipient children. Their higher achievement was linked to the reduced stress in their home environment as a result of their parents using respite care.



Benefits of Respite Care

It is difficult to evaluate respite care in isolation as generally the care recipient and caregiver are receiving other supports. There are very few quantitative studies on the benefits of respite care. Noted below are some qualitative studies.

A Home Support Canada (1995) report noted that:

Respite care has been reported to reduce the burden on families raising a child with developmental disabilities at home by: relieving familial stress; improving family functioning; improving parental attitudes towards their child; and reducing social isolation.

Early studies on the benefits of respite care have shown that:

- the persistent gravity of caring for a cardio-respiratory monitored infant in the home, and fears of incompetency in managing their infant's care, coupled with inadequate respite, were the greatest sources of hardship for these families (Folden & Coffman, 1993);
- during respite, mothers of school-age children with severe disabilities experienced increased feelings of well-being, a less depressed mood, and that these feelings continued after the respite ended (Botuck & Winsberg, 1991); and

- comparing families who used respite services and non-user families, those using respite services reported increased satisfaction with life; more hope for the future; improved attitudes toward their child with the disability and increased ability to cope (Folden and Coffman, 1993).

Respite care for children lowers the level of anxiety at home. Barnard-Brak and Thompson (2009) conducted a study to examine possible correlations between respite care and academic achievements by children with disabilities. The study found that children who received respite services demonstrated higher scores on academic measures than non-recipient children. Their higher achievement was linked to the reduced stress in their home environment as a result of their parents using respite care.

In cases where the care recipient is suffering from a mental health disorder, family-centred respite is a valuable service as it “recognizes the vital role caregivers play by providing them with an opportunity to attend to their own personal needs” (British Columbia Schizophrenia Society, 2011). Respite care reduces stress at home and can improve the well-being of the family unit.

Studies conducted to measure the effectiveness of respite services on the well being of caregivers have shown mixed results. Lund et al (2009) studied what caregivers do during their respite time. The results indicated that caregivers who had goals for their free time and participated in planned activities were most likely to improve their level of well-being.

Advantages of In-Home Services

In-home services provide:

- flexibility for the caregivers in that they may choose to take their break within the home or get away for a time to run errands or re-energize;
- familiar surroundings allowing family routines and relationships to be maintained;
- cost containment because transportation is not an issue, and special facilities are not required; and
- an opportunity for the respite worker to be able to perform some housekeeping tasks and in the case of children, care that includes siblings from the same family allows caregivers some time away.

Advantages of Out-of-Home Services

Out-of-home services provide:

- a change of routine for the care recipient and the opportunity to socialize and develop other relationships that can promote independence;

- time for caregivers to concentrate on other family matters and activities without the distraction of caregiving tasks;
- economy of scale as respite workers may be able to attend to several recipients at one time; and
- closer supervision of respite workers and volunteers along with opportunities for in-service education and other types of learning.

Folden, S.L., & Coffman, S. (1993). Respite care for families of children with disabilities. *Journal of Paediatric Health Care*, 7(3), 103-10.

Botuck, S., Winsberg, B. (1991). Effects of respite on mothers of school age and adult children with severe disabilities. *Mental Retardation*, 29(1), 43-7.

British Columbia Schizophrenia Society. (2011). Family Respite Program.
Retrieved from: <http://www.bcss.org/2007/07/programs/family-respite-program/>.

Lund, D., Utz, R., Caserta, M., & Wright, S. (2009). Examining what caregivers do during respite time to make respite more effective. *Journal of Applied Gerontology*, 28(1), 109-31.

Many families today are challenged to have a reasonable worklife-family balance. Adding the provision of care and support to a disabled family member on a day-to-day basis can lead to physical, emotional, spiritual, and financial stress, duly labelled in the literature as caregiver burden.



Barriers/Challenges to Using Respite Services

Barriers include difficulty in finding appropriate respite, caregiver burden, human resources issues, and insufficient funding.

Case Example:

A single parent with two children with disabilities is requesting out-of-home respite care. She has no family support and relies on the respite services that are provided by an external agency. The request for respite cannot be planned well in advance because of the high demand for service so this parent has difficulty making plans.

Persons with chronic disabilities — children, young adults and seniors — are living longer today than at any time in our history. Their caregivers may be working outside the home and paying for some services or providing care full-time to their family members. Caring for someone at home who requires the use of assistive devices or someone with dementia can be both physically and emotionally draining. Caregivers may experience sadness, guilt and a sense of failure if they use respite services (Leland, 2008). Many caregivers do not seek respite “until their own health deteriorates” (Sorrell, J.M. & Cangelosi, P.R., 2009, p. 21).

Case Example:

Parents have an autistic 12-year-old that was born a hermaphrodite/intersex. The family chose to make her a girl. They are seeking some respite after years of caregiving. The child is not allowed into school because of toileting issues related to her birth condition. The family does not even have time during their day to do their grocery shopping as the child is home at all times. In this jurisdiction respite is not provided during the school hours as that is considered the role of the school boards. The family is under intense pressure to cope with day-to-day activities, which in this case, prevents either parent from attending school or finding full-time employment, consigning them to a life of poverty and impacting the social services system. The child is not developing any skills in the current situation and the family is approaching the breaking point.

Caregivers often refuse respite because they worry that the care recipient might think they are unable to cope with the home situation. If the care recipient shows any type of resistance to respite care, caregivers are more likely to reject respite as a viable option.

Case Example:

Families are not always kept up-to-date about available services. A 78-year-old woman has been caring for her 82-year-old, developmentally disabled brother for the past 20 years following the death of their parents. These siblings were raised at a time when family was the sole support and the health system did not provide assistance. The sister requires knee surgery and is at a loss as to how to get care for her brother during her hospitalization and recovery.

The labyrinth of government departments involved in the delivery of respite care may seem daunting to caregivers. Searching for resources can be a frustrating experience for caregivers and this may be one of the factors that accounts for the low use of certain services. Caregivers often need an advocate to assist them in finding out what respite services are available. Individuals connected to a home care program are in the best position to learn about, and take advantage of, respite care.

A study in Australia (Vecchio, 2008) reported that as the age of the caregiver(s) increased there was a corresponding greater use of respite services. The longer period of time that care was required increased the use of respite services. Those living in remote areas were more likely to use these types of services, mainly due to lack of family supports to share the burden. Caregivers born outside of Australia were less likely to pursue respite services. Caregivers in the workforce (part-time or full-time) were higher users of respite than those not working outside the home. Those people caring for relatives with physical disabilities were less likely to use respite services than caregivers who looked after family members with a mental disability.

“Of all the carer relationships, spouses were most likely to be non-users of respite services compared with parents, adult children, or friends” (Vecchio, 2008, p. 461).

Many families today are challenged to have a reasonable worklife-family balance. Adding the provision of care and support to a disabled family member on a day-to-day basis can lead to physical, emotional, spiritual, and financial stress, duly labelled in the literature as caregiver burden. The nature of the relationship between the caregiver and care recipient is a critical factor in the perceived quality of the caregiver’s life. Warm relationships are more apt to lead to the caregiver’s well-being. Dysfunctional relationships can add to caregiver stress and anxiety. Giving care to a person who is cognitively impaired can be especially challenging, as most family/friend caregivers of people with Alzheimer’s disease report that they frequently experience high levels of stress, and nearly half say they experience depression.

A vast array of human resources may be required depending on where respite care is provided. Facility-based services and day programs may include the services of numerous health professionals: physicians, nurses, social workers, dietitians, physiotherapists, occupational therapists, speech language therapists, and pharmacists. In-home services may require some of the same professionals; however, the majority of the non-relatives providing care are friends and neighbours, home support workers, personal support workers, care attendants and medical equipment suppliers.

Personal support workers and home support workers are either part of the home care team or are privately contracted by the family to provide services at home which allows the day-to-day caregiver some respite. These workers can provide a variety of services: cleaning, shopping, meal preparation, personal care, and assistance with mobility, social and recreational activities. These service providers are “one of the largest groups to interact with seniors in their homes and may be the only contact the senior has with the broader community” (Special Senate Committee on Aging Report, 2009, p. 150).

Unfortunately, personal support workers and home support workers are often under-trained, under-paid and under-valued. Their talents may be under-utilized if they are not working to their full scope of practice or fully engaged as members of a multi-disciplinary team. Opportunities for formal training in this field are limited to Alberta, Nova Scotia and Ontario. There are no national standards and much of the training is done on the job or by the for-profit organization which hires these support workers.

The Federal/Provincial/Territorial (FPT) Health Human Resource Strategy does not include home and community support services. A Special Senate Committee on Aging report recommends “that the federal government work with the provinces and territories to address the recruitment and retention of home care and home support workers as part of the FPT Health Human Resource Strategy” (p. 152). There is a definite need to develop a national training curriculum for home care and personal support workers. “These efforts would have the added benefits of raising awareness of the value of home care and personal support workers, foster wage parity, and help address recruitment and retention issues” (p. 153).

A large component of the human resources related to respite care is the network of caregivers comprised of family and friends. Using data from the Statistics Canada *2002 General Social Survey*, Hollander et al. (2009) in looking at unpaid caregivers providing care to the elderly, estimated there were 2,061,673 unpaid caregivers over 45 years old, providing an estimated \$26 billion annually. “This study, on estimating the replacement costs of unpaid care in Canada, clearly indicates that unpaid caregivers contribute much to Canadian society, its economy and the well-being of its citizens. And they do so, by and large, willingly” (p.48).

The physical and emotional demands on the caregiver risk increased caregiver burnout and long-term health consequences. The diverse needs of caregivers and care recipients must be addressed in order to maintain this critical resource. Caregiving needs to be formally recognized and supported at all levels — financially, physically, emotionally, socially and spiritually.

CHA's 2009 policy brief, *Home Care in Canada: From the Margins to the Mainstream*, noted “caregivers play a critical role in allowing people to remain in their community and maximize their independence. Support programs for these individuals could include greater financial support, recognition, and more opportunities for respite care or day-away programs” (page 53).

Although the male caregiver population is growing, a Decima Research study in 2002 (conducted for Health Canada) revealed that 77% of caregivers are women, usually wives or daughters of care recipients. This group of caregivers is aging and many have additional responsibilities and stresses related to limited income, inadequate family resources to provide assistance, and the risk of losing paid employment. “Identifying older caregiver’s needs and enhancing their health is important for the continuation of a vulnerable caring relationship” (Salin & Astedt-Kurki, 2007, p. 39).

The Statistics Canada’s 2007 *General Social Survey on Caregiving* indicates that between 2002 and 2007:

- the number of caregivers increased from 2 million to 2.7 million;
- nearly 70% of care was provided by close family members;
- nearly 40% of female caregivers and some 20% of male caregivers provided personal care, including bathing and dressing;
- approximately 60% of women and 30% of their male counterparts performed regular tasks inside the house, such as meal preparation, cleaning or laundry;
- caregivers were less likely to take on medically related tasks than other types of tasks. Of those who did, women (25%) were more likely to do so than men (16%);

- women (42%) were more likely to assist with care management (scheduling appointments) than men (33%); and
- the majority of caregivers expressed that they were coping with their caregiving responsibilities. More than half said they were coping very well; more than 40% were managing fairly well; less than 5% indicated they were not doing very well or not well at all. Of the caregivers who said they were coping well to very well, 70% also said they experience burden/stress.

The survey also revealed these statistics from 2007:

- Nearly 43% of caregivers were between the ages of 45 and 54, a time of life when many Canadians still have children living at home. About three in four caregivers were married or living common-law. 57% of caregivers were employed.
- Family/friend caregivers between the ages of 45 to 64 years had been providing care for an average of 5.4 years. Caregivers over 65 years old had given assistance for an average of 6.5 years.
- Approximately 10% of all caregivers aged 45 and over had been providing care for at least 13 years; the majority of these were married women, half of them were employed.

CHA's *Home Care in Canada – From the Margins to the Mainstream* provides further insight into this Statistics Canada report:

The results are limited in that they reflect only data about caregivers between the ages of 45 and 64. The 2007 survey affirms and elaborates upon the findings of the earlier surveys that caregiving is common, that females are more affected and provide a deeper level of care, and that caregivers have responsibilities beyond providing care. The most interesting difference between the 2007 survey and the earlier ones is that the majority of caregivers in the 2007 one indicate they are coping quite well, perhaps because of the youthful age group surveyed and the exclusion of the majority of caregivers – those aged 65 and over (p. 66).

The 2009 Special Senate Committee on Aging report indicated that 90% of home care needs are not met by the public health care system. “With smaller family sizes and an increasingly mobile population separating family members, it is likely that more and more seniors will require external support” (p. 149).

The Canadian Medical Association (CMA) in their 2010 report, *Health Care Transformation in Canada*, reminds us that “the continuing care needs of the disabled population at all ages must also be appropriately addressed” (page 17).

The shortage of physicians, nurses and other health care professionals in Canada is well documented. The federal government launched the Pan-Canadian Health Human Resource Strategy in 2004 to focus on recruitment and retention strategies. It has evolved to include increasing the supply of health care providers and supporting the effective use of skills across the health workforce (Health Canada, 2010).

While adequate supply of health professionals remains a critical issue, ongoing studies into health human resources have broadened to include the examination of different skill sets for health promotion and chronic disease management required in home care settings.

A major human resource challenge is how to maintain caregiver well being. At the individual level, where and when is it most effective to introduce respite services along the continuum of care? Addressing the myriad of services required by caregivers and care recipients in an effective and efficient manner is critical to maintaining a sustainable health care system (Health Canada, 2005).

The August 2010 Canadian Institute of Health Information (CIHI) report, *Supporting Caregivers — the Heart of Home Care*, confirms that caregivers experience distress. The study reviewed over 130,000 seniors (persons aged 65 and over) receiving publicly-funded long term home care in 2007-08. Many of these clients had complex health conditions and 98% of them also relied on a caregiver to provide emotional, physical and other home supports. The majority of these caregivers were spouses and adult children.

While some 25% of spouses reported distress, the greater the amount of care provided increased the risk of caregiver stress. This is noteworthy as caregivers at risk of distress need to be identified and respite provided if the alternative is having the care recipient unnecessarily becoming a permanent resident in facility-based care. Uprooting from one's home to a long term care home can add stress to the care recipient and tremendous guilt to the caregiver. Home care clients with moderate to severe cognitive impairment, depression or the displaying of aggressive behaviours typically lead to higher rates of caregiver stress, up to 52% higher than the average in the CIHI study.

The Canadian Medical Association also notes that there is a lack of support for caregivers, stating that “much of the burden of continuing care falls on (unpaid) caregivers. More than one million employed people aged 45-64 provide care to seniors with long-term conditions or disabilities and 80% of home care to seniors is provided by unpaid caregivers” (Canadian Medical Association, 2010).

The June 2005, *Environmental Scan for First Nations Health Human Resources Strategy Development*, noted that “a problematic aspect for ensuring the effective delivery of primary care services include the absence of data for community health planning, including health human resources” (p. 17).

In 2005, the Assembly of First Nations *Action Plan on Continuing Care*, which includes respite care, identified five key areas to be addressed: sustainable funding, flexibility in program design, culturally appropriate services, health human resources, training and capacity development.

In 1999, Health Canada introduced its First Nations and Inuit Home and Community Care (FNIHCC) Program to work with First Nations and Inuit communities in developing comprehensive home and community care services that respect traditional, holistic and contemporary approaches to healing and wellness. In-home respite care is offered by the FNIHCC Program. A 2004 evaluation report on the FNIHCC Program noted that training and staffing were the key challenges during program planning. The report recommended that a study be conducted to better understand its health human resources; as these were insufficient to meet the needs of remote and small communities whose population and funding formulas were insufficient to retain nursing and personal care workers services.

Health Canada initiated a study for the FNIHCC Program to better understand its health human resources needs especially in light of the home care basket of services announced in the 2004 First Ministers Health Accord (short-term acute home care, short-term acute community mental health home care and palliative care). These were insufficient to meet the needs during the implementation, particularly in remote and small communities whose population size (due to funding formulas) would provide insufficient funds to retain the services of a full-time nurse or personal care workers. Recruitment and retention in these communities pose an additional challenge in program implementation, causing delays in service provision while high turnover rates provide inconsistencies in service delivery.

The underfunding of respite services represents another barrier. Families may believe that the burden of searching out the most appropriate type of respite and then potentially paying the additional costs is simply not worth the effort.

Sorrell, J.M., & Cangelosi, P.R. (2009). Caregiver burden or caregiver gain? *Journal of Psychosocial Nursing*, 47(9), 19-22.

Leland, J. (2008) For families of the ailing, a brief chance to relax. *New York Times*, August 19, A13.
Retrieved from: <http://www.nytimes.com/2008/08/19/health/19aging.html>.

Vecchio, N. (2008). Understanding the use of respite services among informal carers. *Australian Health Review*, 32, 459-67.

The Special Senate Committee on Aging. (2009). *Canada's Aging Population: Seizing the Opportunity*. Ottawa, ON: The Senate.

Canadian Healthcare Association. (2009). *Home Care in Canada: From the Margins to the Mainstream*. Ottawa: Author.

Salin, S., & Astedt-Kurki, P. (2007). Women's views of caring for family members: Use of respite care. *Journal of Gerontological Nursing*, 33(9), 37-45.

Canadian Medical Association. (2010). *Health Care Transformation in Canada*,
Retrieved from: http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Advocacy/HCT/HCT-2010report_en.pdf

Some respite care is funded through home care programs.

There are no data available indicating how much is funded.

Most respite is paid for by the families that need it.



Funding of Respite Care in Canada

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hile provincial and territorial governments across Canada provide some publicly-funded home care/home support programs, users find the system difficult to navigate. Six of the provinces require income-testing and fees for home care services generally apply to long-term home supports and/or residential care. The other seven provinces and territories have no income-testing for home care services.

The federal government supports the Veterans Independence Program, through Veterans Affairs Canada, and the First Nations Adult Care Program, through the Department of Indian Affairs and Northern Development, and First Nations and Inuit Home and Community Care Program through Health Canada. These programs include respite care and palliative care and have no income-testing for home care services.

Home care is recognized by both governments and stakeholders across Canada as being an important component of the health care system. Home care services are designed to assist Canadians with acute, chronic, palliative or rehabilitative needs to live independently and to coordinate admission to facility-based care when required. Home care services are not intended to supplant the efforts of individuals and their friends and families to provide self-care. Home care programs support community and family care by making referrals to other services as needed and to arrange support and respite to family members. All home care services across the country are based on assessed need.

Ontario, Manitoba, Quebec, Prince Edward Island, Northwest Territories, Yukon, Nunavut and federally funded programs do not charge any direct fees for home care services. Professional services are provided at no cost in the other six provinces, but there are charges for home support

and homemaking services. In some regions there are direct fees associated with adult day care, meal delivery and respite.

Numerous reports have identified home and community based care as a strategic area for the health care system to be able to address current and future needs of Canadians. In 2002, the Romanow Report, *Building on Values: The Future of Health Care in Canada*, described home care as the next essential service in the health care system. In 2004, the First Minister's Meeting on the Future of Health Care produced *A 10-Year Plan to Strengthen Health Care*. A key element of that plan was the recognition that "home care is an essential part of modern, integrated and patient-centred health care. Improving access to home and community services will improve the quality of life for many Canadians by allowing them to be cared for or recover at home" (Health Canada, First Minister's Meeting on the Future of Health Care, 2004). In 2004, the First Ministers agreed to provide first-dollar coverage by 2006 for some home care services, based on assessed need. Included were the following services:

- 2 weeks short-term acute home care which could include nursing and personal care;
- 2 weeks short-term acute community mental health home care, including crisis response services; and
- End-of-life care.

Some respite care is funded through home care programs. There are no data available indicating how much is funded. Most respite is paid for by the families that need it. Donor-funded programs of charitable organizations and religious organizations provide some home support in terms of friendly visiting, transportation to appointments, and physical stimulation programs.

In its 2009-10 budget, the Province of Quebec committed to continuing an annual refundable tax credit up to \$1,560 for informal caregivers who pay for respite care out of pocket.

Compassionate Care Leave

Governments across Canada have recognized the burden of care to caregivers with a seriously ill family member. However, there are some jurisdictional differences in the provision of compassionate care leave.

Between 2003 and 2006, all jurisdictions (federal, provincial, and territorial) included compassionate care leave provisions for caregivers in their employment standards legislation (Human Resources and Skills Development Canada, 2008). This provision allows family members, through the Employment Insurance program, to apply for paid leave (up to six weeks) if a family member has a serious medical condition with a significant risk of death within 26 weeks. A medical certificate is required and must indicate that the family member requires the care or support of one or more family members. In January 2010, this benefit was extended to self-employed workers who have contributed to Employment Insurance for at least 12 months.

The Compassionate Care Benefit is intended only for those caregivers who care for a person who is expected to die within six months. Caregivers who provide care to the chronically ill, those who are mentally or

cognitively disabled, or the elderly, are excluded from this benefit program, unless the care recipient is expected to die within next six months.

In 2010, an estimated 500,000 Canadians suffered from Alzheimer's disease or a related form of dementia. Approximately 71,000 of these people were under age 65. Fifty-five percent of people diagnosed with Alzheimer's disease live in the community. Women represent 62% of dementia cases. While there is no definitive answer to explain the higher incidence of Alzheimer's disease among women, many believe that it is simply due to the fact women live longer than men. Some believe that there are other contributing factors besides longevity, such as the changes to women's hormones at menopause, and the existence of a gene that occurs only in women. It is estimated that the hours of unpaid care delivered by family members was 231 million hours in 2008 (Alzheimer Society of Canada). These caregivers would not be eligible to receive the Compassionate Care Benefit.

Under this leave provision all jurisdictions provide for a maximum of eight weeks paid leave, other than Saskatchewan and Quebec which both provide for 12 weeks annually. In Saskatchewan, an employee can also take this leave due to his/her own serious illness or injury. Quebec may extend an employee's absence to 104 weeks if a child of the employee under the age of 18 has a serious and potentially fatal illness. British Columbia, Saskatchewan, Ontario and Quebec provide extensions in special circumstances. Eligibility requirements vary across the jurisdictions. British Columbia and Manitoba require a medical certificate, while the other jurisdictions may request one. Most jurisdictions allow the compassionate leave to be shared between caregivers.

The protection of seniority and benefits differs across the country. Some jurisdictions protect both seniority and benefits, some protect one or the other, and others do not specify in the legislation whether or not these benefits are covered.

Compassionate care legislation does not take into account caregiver stress which may make it more difficult for some caregivers to complete the necessary application, obtain a statement from their employer, or obtain a physician's statement that death is imminent. The current criteria to participate in this program contributes to the large number of caregivers who find themselves ineligible to receive the benefit. A Pollara 2007 survey found that 90% of caregivers either did not apply or did not receive this benefit.

Fewer workers will be eligible to receive the Compassionate Care Benefit as non-standard employment continues to grow. Persons without steady employment, those working reduced hours, rotating in and out of the workforce, or who are homemakers or living on a pension, are likely to be first within a care recipient's network to be relied upon for end-of-life care due to their availability. These are the people who may be in greater need of the Compassionate Care Benefit than those who have sustained regular employment.

Health Canada. (2004) First Minister's Meeting on the Future of Health Care 2004. Retrieved from: <http://hc-sc.gc.ca/hcs-sss/delivery-prestation/ftpcollab/2004-fm>

Human Resources and Skills Development Canada. (2008). Compassionate care leave provisions in employment standards legislation in Canada. Retrieved from: http://www.hrsdc.gc.ca/eng/labour/labour_law/esl/compass.shtml

Alzheimer Society. (2010). *Key facts about Alzheimer's disease and related dementia*. Retrieved from: <http://alzheimer.ca/english/disease/stats-intro.htm>

Australia has had a National Respite for Carers Program in place for over a decade. This program supports carers of older people and those with disabilities to take time out from their caregiving roles.



International Experience

Australia

Australia has had a National Respite for Carers Program in place for over a decade. This program supports carers of older people and those with disabilities to take time out from their caregiving roles. The program provides advice about respite services, coordinates access to respite services at the local level, and can arrange for emergency respite support outside of standard business hours. A national website contains contact information for local services as well as a toll-free phone number for information. An integral part of this program is the Commonwealth Respite and Carelink Centres. These provide a single point of contact for the public, service providers, physicians and other health professionals for information on community, aged and disability services and carer support. Each of these Centres has extensive regional networks, ensuring they develop an awareness of the entire range of services available. The Centres also help arrange respite, including in-home respite, and residential respite care, by organizing, purchasing, or managing respite care assistance packages for carers (Government of Australia, 2009).

The United Kingdom (UK)

The UK has a National Strategy for Carers. The UK's *National Health Service and Community Care Act* of 1990 was the first legislation to formally acknowledge the need to support family caregivers. In 2000, England and Wales passed the *Carers and Disabled Children Act*, giving local councils the power to supply certain services directly to caregivers.

The Carer's Allowance is an income-tested program that supports caregivers of a disabled child or adult. The caregiver receives a taxable allowance of CA\$108 per week, which may be paid for up to four weeks in any 26-week period if either the caregiver or care recipient goes on holiday, and can continue for up to 12 weeks if either party is hospitalized. This helps provide stability for caregivers to weather temporary changes in their caregiving situation. A means-tested top-up is available to eligible carers. A pension for carers targets caregivers whose labour force participation may be impacted by caregiving resulting in longer-term consequences.

In 2007, the UK introduced the *Aiming High for Disabled Children* strategy which identified the need for efficient and effective short breaks. These short breaks are flexible and can be used to offer children time away from parents and carers. Alternatively, families may use the resources of a personal assistant to accompany them on a holiday or day-outing.

Case Example

While families with disabled children told the UK government that their number one priority was regular and reliable short breaks from caring, young people advised that they wanted more things to do and more places to go. Josh is a 14-year-old blind boy with autism. He lives with his mother, who rarely goes out. The short breaks funding package enables Josh to go out on outings, make friends and engage in interests common to his peer group. Josh's mother was recently able to spend a day outside the home while Josh participated in a Harry Potter outing.

In June 2010, the UK government announced that "an additional 8,000 week-long respite breaks will be available to the families of children with disabilities" (Doulton & Dean, 2010, p. 6).

Europe

Six countries (Austria, France, Germany, Italy, the Netherlands and Sweden) offer cash for care plans instead of services provided to dependents. The objectives are to enable choice, foster family care, develop care markets, and contain costs. There are no age limits for care recipients, with the exception of France who limits their plan to provide for those 60 years old and over (Da Roit & Le Bihan, 2010).

In the Netherlands, a care receiver is given a budget based on an assessment of need. A national assessment tool has been implemented by local assessment boards to determine eligibility for this program. With this personal budget, a care receiver can arrange for services through an organization or can employ an individual, including family and caregivers, to provide care. The caregiver can deduct from their annual taxes medical expenses and other extraordinary expenditures in relation to the care receiver where these expenses exceed 11.2% of income. Additionally, the employed caregiver receives 10 days care leave per year. The employer pays 70% of wages and the government compensates the employer (Special Senate Committee on Aging, 2009; Da Roit & Le Bihan, 2010).

Sweden offers direct payment options, pension credit accrual and a comprehensive paid leave policy for caregivers. Two direct compensation programs target long term care needs — the Attendant Allowance and the Carers' Allowance. The Attendants' Allowance is an untaxed payment that goes to the care receiver to be used to pay the family caregiver. The maximum payment is CA\$860/month, but payment amounts vary by municipality. The Carers' Allowance ensures that the caregivers' salary is equal to that of a formal service-provider employed by the municipality. This compensatory scheme recognizes the value of the caregivers' time and effort. Caregivers who receive a Carer's Allowance or Care Leave are entitled to pension credits (Special Senate Committee on Aging, 2009; Da Roit & Le Bihan, 2010).

France offers the Allocation personnalisée d'autonomie plan for care recipients over 60 years of age. This national legislation is implemented locally with mainly local funding. Benefits pay for a care package defined by professionals. Relatives other than spouses can be hired (Da Roit & Le Bihan, 2010).

Germany offers a cash-for-care program through long term care insurance for insured dependants. There is no age limit and income is not considered, but coverage is basic and must be supplemented by either the family's resources or social assistance. The legislation is national in scope and implemented locally (Da Roit & Le Bihan, 2010).

Austria's program is similar to that of Germany, with the exception that it covers all dependents, not just those who are insured (Da Roit & Le Bihan, 2010).

Italy's program provides for dependents. It includes no age limit, a needs test (100% disability and need for continuous care), and income of the caregiver is not considered. Assessment is based on loose national criteria, locally implemented. Caregivers have free use of these payments (Da Roit & Le Bihan, 2010).

Government of Australia. (2009) Commonwealth respite and carelink centres, Retrieved from <http://www9.health.gov.au/ccsd>

Da Roit, B., & Le Bihan, B. (2010) Similar yet so different: Cash-for-care in six European countries' long-term care policies. *The Millbank Quarterly*. 88(3), 286-309.

The Special Senate Committee on Aging. (2009). *Canada's Aging Population: Seizing the Opportunity*. Ottawa, ON: The Senate.

Caregivers could enjoy some in-home respite while the care recipient is engaged in an activity with a centralized care provider or off-site volunteer. This could be particularly valuable in rural and remote communities where face-to-face respite services may be difficult to arrange.



Technology

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ill technological advances provide some solutions to respite issues? Video chat is a set of interactive telecommunication technologies which allow two or more locations to interact via two-way video and audio transmissions simultaneously. Current video chat services include: seeing a psychiatrist for therapy, taking guitar lessons, and learning how to apply makeup. A psychiatrist reports that he initially used video chat during a blizzard when two of his clients were isolated. Video chat now accounts for 20% of his practice. The quality of this media has improved greatly and is getting easier for older users to manipulate (*Ottawa Citizen*, p. D3). Caregivers could enjoy some in-home respite while the care recipient is engaged in an activity with a centralized care provider or off-site volunteer. This could be particularly valuable in rural and remote communities where face-to-face respite services may be difficult to arrange.

This technology could also provide support to family and informal caregivers, if opportunities were organized for them to connect with other caregivers to discuss issues and possible solutions to some of the day-to-day challenges they face.

Ottawa Citizen. (2010). All from the comfort of your home – video chat is revolutionizing how one-on-one services are delivered, September 7, D3.

More research is required to better identify all relevant costs and appreciate their impact on individuals, families, the health care system and society. What are the benefits of in-home and out-of-home respite? What is the balance? When care recipients need additional therapeutic care, is it more effective to admit them to an acute care setting or a continuing care environment? Answers to these and other questions will help prepare the appropriate respite services for the future.



Issues, Analysis and Recommendations

Increase in the Need for Respite

According to the World Health Organization, all European countries project dramatic growth in the costs and use of formal and informal care as the number of dependent older people with long-term chronic illnesses grows. This growth is not limited to Europe. Statistics Canada predicts that by 2036, the number of seniors in Canada will reach 10.4 million, more than double the level of 4.8 million in 2010. In addition to that group, individuals born with physical and mental disabilities are growing older, as are their family caregivers.

Many of today's disabled are living at home with the support of medical technology. More people are living at home with deteriorating conditions such as muscular dystrophy, multiple sclerosis, and amyotrophic lateral sclerosis. Their caregivers are aging and will be in need of respite care. An increase in palliative home care will also result in an increased need for respite care for those caregivers.

“The projected decline in the supply of care will require investment in home-based self-care and increased caregiver support in the home environment” (World Health Organization, 2008). Planning is required to help mitigate the costs associated with providing respite care and service to this future population.

There has been considerable progress in the area of respite care, but services are disorganized and disconnected in many jurisdictions. With the projected increased need for respite and the

reality that many care recipients and family/friend caregivers are themselves in the elder demographic, the need for better planned and coordinated services is essential. Policy makers would be wise to ensure that caregivers are at the table to help inform the way forward.

Cost Effectiveness

In 2005, Health Canada produced a paper, *The Cost Effectiveness of Respite: a Literature Review*, that attempted to shed some light on whether the provision of respite services is cost effective to governments. A search of national and international studies produced few findings to answer this query.

Since that time researchers have completed systematic reviews of the international literature and determined that better quality evidence is needed to inform policy makers on the cost effectiveness of respite care given the upcoming surge in the numbers of the elderly with chronic conditions and/or dementia.

The economic costs associated with this aging population include not only the cost of formal care, (health care, social and community care, respite care and long term residential care) but also informal care – unpaid care by family members, including their lost opportunity to earn income.

Fragmentation of Respite Services

The healthcare system has responded to the *Canada Health Act* by primarily concentrating funding on acute care services delivered within hospitals. With improvements in diagnostics, treatments, and pharmaceuticals, the system has been able to streamline acute care services while downloading more care and treatment to home care settings. Most respite falls under home care services and because the needs are so diverse it often falls through the cracks. Residents of rural and remote communities are at a particular disadvantage in trying to obtain respite care.

Providers of respite services require adequate training. Standards of practice and standardized curricula need to be developed in order to prepare competent personnel. A national respite strategy needs to be developed in order to address all the issues and scenarios unique to respite care.

More Research is Required

Research in respite care is still in its infancy and requires more resources. There is a pressing need for additional research to look at the macro issues to:

- assist with future planning/funding of respite services;
- estimate the total economic benefit of respite services rather than trying to determine the cost benefit of respite services to governments (Health Canada, 2005); and

- develop common (across all jurisdictions and services) client assessment tools and comparable data reporting (Canadian Home Care Association, 2008).

There is a need to pursue research on micro issues so that we can make improvements in the services themselves.

There is no one perfect type of respite that suits all circumstances. With the potential of a looming crisis in the need for respite, health service planners/providers need to comprehend the costs of supporting facility-based care versus those associated with in-home respite care. Furthermore, it must be understood that the lack of access to respite care has several kinds of costs — spiritual, familial, financial, emotional.

More research is required to better identify all relevant costs and appreciate their impact on individuals, families, the health care system and society. What are the benefits of in-home and out-of-home respite? What is the balance? When care recipients need additional therapeutic care is it more effective to admit them to an acute care setting or a continuing care environment? Answers to these and other questions will help prepare the appropriate respite services for the future.

Thurgate (2005) suggests the following with regards to families of children, but these questions could be applied to all families who provide care and support to other family members.

- How do you evaluate the need for respite to ensure that it is needs-led and not service-led?
- How can you prepare care recipients and caregivers for respite so that it is less stressful on both parties?
- Why do some families not use respite services?

World Health Organization. (2008). *Policy Brief: How can the settings used to provide care to older people be balanced?* Available at: <http://www.euro.who.int/en/what-we-do/conferences/who-european-ministerial-conference-on-health-systems/documentation/background-documents/how-can-the-settings-used-to-provide-care-to-older-people-be-balanced>

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Recommendations for Action

1. To address increased need for respite care, the federal government develop a pan-Canadian approach to support caregivers as outlined in CHA's August 2010 brief, *Modest Investments – Maximum Gains for the Health of Canadians* (page 5), by:
 - the creation of a provision in the CPP/QPP to allow for adjustment in pension calculation for Canadians who have taken time from the workforce to provide care or permit those caregivers who leave the labour force to continue to contribute to CPP/QPP; and
 - that the amount reserved for the Compassionate Care Benefit be treated in the same manner as the Maternity Benefits program. Benefits should be based on the number of hours of care provided and earning capacity of the caregiver.
2. The federal, provincial and territorial governments undertake research to determine the cost-effectiveness of respite care by:
 - supporting, with additional funding, the Canadian Institutes of Health Research (CIHR) strategic plan *Health Research Roadmap: Creating Innovative Research for Better Health and Health Care*. The plan's second strategic initiative describes the role of health research in addressing health and health system research priorities. The *Roadmap* lays out plans for a much-needed patient-oriented research strategy. Additional funds would be provided with the caveat that the CIHR include family-centred research as it pertains to respite care in their *Roadmap*.
3. The federal government create transitional funding to the provinces to explore ways and means to ensure equitable access to, and delivery of, quality respite services for all Canadians with specific attention to:
 - resolving the lack of coordination and integration of available services;
 - improving the effectiveness of centralized access systems; and
 - the nature of the support of in-home respite.
4. The federal, provincial and territorial governments establish standardized curricula for front-line respite care providers, by:
 - contributing funding to the Association of Canadian Community Colleges specifically for building on the expertise of the provinces currently offering such education programs; and
 - contributing funding to local healthcare organizations to provide respite training and follow-up to informal caregivers.

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