

A Healthy Balance: Caregiving Policy in Canada

BACKGROUND

Healthy Balance Research Program (HBRP)
Hidden Costs, Invisible Contributions Research Project (HCIC)
Canadian Policy Research Networks (CPRN)

Roundtable for Canadian Policy-Makers

26 September 2005 – Ottawa, Canada

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The Atlantic Centre of Excellence for Women’s Health (ACEWH), on behalf of the Healthy Balance Research Program, approached the Family Network of Canadian Policy Research Networks (CPRN) to organize a roundtable with members of the Canadian policy community, researchers and other stakeholders to disseminate the results of their research, entitled *Supporting Caregivers of Dependant Adults in the 21st Century*. This backgrounder has been prepared to facilitate discussion of the policy implications of project research to date.¹ The CPRN roundtable is intended to shape and influence public policy and contribute towards building a “caring society” in Canada, one that takes equity and fairness for caregivers as well as care receivers as a central issue.

I. The Project

The Healthy Balance Research Program (HBRP) is a five year Community Alliance for Health Research (CAHR) project funded by the Canadian Institutes for Health Research (CIHR) and led by the Atlantic Centre of Excellence for Women’s Health, the Nova Scotia Advisory Council on the Status of Women, and the Institute of Population Health at the University of Ottawa. The aim of this innovative and collaborative program is to better understand the connections between women’s health and well-being, family life and earning a livelihood. Using the findings of the Healthy Balance Research Program, Canadians can improve their understanding of the ways in which caregiving is now organized, how caregiving affects people’s sense of empowerment in their lives, and, in turn, how empowerment – or the lack thereof – affects their health and well-being.

¹ This backgrounder is partly based on a draft research synthesis prepared by B. Rajnovich, J. Keefe, and J. Fast. Additional content and commentary were developed by Barbara Clow, Carol Amaratunga and Brigitte Neumann, Co-Directors of the Healthy Balance Research Program. The findings of this paper are the sole responsibility of the authors, and not necessarily those of any government or agency with which they are affiliated.

II. Roundtable with Canadian Policy-Makers

In collaboration with CPRN, the Healthy Balance Research Program and the Hidden Costs, Invisible Contributions Research Project are hosting a roundtable on the future of caregiving policy and practice in Canada.²

The aim of this day-long roundtable is to discuss the policy implications emerging from the findings of the two research projects – from both a Canadian and a comparative international perspective. More specifically, the objectives of the roundtable include:

- Communicating the policy implications of project research results to members of the Canadian policy community;
- Fostering discussion and innovative ideas to develop and support a common vision for caregiving policy in Canada; and
- Developing a Call to Action for caregiving policy in Canada.

III. Definitions and Perspectives

The following working definitions or perspectives have informed the work of the projects and/or arisen from the research findings:

Caregiving – Caregiving refers to the mental, emotional, financial and physical efforts involved in looking after, responding to, and supporting others (Baines, Evans, and Neysmith, 1999). While caregiving work includes the performance of specific tasks, such as personal care, homemaking, running errands, monitoring well-being, decision-making, and medical care, it also rests on a *relationship* between the person who gives and the person who receives care. The relationship involves many dimensions – psychological, spiritual, financial and others – that go far beyond completing tasks and which have profound implications for the well-being of both caregiver and care receiver.

Caregiver – For the purposes of this discussion, a caregiver is an individual who provides ongoing care, support and assistance, without pay, for another individual – most often a relative, friend or neighbour – who is in need of care due to physical, cognitive or mental health conditions (Unpaid Caregiving Forum, 2003: 4).

Care Receiver – For the purposes of this discussion, a care receiver is defined as an adult of any age with a chronic illness, physical or mental debility, or a disability that necessitates episodic or on-going support, assistance and care.

² The two collaborating and interrelated projects are: *A Healthy Balance: A Community Alliance on Unpaid Caregiving and Women's Health* (Carol Amaratunga, Brigitte Neumann and Barbara Clow, Principal Investigators) funded by the Canadian Institutes of Health Research (CIHR); and *Hidden Costs, Invisible Contributions: The Marginalization of Dependent Adults* (Janet Fast and Janice Keefe, Principal Investigators), funded by the Social Sciences and Humanities Research Council (SSHRC).

Family – A family consists of two or more people, whether living together or apart, related by blood, marriage, adoption or a commitment to care for one another (Family Service Association of Toronto).

Gender and Diversity Analysis – Caregiving is performed predominantly by women. While many men are caregivers, the type of care they provide, its duration and its consequences are different than for women caregivers. Therefore, it is imperative to understand the role of gender in paid and unpaid work, as well as in unpaid caregiving work, to ensure the development of equitable and inclusive policies. A gender-based analysis recognizes that roles, responsibilities and access to resources are gendered, and that men and women have different social realities and different socio-economic locations that affect their lives (Morris, 2001). Gender-based analysis further recognizes the importance of understanding the impact of other sources of inequality, such as those based on race, ethnicity, level of ability, sexual orientation and so on, when developing and evaluating policy (Health Canada, 2000).

A Gender and Diversity Analysis serves as the *lens* through which we view current and future social and economic policies affecting unpaid caregivers in Canada.

Values – Researchers have argued for policy approaches that make transparent the values underlying discourse and policy, and for the use of principle-based frameworks for developing and evaluating policy. Furthermore, policy should not be based only on empirical evidence, but also set within an ethical framework. By applying an analysis of values and principle-based frameworks in this way, it becomes possible to focus attention on the needs, wants, and rights of caregivers for support, and to expose the problems with current community care discourse and policy. A values framework facilitates a shift away from policy approaches based largely on cost reduction, to an approach where caregiving is deemed a worthwhile activity and supporting caregivers is recognized as a social responsibility.

IV. Supporting Caregivers of Dependant Adults in the 21st Century

1. The Background Paper

The Background Paper provides an overview of knowledge collected from recent research on caregiving. Much of the information is the product of two recent and ongoing programs of research. The first, the Healthy Balance Research Program, has the goal of improving our understanding of women's unpaid caregiving work – how it affects their choices, opportunities and sense of empowerment as well as their health and well-being, and what challenges they face in trying to balance paid and unpaid work (Healthy Balance Research Program, 2005). The second, the Hidden Costs, Invisible Contributions Research Project, has the goal of creating a deeper understanding of the place of those characterized as dependent in our society, specifically older adults and those with chronic illnesses and disabilities.

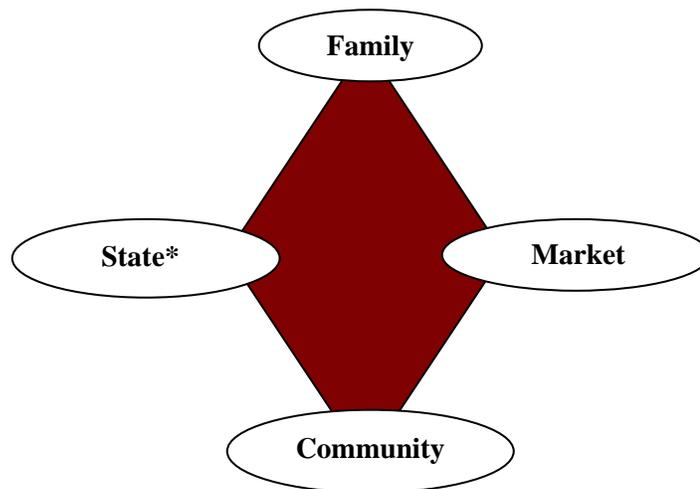
The objectives of the background paper are threefold: to paint a picture of the context in which caregiving takes place in Canada today; to look at innovative ways of supporting caregivers with a view to reducing the negative consequences and costs of caregiving, and; to ensure the sustainability and quality of caregiving relationships.

By examining what has been learned from research within these two research programs and from prominent researchers within the field of caregiving and caregiving policy, a synthesis of work done to date is provided in the background paper to guide decision-makers. This backgrounder summarises the key findings and themes as a point of departure for further discussion regarding policy development.

2. Well-Being in Canada

Jane Jenson's (2004a) conceptions of the well-being diamond and social policy architecture provide a framework for understanding the complexity and interaction of factors that shape the experience of those who give and those who receive care. It also enables us to understand where problems lie and guides us in the formulation and implementation of appropriate responses.

Figure 1. The Well-Being Diamond



* State includes governments (federal, provincial, territorial and municipal) and core public services such as education and health care

The well-being diamond reminds us to consider each of its four points as sources of well-being and what the appropriate balance between the contributions should be. Traditionally, we have tended to place care receivers at the centre of this model and their need for care becomes the focus of policy analysis and policy development. For care receivers, contributions to well-being come from family, from which typically the caregiver is drawn; the state, from which various types of support and compensation are expected; the community, which provides a range of formal and informal services and social support to both caregivers and care receivers; and finally, the market, which provides opportunities for income generation as well as labour policies and legislation that affect both caregivers and receivers. Social and economic policies emerge at each of these points of the diamond, with the result that the model allows policy-makers to better understand not only the current state of caregiving support in Canada, but also the potential for re-balancing and strengthening the supports available to care receivers and their caregivers.

This approach to understanding policy is a powerful one. We are using it to inform analysis of caregiving policy but with a critical difference that reflects the underlying principles of the Healthy Balance Research Program and the Hidden Costs, Invisible Contributions Research Project. Rather than making the care receiver the focus of analysis, we concentrate on those providing care, both short and long term. We want to understand how the needs of caregivers are, or are not, being met by the four actors of the well-being diamond: within families, in communities, in the marketplace and in all levels of government.

3. The Canadian Context

Citizens involved in CPRN's recent dialogue on the future of Canada (MacKinnon, 2004) spoke about a disconnect between their core values and the realities of their lives in Canada today.³ According to many Canadians, the current contributions of families, communities, the market and the state don't meet their needs or expectations. Things are out of balance. Why? What, if anything, has changed (Hay, 2005)?

Arguably, when it comes to caregiving, balance has always been elusive, especially for women. For more than one hundred years, governments and communities in Canada have assigned responsibility for care to families and "most families, then and now, care for their kin" (Armstrong and Kits, 2001). But while caregiving occurs largely within the context of the family, it is not usually the entire family unit that struggles to provide care. More commonly, a woman within the family accepts, willingly or otherwise, the primary responsibility for care. Indeed, the family point of the well-being diamond, in relation to caregiving, has long been a euphemism for mothers, wives, daughters and daughters-in-law. And now, as then, this unpaid caregiving work has serious implications for women's social, psychological, emotional and economic well-being.

Nonetheless, in recent decades, significant changes in Canadian society – at all four points of the well-being diamond – have altered and deepened the impact of unpaid caregiving work, especially for women. Indeed, change at all levels is a major reason for the increased importance of caregiving to social policy dialogue.

Most obvious are the demographic changes in our society. On average, Canadians are living longer, having fewer children and having them later in life than they did in the past. While the baby boom generation still supplies an ample number of caregivers, they themselves, with fewer children, will have it far more difficult to sustain traditional caregiving arrangements (Keefe, Légaré, and Carrière, 2005). Moreover, many caregivers are already in the "sandwich generation": born to older parents, they find themselves caring simultaneously for aging parents and young children.

At the same time, we are witnessing radical changes in family structures and living arrangements: divorce and remarriage are more common, increasing the numbers of blended families in which care responsibilities may be unclear or contested; adult children are more likely to leave home later and to return to the parental home in larger numbers, complicating caring roles and relationships; families tend to be more geographically dispersed than in the past,

³ This disconnect is reflected in Jenson's two papers on social architecture (Jenson, 2004a; 2004b).

creating significant challenges for providing care from a distance; same-sex marriages are more common than in the past, but rights to and responsibilities for care remain ill-defined; increasing cultural diversity also contributes to the variety of household arrangements, including extended kin living together and friends taking on family roles and responsibilities. According to Fast and Keating (2000), the net effects of these changes are smaller families, less stable families, and more complex family relationships – all of which have implications for caregiving.

In addition to the demographic shifts evident in the population and the diversity of living arrangements and family lives, women are increasingly assuming a new role in the marketplace and in the household economy. Women's participation in the paid labour force has grown steadily since the end of World War II, as has the incidence of two-earner households. Given this new economic reality, families with caregiving responsibilities are left in a precarious position. If the demands of paid work make it impossible to provide care, one earner may be forced to curtail employment or leave the labour market. Traditional roles and income inequities between women and men, frequently dictate that women give up or limit paid employment to provide unpaid care (Armstrong and Armstrong, 2004). But the reduction or sacrifice of income to the imperatives of caregiving may have serious consequences for women and their households. Moreover, when women continue in paid work, full or part-time, they still carry the largest share of unpaid caregiving work. They are doing double duty or more.

Notwithstanding these profound changes in the Canadian way of life, governments have been slow to address these changes. Restructuring of government programs and reduced commitment to collective solutions have been, in part, responsible. Following the Second World War, social policy discourse and action were based on shared risk and collective rights. More recently, however, governments in Canada – and in many other jurisdictions around the world – have moved to social policy focussed on individual responsibility and on markets, with a reduced role for the state as the mechanism for redistribution and social justice.

A number of significant trends in public policy have accompanied this shift from collective to individual responsibility for care, including:

- 1) **Cost containment in health, income security and social services**, which limit the capacity to provide supports for unpaid caregivers and affect women disproportionately;
- 2) **Increased privatization of health and continuing care**, leaving caregivers and care receivers to cover the costs of private services, or for unpaid caregivers to fill the gap by providing additional care;

Questions to Consider:

1. What measures do women and men already take to address the need for care within their families and how can these be better supported?
2. How can community capacity to respond to various care needs be enhanced? In transportation, for example?
3. Many caregivers are embarrassed to ask for help. How can services become more user-friendly and accessible?
4. What kinds of innovations can be introduced to improve household arrangements to help caregivers to undertake care in their homes e.g. changes to R1 municipal zoning laws etc.?

- 3) **A shift from institutional to community-based health and continuing care**, resulting in increased demands on unpaid caregivers as they strive to maintain the care receiver in the home or community;
- 4) **Increased geographic inequity in health and social service delivery**, arising from the emergence of a different range of supports, with different eligibility criteria and co-payments, in different regions of the country.

While all of these policy changes have profound implications for caregivers, the shift to community-based care is of special concern because it places additional burdens on caregivers. New medical techniques, technology and drugs have made it possible to relegate more procedures to outpatient or day surgery and to shorten hospital stays. Although community-based care has no doubt contributed to longevity and rates of survival after serious illness and injury, it has also resulted in more frail, ill and disabled people being cared for at home and increased pressures on unpaid caregivers to provide more intense and complex care (Armstrong and Kits, 2001).

Simply put, unpaid caregivers in Canada are doing more than ever before: more hours of care and work; more juggling of multiple responsibilities; more managing of multiple services and providers; more negotiating and advocating for care; more complex care.

4. A Profile of Caregivers and Caregiving

Equitable and inclusive policies for caregivers must be based on a clear understanding of who provides care, what types of care they provide, and to whom they provide care. A host of researchers have generated a wealth of information on each of these topics and both HBRP and HCIC are building on that foundation. Details of some of the findings of these two programs of research can be found in the research synthesis,⁴ but for the purposes of this summary we will confine ourselves to briefly outlining the salient characteristics of caregivers and caregiving in Canada today.

A. Who Provides Care?

While more men are providing care than in the past, women still constitute the majority of caregivers. For example, data from Statistics Canada's 2002 *General Social Survey* (GSS) reveal that 59 percent of people providing care to a senior in the preceding 12 months were women, as compared with 41 percent who were men. In addition, there are increases in the number of older parents caring for an aging child with a life long disability (MacLellan, Norris, Flowerdew, and MacPherson, 2002), and caregivers in their 80s and 90s who are looking after a disabled partner.

Age also plays a role in determining who becomes a caregiver. Forty-three per cent of women and 42 percent of men caregivers are between the ages of 45 and 59. A slightly higher proportion of caregivers (47.7% of women and 48.8% of men) are between the ages of 60 and 74. According to Guberman (1999), this is a new trend associated with increased life expectancy. In other words, older people are not only care receivers, they are also caregivers.

⁴ The research synthesis, upon which this backgrounder is based, will be available at the roundtable.

Caregivers tend to be married or living in common law relationships. According to the 2002 GSS, 71 percent of women providing care reported being married or living in a common-law relationships as compared with 83 percent of men.

Employment status is also important in the caregiver profile. Data from the 2002 GSS indicates that higher proportions of men than women caregivers were in the paid labour force (67% vs. 45%), and more women than men were employed part-time (19% vs. 7%).

Most caregivers live in urban areas (77% of women and 75% of men). The majority are caring for a parent, though interestingly, 23 percent of women and 28 percent of men indicated that the person they were caring for was a friend or neighbour (Statistics Canada, 2002).

It is more difficult to characterize caregivers on the basis of culture, ethnicity/race, disability, sexual orientation, or other aspects of identity and circumstance, but they must be factored into our understanding of caregiving in Canada. For example, immigrant women who participated in focus groups for HBRP identified tensions between their own cultural caregiving practices and Canadian approaches (Gahagan *et al.*, 2004). Furthermore, because sponsored immigrants are ineligible for many publicly funded supports, including hospitalization, home care services and institutionalization, they and their caregivers may experience even greater burdens (Guberman, 1999).

Similarly, Aboriginal communities confront a different constellation of caregiver supports and stresses. Chronic disease and disability rates are twice as prevalent in Aboriginal as in non- Aboriginal communities, which translates into increased needs for care (Keefe, 2003). Caregiving in Aboriginal communities also involves extended kinship networks, which may create more diverse and complex caregiving arrangements (Gahagan *et al.*, 2004). Services available to Aboriginal caregivers living on and off reserve can be quite different, thereby complicating efforts to secure supports (Gahagan *et al.*, 2004).

While some characteristics are shared among a larger proportion of caregivers in Canada, it is also the case that caregivers – as well as care receivers – bring with them different beliefs about caring as well as diverse life goals and life histories. We must be mindful of both the commonalities and the differences among caregivers when we think about the formulation of policies to meet the needs, wants and rights of those providing unpaid care.

Questions to Consider:

1. What is the proper role of employers in supporting caregivers?
2. Given the rise in the number of self-employed people, what needs to happen to support them in caregiving?

Questions to Consider:

1. How should we change the way we gather – or do not gather – data on diverse populations of caregivers?
2. How can we utilize the expertise and experience of these caregivers to improve policies and programs?
3. How can the state address jurisdictional issues that deepen the burden of caregiving?

B. What are Caregivers Doing?

According to Armstrong and Kits (2001), caregiving falls into four broad categories: instrumental activities of daily living, such as cooking and shopping; assistance with activities of daily living, including personal needs for bathing and grooming as well as dispensing medications; management of care, which involves finding out about and arranging for formal and informal services, and; social and emotional support. Not all caregivers provide all of four kinds of care. Women are more likely to have responsibility for care within the household, such as housework and personal care. Men may help with these types of care, but they do most of their caregiving outside of the home, on transportation and home maintenance. In other words, women are more likely to be engaged in intensive and deeply intimate caregiving while men are more often involved in episodic and instrumental caregiving activities.

There are also significant differences between the amount of care that men and women provide. Women caregivers aged 45 to 64 spent almost twice the amount of time (29.6 hours per month) on caregiving tasks as their male counterparts (16.1 hours per month). Moreover, Stobert and Cranswick (2004) found that these amounts are not greatly reduced when looking at women caregivers who are employed. Women continue to spend 26.4 hours a month and men spend 14.5 hours.

The data show that caregiving can be a long term commitment. Most women (73%) and men (81%) have been providing care for two years or more. Among the 98 participants involved in HBRP focus groups, the average period of caregiving was 10 years, with the longest reported period being 71 years (Gahagan *et al.*, 2004), although this was by no means a representative sample.

C. What are the Consequences of Caregiving?

Keating *et al.*, (1999) note that caregivers identify both rewarding and challenging dimensions to unpaid caregiving work. The research synthesis⁵ focuses on the stresses and strains of caregiving because these can have serious consequences for caregivers and because policy changes could ameliorate the burdens of caregiving.

The consequences or costs of caregiving can be grouped into two broad categories, economic and non-economic. Economic costs, out-of-pocket costs such as pharmaceuticals and medical supplies, employment-related costs, and unpaid work. Non-economic costs, which “result from declines in certain aspects of one’s life” (Fast *et al.*, 1999: 304), include social, emotional and physical well-being.

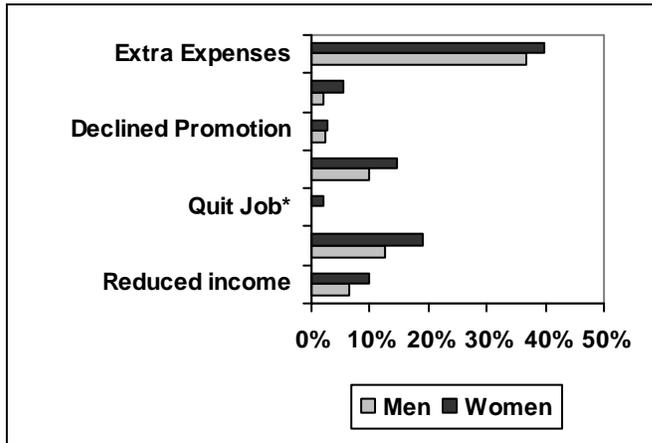
Questions to Consider:

1. How do the needs of caregivers vary according to the length of time they provide care?
2. How do we respond to these differences?
3. Caregivers in the paid labour force have different needs than those who have retired from the labour force. Which differences require what kinds of accommodations?

⁵ The research synthesis, upon which this backgrounder is based, will be available at the roundtable.

Analysis of the GSS 2002 demonstrates that while the economic costs of caregiving are substantial for all caregivers, a larger proportion of women caregivers feel the impact on their immediate and future earnings, on their job and promotion prospects, and on their long-term economic security.

Table 1. Economic Costs of Caregiving

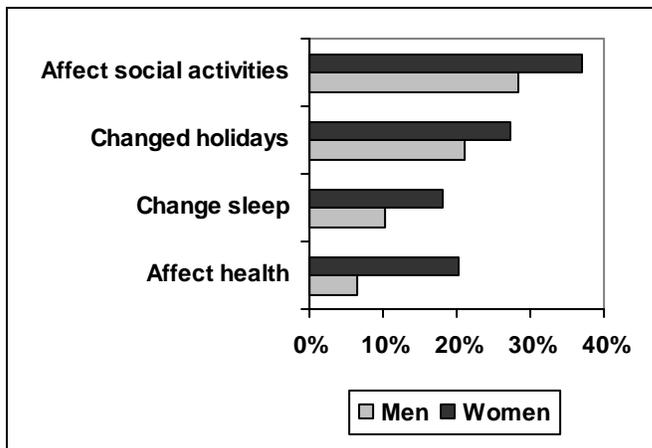


* The data for men is too small to be expressed.

Source: Statistics Canada, *General Social Survey*, 2002.

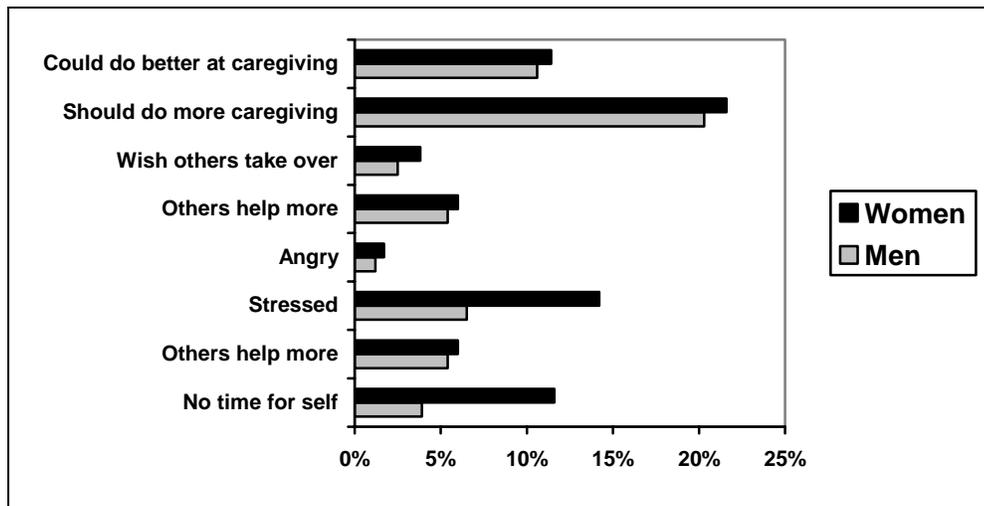
Similarly, the non-economic toll of caregiving is greater for women than for men caregivers. A larger proportion of women than men report lost friendships, lost leisure, increased fatigue and stress, and heightened feelings of guilt and resentment.

Table 2. Non-Economic Costs of Caregiving: Social and Physical



Source: Statistics Canada, *General Social Survey*, 2002.

Table 3. Non-Economic Costs: Emotional



Source: Statistics Canada, *General Social Survey*, 2002.

In sum, this brief portrait of caregivers and caregiving not only tells us that more women than men are providing care, but also that women are spending more time on caregiving, are involved in more intimate and intensive caregiving, and report incurring greater economic and non-economic costs as a result of unpaid caregiving. The gendered nature of care work, the changing face of caregivers, and the diversity of caregiving situations must all be considered when determining how better to support caregivers.

4. What Supports do Caregivers Need?

Findings from focus group and ethnographic studies conducted as part of the Healthy Balance Research Program – as well as other research – demonstrate that caregivers need many things to facilitate a “healthy balance” in their lives: they need information about available supports; they need recognition, validation and support from family, community, employers, government and health care providers; they need training and skill development; they need respite and help with daily caregiving activities; they need both emotional and financial support (Gahagan *et al.*, 2004; Beagan, 2005).

How do we, as a society, meet these needs? Numerous approaches for state action to better support caregivers have been suggested, including the development or expansion of educational, information and support programs that enable caregivers to improve skills and to better cope with the strains of caregiving (Keefe, 2003). There have also been proposals to alter provincial drug and health plans to cover the costs of medications and supplies used in the home. Increases to amounts of home care and respite care for caregivers and improved access to the benefits (Guberman, 1999), as well as reductions in user fees for low income care receivers (Fast *et al.*, 2001) have also been proposed.

Questions to Consider:

1. How do we ensure that women’s fundamental rights are addressed in policies that support caregivers?
2. How do we ensure that equity is a core value of caregiving policies and programs?

Other suggestions have represented systemic changes in our approach to supporting caregivers, including significant policy shifts and innovative programs. For example, discussion at the Unpaid Caregiving Forum in 2003 led to calls for the development of a list of core services and guiding principles as well as the formulation of indicators to evaluate supportive home and community care for Federal/Provincial/Territorial discussion. Guberman *et al.*, (2001) have suggested that caregivers should be viewed as partners in the delivery of home care services and/or intake into the home care system should involve a needs assessment for the caregiver as well as the care receiver. Other analysts and advocates have proposed that the *Canada Health Act* be amended to extend public funding to home care services, or that a national approach to home care be developed (Keefe, 2003). Finally, improvements to existing financial compensation policies or the development of new policies for caregivers have also been popular recommendations.

Caregivers participating in ethnographic studies as part of the Healthy Balance Research Program remind us that any changes to existing supports or any new supports must be designed with a view to the diverse identities, situations and needs of caregivers (Beagan, 2005). Although some needs will be shared by most, if not all caregivers, differences in social location – such as ethnic identity, sexual orientation, place of residence and legal status – require policies that are sensitive and responsive to these differences (see *Caregiver Portraits* (Beagan, 2005), available at the roundtable, for further details).

5. What Policies and Programs are Available to Support Caregivers?

A. In Canada

While caregivers in Canada incur significant costs as a result of their unpaid caregiving work, the Canadian government has yet to develop a comprehensive strategy to support them. Rather, there is a mix of programs and policies in place at the federal, provincial and territorial levels, which currently fall into two main categories – home care services and financial compensation.

Home Care

One of the main ways of providing support to caregivers in Canada is through the provision of home care services, whether they are direct to care receivers, or specifically intended to meet the needs of the caregiver, as in respite services. These programs fall largely under the responsibility of provincial departments of health or social services, with the exception of veterans and members of First Nations, who fall under federal jurisdiction. While there have been calls for the development of a universal home care program, current federal health policy does not provide standards or guidelines for the development or delivery of home care services in Canada. As a result, home care programs vary widely across Canada and meet the needs of caregivers with varying degrees of success (see the research synthesis⁶ for further details).

⁶ The research synthesis, upon which this backgrounder is based, will be available at the roundtable.

Financial Compensation

Another policy option for supporting caregivers is financial compensation. Many countries have chosen to provide financial support to caregivers, whether to recompense financial sacrifices, to provide economic motivation, to acknowledge the social importance of the work they do, or to reduce health care and institutional costs by shifting care into the communities and onto family and friends.

Financial compensation policies can take several forms, including direct compensation (wages, allowances), indirect compensation (tax relief, pension security) and labour policies that provide employees with paid time off or with job protection to provide care. The emphasis in Canada has been on using the tax system to provide some financial support to those providing care to disabled or elderly relatives. There are currently five tax relief measures that can be claimed by caregivers at the federal level. A central criticism of the Canadian tax relief measures for caregivers is that these credits are least useful to those who most need them. Data from the 2000 tax year indicates that only 39 percent of claimants for the Caregiver Credit were women, despite evidence that women constitute the majority of caregivers. Preliminary research suggests that this disjuncture is due in part to the fact that many women caregivers do not have sufficient income to benefit from a non-refundable credit (Shillington, 2004; Young, 2000). While many caregivers meet some of the eligibility criteria for most tax deductions and credits, they rarely meet all and so do not benefit from financial compensation policies. Furthermore, the complexity of the systems is such that many potential beneficiaries never make claims to which they are entitled.

Outside of tax credits, there is only one other national program that offers financial compensation to caregivers in Canada. This is the Compassionate Care Benefit, an element of the Employment Insurance (EI) program. The Compassionate Care Benefit, which came into effect in January 2004, provides temporary income support for eligible workers who must take a leave from work to provide care to a family member who is likely to die within the next six months. Not only is it difficult to predict the timing of death, the imperative to do so may have severe emotional repercussions for caregivers and care receivers. Moreover, as with tax credits, there are many significant restrictions on eligibility for receipt of the compassionate care benefit. The care receiver must be the caregiver's spouse or common-law partner, child, or child of spouse or common-law partner, or the caregiver's parent, or parent's spouse or common-law partner. The caregiver must also be eligible for employment insurance, which many are not (e.g. self-employed persons are not eligible). While the introduction of the Compassionate Care Benefit marks a shift in policies, it does not support all caregivers.

The provinces and territories have also used the tax system to provide financial assistance to caregivers. But tax credits available in the provinces and territories, where they exist, largely parallel those found at the federal level, although amounts and eligibility criteria vary. The concerns with these approaches are the same as at the federal level (see the research synthesis⁷ for further details).

Questions to Consider:

1. What principles should underlie Canada's efforts to compensate caregivers?
2. What measures are most promising, affordable and practical?

⁷ The research synthesis, upon which this backgrounder is based, will be available at the roundtable.

B. International Approaches

While Canadian policies to support caregivers have remained relatively static, some other countries have taken a more active approach to meeting the needs of caregivers. A review of international approaches can provide decision-makers with new policy alternatives, and with information about the strengths and weaknesses of these approaches.

The nine countries examined were selected because they represent a mix of welfare and health systems as well as approaches to supporting caregivers. Eight of the nine countries – the United States being the exception – provide multiple comprehensive supports to caregivers and care receivers.

Home Care

As in Canada, a fairly standard approach to supporting caregivers in other countries is through home care policies and programs. In this case, home care refers to “any kind of health care, personal care, or assistance with independent living given to functionally impaired, disabled, or ill persons in their own homes” (Kane, Kane, Illston, and Eustic, 1994). All of the nine countries examined had some form of home care, though some operate at the national level while others are regional or local. In some countries, home care needs are met through direct financial compensation, either to the caregivers or the care receivers. While more information about the scope of home care elsewhere in the world would be valuable, the challenges of researching programs and policies across nine countries and many more regions have proven considerable. Future research on this topic will undoubtedly serve to deepen the dialogue about policy alternatives for supporting caregivers in Canada.

Financial Compensation

Financial compensation policies and programs are easier to track in these nine countries because they operate nationally. Financial compensation policies have multiple purposes; some are intended to replace lost income, some are intended to provide long-term financial security, others are intended to acknowledge the social value of caregiving (Keefe and Fancey, 1998). For the purposes of this discussion, we have identified three types of compensation policies available in other countries: direct compensation, indirect compensation and labour policies.

Direct compensation policies allocate funds to the caregiver or care receiver with the intention of compensating the caregiver. These programs take many forms: wages, allowances, stipends, and vouchers. Eligibility criteria vary widely from one country to the next. While some provide hourly wages equivalent to those provided for formal care, others offer minimal amounts meant to acknowledge the caregiver’s contributions. The purpose of these programs may be to compensate caregivers for their work, for out-of-pocket expenses incurred by the caregiver, or to facilitate the purchase of support services (Keefe and Fancey, 1998).

Indirect compensation programs take two main forms: tax relief and pension security. Tax relief includes measures such as tax credits, tax deductions and tax exemptions. The purpose of tax relief programs may be to recognize the contribution of time or the out-of-pocket expenses incurred by caregivers (Keefe and Fancey, 1998). Pension security involves third party payment of pension credit or insurance premiums, or a drop out clause for periods while caregiving. The purpose of pension security programs is to acknowledge the financial sacrifices made by caregivers and to provide them with long-term financial security (Colepaugh, 2004; Keefe and Fancey, 1998).

Labour policies provide paid leave from work for a caregiver, or they provide access to employment benefits if the caregiver must leave paid work to provide care. Paid leave programs range from days to several months. Payment may be at full pay or partial pay. Some programs allow leave only to provide terminal care. The purpose of these programs is to allow employed caregivers to leave work to provide care without losing their income.

Summaries of the supports available to caregivers and receivers in the nine selected countries can be found in the Hidden Costs, Invisible Contributions (HCIC) Fact Sheets⁸ and a fuller discussion of country specific policies and programs can be found in the research synthesis.⁹

No doubt further research will help to explicate the relative merits of these approaches to financial compensation for caregivers, as well as the extent to which they may be adopted or adapted for use in Canada. Political cultures, geography, fiscal realities, Canadian values and the needs and rights of caregivers will shape the potential for new and renewed policies and program. These summaries provide us with a glimpse of other possibilities and a challenge to change our own approach to supporting caregivers.

6. The Policy Agenda

Change is seldom easy and we cannot expect that new policies and programs to support caregivers will emerge without debate, disagreement and compromise. But the inclusion of caregivers in the *Romanow Report* (Commission on the Future of Health Care in Canada, 2002) and the establishment of a federal Minister of State for Families and Caregivers confirm that caregiving and caregivers are on the national policy agenda. There is an opportunity to deepen the dialogue on supporting caregivers and to turn collective knowledge into action.

Where do we start when considering a new or renewed policy agenda for caregiving in Canada? As mentioned earlier, in the definition of values, some researchers have argued for policy approaches grounded on values and situated within ethical frameworks. For example, Kenny (2004: 2) argues for a shift from public policy based on economic imperatives to an understanding of public policy-making “as a moral endeavour

Questions to Consider:

1. What kind of a society do we want to live in?
2. What values and principles should inform caregiving policy?
3. What will a “caring society” look like in the 21st century?

⁸ The HCIC Fact Sheets are available at www.hecol.ualberta.ca/hcic/publications/fact_sheets.htm.

⁹ The research synthesis, upon which this backgrounder is based, will be available at the roundtable.

that involves decisions about who we are and who we desire to be as a country.” Her framework is based on an “intergenerational equity” approach, which is “concerned with justice and fairness in the here and now and for future generations” (Kenny, 2004: 2).

Similarly, Nussbaum’s (2000: 245) “human capabilities approach” to policy is rooted in social objectives that include attention to: “life health, bodily integrity, dignity and non-humiliation, associational liberties, emotional health, the opportunity to form meaningful relationships with other people, the ability to participate in politics, the ability to hold property and work outside the home, the ability to think for oneself and form a plan for life.

These philosophies of policy-making are a far cry from the prevailing discourse on cost containment. But as Jenson notes, “any cost-benefit calculation must include the short- and long-term cost of the continuing pressure on family members to provide care” (Jenson, 2004a: 42). Building on values and employing principle-based frameworks can emphasize the realities of caregiving and the limits of existing policies and programs for the support of caregivers.

A. Guiding Principles

What principles, frameworks or values should we use? Clearly, many different models have been developed and proposed, and we would not presume to prescribe the use of one over another. But for the purposes of this discussion, we would like to consider a principle-based framework that emerged from a National Think Tank on Gender and Unpaid Caregiving, which was hosted by the National Coordinating Group on Health Care Reform and Women, the Atlantic Centre of Excellence for Women’s Health, and the Women’s Health Contribution Program, Health Canada. In 2001, co-chairs Pat Armstrong and Carol Amaratunga invited experts from academic, policy and caregiver communities to consider issues around women and home care. Fifty-five participants engaged in discussions that resulted in the *Charlottetown Declaration on the Right to Care*¹⁰ (copies of the *Declaration* will be available at the roundtable). While the central focus of this document is home care, many of the rights and principles that were formulated may be applied to the development and evaluation of caregiving policies and programs (Pederson and Huggan, 2001).

The following guidelines are adapted from the principles laid down in the *Charlottetown Declaration on the Right to Care* and may be used to focus discussions about policies and programs to support caregivers.

- Care should be provided in an environment that *meets the needs of both the caregiver and the care receiver*. We cannot assume that the home is the most appropriate or desirable location for care.
- Caregiving must be voluntary. We must not assume that families and friends – and women in particular – are available or willing to provide unpaid care. New policies or policy changes should not force or coerce individuals into taking on caregiving roles.

¹⁰ Available at www.cewh-cesf.ca/healthreform/publications/summary/charlottetown.html.

- Caregivers must have choices. We should not assume that any and all caregivers can or will provide any and all types of care. They should be able to make choices about what types of care and how much care they provide, and to whom they will provide the care.
- *Caregivers must have access to and awareness of alternatives and appropriate supports.* If they do not, caregiving will not be voluntary and caregivers will not have choices.
- *Caregivers need a continuum of services and supports,* such as training and education, respite and other care services, paid leave to provide care, job security and income programs.

If, as Canadians, we are to increase the adequacy, equity, and accessibility of supports for caregiving, we must make an effort to invoke ethical frameworks for policy development and evaluation, and to understand policy paradigms that constrain innovative approaches to improving programs and services. The patchwork of benefits currently available in Canada should be fundamentally revised to provide women and men – from diverse communities – with fair and appropriate supports for the caregiving work that is so central to the social and economic well-being of the country.

Thus the solutions required to create a “caring society” for the 21st Century will involve not only fundamental changes in caregiving relationships and societal values, but also creative investments in caregiving infrastructure and policy architecture.

B. Rebalancing the Well-Being Diamond

When it comes to making change and meeting needs, we know that the state cannot do it all. As the well-being diamond demonstrates, families, communities and the market are also vital actors in creating and maintaining necessary, appropriate supports for caregivers in Canada. But right now, the diamond is out of balance. While governments cannot do everything, they are in a position to empower and enable other sectors to develop innovative, affirmative and dynamic approaches to supporting caregivers. It is time to have serious discussions about the leadership role of governments in efforts to rebalance the well-being diamond and to achieve a healthy balance for all Canadians.

- What measures do women and men already take to address the need for care within their families and how can these be better supported?
- How can community capacity to respond to various care needs be enhanced
- How can services become more user-friendly and accessible?
- What kinds of innovations can be introduced to improve household arrangements to help caregivers to undertake care in their homes?
- What is the proper role of employers in supporting caregivers?
- How should we change the way we gather – or do not gather – data on diverse populations of caregivers?
- How can we utilize the expertise and experience of diverse communities of caregivers to improve policies and programs?

- How can the state address jurisdictional issues that deepen the burden of caregiving?
- How do the needs of caregivers vary according to the length of time they provide care and how do we respond to these differences?
- How do we ensure that women’s fundamental rights are addressed in policies that support caregivers?
- How do we ensure that equity is a core value of caregiving policies and programs?
- What principles should underlie Canada’s efforts to compensate caregivers?
- What measures are most promising, affordable and practical?
- What will a “caring society” look like in the 21st century?

By considering these questions – and others – about current and alternative approaches to supporting caregivers, we can hope to set the foundations for a new vision of caregiving in Canada.

7. Moving Forward on the Policy Agenda for Caregivers in Canada

The research synthesis¹¹ provides an overview of what is being done in Canada and in other jurisdictions as well as what various experts and researchers have said could or should be done to address some urgent caregiver needs in Canada. What policy options can be generated, using the well-being diamond as a framework for discussion? What innovations in community life, family life, work and state support would give caregivers and care receivers a manageable life, without loss of economic security? What do governments need to do to foster that state of affairs?

¹¹ The research synthesis, upon which this backgrounder is based, will be available at the roundtable.

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