

A National Caregiver Strategy

Submission to the House of Commons Standing Committee on Finance

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A NEW VISION OF AGING FOR CANADA

CARP National Strategy to Recognize and Support Family Caregivers

CARP is a national, non-partisan, non-profit organization committed to advocating for a New Vision of Aging for Canada which means social change that will bring financial security, equitable access to health care and freedom from discrimination; ensuring that the marketplace serves the needs and expectations of our generation and providing value-added benefits, products and services to members; and building a sense of community and shared values among our members in support of CARP's mission.

Aging at home is a major imperative for the formal health care and social services system which cannot adequately address the needs and expectations of growing numbers of older Canadians who must then rely on family and friends. Family caregivers contribute billions of dollars' worth of unpaid work to ensure their loved ones get the care and support they need to age at home rather than in an institution. The financial and emotional burdens are nearly impossible for some especially lower income Canadians. A comprehensive strategy is needed to support family caregivers and the contributions they will continue to make to the public good.

Recommendation: CARP recommends that the federal government commits to the implementation of a National Caregiver Strategy to ensure that family caregivers can continue their vital social role by providing them with financial support, workplace protection as well integration with the formal Health Care System. The specific elements are canvassed below.

Overview

The formal health care system in Canada is straining to cope with the challenges of the demographic shift as the population ages. Recognizing this, the 2002 Romanow report recommended that home care services be treated as the next essential service. With hospital downsizing, the aging population and shorter lengths of stay, the last decade and a half has seen the rapid expansion of the post-acute home care sector. The result is an increased reliance on family and friends to fill home care service gaps.

This trend will only increase: from 2001 to 2031, the number of older adults requiring formal or informal assistance will likely have increased by 200%.ⁱ At present, only 7% of them are in institutional settings. Most do, and prefer to, remain at home as long as possible and successive governments have promised to help them.

In the absence of adequate support from public health care and social services, the responsibility falls to family caregivers, mostly people in the 14 million strong 45+ age group, 18% of whom are assisting their parents regularly yet almost half of them still have children living at homeⁱⁱ.

Family caregivers today are absorbing an ever-increasing part of health care costs and contributing hundreds of millions of hours of unpaid labour. In 1999, an economic assessment of



family caregivers valued their work at 5 billion dollars per year, which could be worth as much as 12.3 billion dollars per year today.^{iv}

They are reporting high levels of financial, emotional and health-related stress including lost wages and medical expenses. A quarter (26%) of Canadians reported they had cared for a family member or close friend with a serious health problem in last 12 months. Of these caregivers, 22% took upwards of one month off work and 41% used personal savings.^v As a result of their work almost 8 in 10 caregivers report suffering emotional difficulties, 7 out of 10 reported they needed respite, 54% reported financial difficulties and 50% reported weaker physical health.^{vi}

Comprehensive National Caregiver Strategy

Canadian families always stand ready to care for their loved ones and studies have shown that care in the home, properly supported and delivered, contributes to better health outcomes. We would argue that it also contributes to family solidarity and social glue.

Public policy can reinforce this contribution to the public good by making sure that family caregivers can afford to take on these duties, that their jobs will be protected and that they have access to information and services from the formal health care and social services system.

Financial Support

The current Canadian system of financial supports for caregivers is composed of three nonrefundable tax-credits, the Compassionate Care Benefit as well as the CPP dropout provision. These do virtually nothing for those who are low-income and absolutely nothing for those who are unemployed. The current system also inadequately compensates gendered work - caregivers are predominantly female (77%) and women are likelier than men to miss work or quit their jobs in order to fulfill their caregiving responsibilities.^{vii}

Other developed countries have recognized the importance of providing financial support to their caregivers and have developed more comprehensive financial schemes that may provide strong examples for Canada:

- Sweden, Germany, Australia, France and the United-Kingdom all provide generous needs and income tested allowances to caregivers.
- Sweden's direct compensation rates are based on and equal to formal home care worker compensation rates. Germany's benefits vary between \$318-\$1033/monthly.
- All of these countries also provide tax benefits for caregivers
- Sweden, Germany, France and the United-Kingdom all have pension schemes to ensure that caregivers have some rate of savings and compensation for the time they spend caregiving.
- Germany contributes up to \$584 monthly to a caregiver's pension insurance while the United-Kingdom has initiated a State Pension for Carers. It began in 2002 and will be payable by 2050.^{viii}

Employers also have a role. Employers can provide their caregiving employees with benefits such as day programs for the care recipients or flexible hours. This would allow employers to



contribute to the care giving responsibilities of their employees as well as attract and retain older workers as discussed below.

CARP recommends that financial support be made available to family caregivers to a level that would allow them to continue devoting their time to caregiving as needed. Various mechanisms can be examined, referencing international examples and including tax credits, allowances, or pension enrichment and they should address the differing needs of lower income Canadians and women who comprise the vast majority of caregivers.

CARP further recommends that financial incentives be made available to employers to provide flexible work environments and supportive programs.

Workplace Protection

The Organization for Economic Co-operation and Development has said that raising the employment rate of older workers is critical to softening the blow of a shrinking labour force. Failing to retain older workers will result in "major consequences for economic growth, public finance and living standards" for countries with ageing populations.

Many caregivers are older adults. A 2003 report indicated that 16% of Canadians between the ages of 45-64 were caring for a relative and that 1 in 12 Canadian seniors was also providing care to a spouse, friend or family member.^x Given the increasing importance of attracting and retaining older and more highly skilled workers, workplace protections are needed for workers who need a leave of absence in order to provide care.

The current Compassionate Care Benefit is available to individuals who can provide evidence of their close relative being at significant risk of death within the following 26 weeks. Employment Insurance will subsequently grant them a paid leave consisting of 55% of their salary (up to a maximum payment of \$435) for 6 weeks. However, even palliative care can often take over six weeks. In fact, 60% of caregivers provide care for more than 3 years.^{xi} Currently, there are no workplace protections in place for employees who need to take a longer leave of absence in order to care for a gravely ill relative.

Such workplace protections already exist for maternity and parental leave. After the federal government passed the bill that extended their paid leave through E.I. from six months to a year, they also amended the Canadian Labour Code to increase job protection. Thereafter, other provinces and jurisdictions also amended their Employment Codes and legislation to bring workplace protection for new parents up to the federal standards.

Canadians have accepted that providing financial support and job protection for the early days of child rearing is good public policy. No less should be offered in support of the public good served by family caregivers for other Canadians.

CARP recommends the federal government extend at least the same workplace protection to caregivers that it has extended to new parents. For example, caregivers should be able to take up to a year's leave to fulfill caregiving obligations. Terminating an employee because they have taken caregiving leave should be prohibited. The employee's service should be



considered continuous during caregiving leave and upon return, she/he should be reinstated in the position occupied by her/him on the date her/his leave started.

Integration with the Formal Health Care System

There needs to be an integrated approach to accessing and delivering home care that will help ensure that caregivers have the necessary information, training, home care services and respite care they require to perform their duties. Caregivers often report feeling frustrated by the difficulties they face receiving training information as well finding the resources available to them. There is a need for an information clearing house to assist new caregivers. Nurses and doctors should ensure that new caregivers know where to access this information.

Other countries' caregiver strategies have succeeded in creating points of interaction and cooperation between the informal and formal care systems. Australia would provide Canada with a great precedent. Their Caregiver program is an extension of their formal Home and Community Care Program. It is jointly administered by federal and state governments and treats the caregiver as a client. The program provides caregivers with access to information, advice, counselling and respite services. France and Germany connect caregivers with the formal system by requiring health professionals to evaluate the care being provided and the level of care needed by the care receiver. This evaluation also determines the rate of the allowance that will subsequently be delivered to caregivers. Another distinction is that German caregivers have the ability to register as "informal caregivers" which provides them with special entitlements and benefits.

Respite care is consistently identified as an absolute need. Some caregivers may not have adequate transportation or have mobility issues themselves, so home-based respite programs may therefore be crucial for certain Canadians.^{xii}

Finally, there is need for innovative approaches and the use of technology in caregiver support strategies. There are new ideas in the marketplace now to keep people safe in their homes, help them and their caregivers with daily activities and to help caregivers keep an eye on their loved ones. Social science research into the attitudes and emotional needs of both the caregiver and care recipient should also be examined. For example, a recent study^{xiii} indicates that day programs for care recipients turn out to be a very effective respite care delivery mechanism partly because the benefits of these programs to care receivers are well publicized and that caregivers feel they are doing something good for the care recipients by placing them in a day program. The potential of day programs as a mechanism to allow caregivers to keep working remains relatively unexplored.

CARP recommends that there be developed a comprehensive system of integration of the formal health care and social services system and the informal family caregiving sector that includes equitable access to appropriate respite care.

Supporting Caregivers is Good Public Policy

While it is true that the implementation of any of these policies would be very expensive there are sound ethical as well as pragmatic grounds for undertaking such costly social programs. There are ethical reasons such as the restoration of gender as well as inter-generational equity, because



it would not ask of caregivers that they completely compromise their own financial and pension security to care for their loved ones.

On a pragmatic basis, the social and economic benefits derived from any of these programs would far outweigh the costs. The Canadian Caregiver Coalition estimates that if monetized, caregivers' work might total 6-9 billion dollars a year^{xiv}, a considerable amount given that in 2003, total government spending on the home care sector totalled \$3.4 billion dollars. A recent policy costing study pegs the cost of a modest caregiver allowance at \$1.1 billion a year, and a new respite program at \$3.8 billion. Assuming these programs supported an individual to provide caregiving for even just a few supplementary months before the care recipient had to enter an institution, the government would realize a savings of 2.7 - 5.4 billion dollars.^{xv}

The existing service gap for people requiring care at home has not been adequately addressed despite substantial health care spending promised for home care services. Canadians will continue to rely on the unpaid contributions of the informal or family caregiver to help fill that gap. The public policy challenge is to provide enough public support and incentive to lever the continued contributions of family caregivers to ensure that Canadians are able to age in health and safety in their own homes as long as possible.



ⁱ Keefe, Janice. et. al. "Developing New Strategies to Support Future Caregivers of Older Canadians with Disabilities: Projections of Need and their Policy Implications", Analyse de Politiques, Vol 23 (2007) ⁱⁱ Strategic Counsel : "State of the Baby Boomers" June 2006,

^{iv} Please see Background Materials available on request

^v Health Council of Canada Report, "Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada" (January 2008) Available Online at:

http://healthcouncilcanada.ca/docs/rpts/2008/phc/HCC_PHC_Main_web_E.pdf, Consulted July 30th 2008 ^{vi} Decima Research Inc. "National Profile of Caregivers in Canada" (2002)

^{vii} Ibid.

viii Please see Background Materials available on request.

^x Stobert, Susan and Craswick, Kelly. "Looking After Seniors: Who Does What for Whom?" Statistics Canada, No.74 (2003)

^{xi} Decima Research Inc./Health Canada.

^{xii} Ontario Human Rights Commission "Time For Action: Advancing Human Rights for Older Ontarians" http://www.ohrc.on.ca/en/resources/discussion consultation/TimeForActionsENGL/pdf 2008

^{xiii} Personnal Communication with Dr. Tamara Sussman, McGill University, August 13th 2008. Study pending publishing. xiv Please see Background Materials available on request

^{xv} Keefe, Janice. Et. al. "Developing New Strategies to Support Future Caregivers of Older Canadians with Disabilities: Projections of Need and their Policy Implications", Analyse de Politiques, Vol 23 (2007)