



Supporting Caregivers of Dependent Adults in the 21st Century

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1.0 Introduction and Overview of the Canadian Caregiving Context

Inasmuch as caregivers provide an estimated 80% to 90% of care in the community (Keefe & Fancey, 1998), supporting caregivers in their work must be seen as an issue worthy of the attention of decision makers in Canada. Changes in Canadian social realities, in terms of demographic shifts, diversity of family structures and roles, labour market participation, and the shift in health care delivery to the community have combined to increase the burden placed on caregivers. These trends are well known but have not resulted in appropriate responses and investment on the part of government (Guberman, 1999; Keefe & Fancey, 1998). This report will look at the trends influencing caregiving, as well as policy and programs currently in place for caregivers, and will make a call for the implementation of new supports for this significant group of people who remain committed to providing crucial services within our communities, but are doing so not only without adequate compensation and supports, but also at the expense of their own well-being.

This report does not present new findings, but rather provides an overview of knowledge collected from recent research on caregiving. Much of 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 the ways caregiving is now organized, how caregiving affects people's sense of empowerment in their lives, and in turn, how it affects the health and well-being of caregivers (Healthy Balance Research Program, 2005). The second project, “Hidden Costs: Invisible Costs: The Marginalization of ‘Dependent’ Adults”, 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 illness and disabilities. Within this program of research are projects that look at the costs incurred by caregivers, as well as international caregiving policies. By examining what has been learned in the course of research within these two programs and from prominent researchers within the field of caregiving and caregiving policy, we provide a synthesis of work done to date as a useful background to guide decision makers. The report is timely. The inclusion of caregivers in the *Romanow Report* (Commission on the Future of Health Care in Canada, 2002) and the recent development of the Ministry of State for Families and Caregivers indicate that caregiving is beginning to claim its place on the national policy agenda. This action suggests that now is the time to move forward the dialogue on supporting caregivers and to turn our collective knowledge into action.

Caregiving is a complex issue and in order to have a clear discussion of how to support caregivers we must first define what we mean by “caregiving”, “caregivers” and “care receivers”. As Hayward, Amaratunga, Colman, Kiceniuk, and Neumann (2002) point out, much of the literature about caregiving defines it as “a mechanical performance of tasks required to provide physical necessities to those who are ill and disabled”; but “care” has another meaning: “concern about or interest in others” or “a feeling of love or liking” (p. 5). Understanding the dynamic interplay between these two kinds of care is crucial for the understanding of caregiving that informs this report. Baines, Evens, and Neysmith (1999) provide a definition that attempts to marry the two: “Caring refers to the mental, emotional, and physical effort involved in looking after, responding to, and supporting others” (p.11). While caregiving work includes tasks such as personal care, homemaking, errands, monitoring, decision making, and medical care, it must

be remembered that there is much more involved and invested in these relationships for both caregiver and care receiver.

Because we are interested in only specific groups of caregivers and care receivers it is also necessary to define what is meant by these terms. Care provided throughout the life course as part of the normal exchanges of everyday life is not the focus. Rather, we are interested in those situations in which care demands are more substantial. For this report, a care receiver is defined as “an individual who, due to physical, cognitive, or mental health conditions, requires additional care to compensate for reduced independence in their own care” (Unpaid Caregiving Forum, 2003, p. 4). Our focus is on care receivers who are adults and seniors with chronic illness and disability. While children with chronic illness and disability could be included in our review, the needs of these groups are different and deserve separate investigation. While the terms “family caregiver” or “informal caregiver” are commonly used in the literature for those who provide care, they are problematic. Family caregiver does not reflect the diverse kinds of relationships between caregivers and care receivers. Informal caregiver is “sometimes seen as a misnomer because the formal system actually relies on the existence of ‘informal caregivers’” (Morris, 2001, p. 5). Instead, the more inclusive term “caregiver” will be used here, defined as “an individual who provides ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive or mental health conditions” (Unpaid Caregiving Forum, 2003, p. 4).

A word of caution about the use of the term “caregiver” is required: while this term is gender neutral, caregiving is not. It is well substantiated that more women than men are caregivers and that women provide more hours of care than men do and, as a result, disproportionately incur costs as a result of their caregiving responsibilities (Keating, Fast, Frederick, Cranswick, & Perrier, 1999; Morris, 2001). In order to make obvious the gendered nature of care work we will use a gender analysis lens throughout this report. Morris (2001; 2004) argues that a gender lens is critically important when looking at caregiving because without it the distribution of the burden and consequences of caregiving can be obscured. Furthermore, as men and women both respond differently to policy and programs and are impacted differently as a result of the socioeconomic contexts in which they are situated, a gender lens is needed to ensure that changes to current programs and new policies to support caregivers include an awareness of the realities of women's and men's lives in order to make them equitable and as effective as possible (Status of Women Canada, 1996). A gender analysis lens requires considering such questions as: How are caregiving responsibilities, roles and costs gendered? What other factors, such as socio-economic status, employment status, age, ethnicity, sexual orientation, and disability, affect the caregiving experience? How does current policy impact men and women differently? How will policy changes impact women and men differently? What unmet needs do women and men have regarding their caregiving roles, and how are these needs gendered? What roles can caregiver policy and supports play in improving gender equity and support women's independence?

It is the goal of this report to paint a picture of the context in which caregiving is taking place in Canada today and to look at new ways of supporting caregivers, both to reduce the consequences and costs of caregiving, and also to ensure the sustainability and quality of the caregiving relationships. In Section 2.0 we examine who caregivers are, what they do and at what costs. In

Section 3.0 we look at the current state of policy in Canada as it supports caregivers, including an overview of home care and financial compensation policy. In Section 4.0 we address the gaps in Canadian policy of support to caregivers by comparing international caregiver policies, with a focus on financial compensation policies. This section will not only outline the types of policies available in other countries and but will also look at the factors that shape access to and benefit from these policies for caregivers. The final section of the report will make recommendations about how to improve or develop new policies for supporting our caregivers in Canada.

Before moving to an examination of who caregivers are and what policy options are available to them, it is necessary to examine the broader social reality and policy issues that shape the caregiving context in Canada today.

1.1 The Welfare Diamond and Caregiving in Canada

Jenson's (2004a) conception of the welfare diamond and social architecture provides a framework for understanding the complexity and interaction of factors that shape the caregiving experience. It also enables us to understand where problems lie and change is needed.

The welfare diamond comprises 4 principal sectors of society that provide for an individual's well-being. Jenson (2004b) writes:

For the majority of people, by far their major source of welfare is market income, earned themselves or by someone in their family, such as a spouse or parent. But we also gain part of our welfare from the non-marketized benefits and services provided within the family, such as parental child care, housework and care for elderly relatives. Access to welfare also comes from states, via public services such as child care, health care or other services for which we are not required to pay full market prices, as well as by income transfers. The fourth source is the community, whose volunteers and non-market exchanges generate welfare by providing a range of services and supports, such as child care, food banks, and recreation and leisure. (p. 1)

While using the welfare diamond helps us to identify and distinguish the current distribution of well-being within the 4 sectors, looking at Canadian social architecture helps to identify “the *roles and responsibilities* as well as *governance arrangements* that are used to design and implement relationships among family, market, community and state” (Jenson, 2004a, p. 3). For Jenson, social architecture is a “blueprint” that informs decision making and development of social policy as it relates to how the welfare diamond will be balanced (Jenson, 2004a). For example, while all countries see employment income from the labour market as the primary source of well-being for citizens, Canada and other countries have decided that services such as education and health care are too important to well-being to be left to the market, and instead are provided by the state (Jenson, 2004a).

Jenson argues that it is “when there is a mismatch between life situations and expectation in policy responses that a ‘problem’ exists” (Jenson, 2004a, p. vi). What becomes apparent by looking at the 4 sectors of the welfare diamond and our current social architecture in Canada

from the perspective of caregivers is that there has not only been significant change within the sectors of the welfare diamond, but that for caregivers there has been an inadequate redesign of social architecture to rebalance the roles of each sector providing well-being. This has resulted in significant gaps that put caregivers at risk.

What we are faced with now is a turning point; we can continue on the current path leaving both caregivers and care receivers at increased risk, or we can take a new approach that will not only improve the quality of life for caregivers and care receivers, but make for healthier communities and a healthier future for our country. We must remember that today's caregivers will one day themselves need care, and the costs they incur today as caregivers will have consequences for our society as a whole.

To find this new path we need to consider: How has caregiving changed? What are the sources of this change? What costs do caregivers incur? What supports are currently in place for caregivers? What can we reasonably expect caregivers to do? What supports should be provided to help caregivers? Who should provide them (World Health Organization, 2002)?

1.2 Changing Realities and Caregiving: Family, State, Market and Community

Numerous changes have taken place in all four sectors of the welfare diamond that have implications for caregiver well-being. As changes in one sector may be a reaction to or produce a response within the other sectors, an attempt to discuss change in each sector separately would be artificial. Rather, the process of change is much more organic and complex. Since the type of caregiving we are examining is seen largely as the responsibility of families, and in particular as the responsibility of women within the family, it seems natural to begin with the changes in family structure and family life that have altered caregiving relationships both within the family and that have led to the involvement of friends and neighbours in caregiving. This will be followed by an examination of how changes in the state, market and community intertwine to create the current context in which care is being provided.

The structure, composition and division of responsibilities for the provision of well-being have changed significantly within families over the last three decades. Trends such as delayed marriage and childbearing, adult children leaving home later and returning to their parental home in larger numbers, and high divorce and remarriage rates, have radically changed the reality of family life (Fast & Keating, 2000). There is also growing awareness that Aboriginal peoples have different family structures, as extended family members and non-kin may be commonly including in family networks impacting who provides care and to whom within these communities (Gahagan, Loppie, MacLellan, Rehman, & Side, 2004). Additionally, Canada has experienced an influx of immigrants from non-European sources resulting in further diversity in family and living arrangements as a result of both cultural traditions and socio-economic conditions (Fast & Keating, 2000; Gahagan et al., 2004). New family forms have also emerged: such as same-sex couples, extended kin living together, and friends living together and taking on family roles and responsibilities (Janz, 2000; Shillington, 2004). Families are also more geographically dispersed (Canadian Council on Social Development, 1999; Shillington, 2004). The resulting changes have led to smaller families, less stable families, and more complex family relationships (Fast & Keating, 2000).

All of these changes and trends have consequences for caregiving. While families have not abandoned caregiving responsibilities (and indeed, as will be discussed below, are being pressured to take on greater amounts and more complex care), new family structures have made it increasingly difficult for families to take on and provide adequate amounts of care. For example, fewer children within the family may mean that there is less help from siblings when providing care for a parent. Couples without children or with children who live at a distance may have to seek out care from other sources, such as nieces, siblings, friends or neighbors. Divorce and remarriage result in extended kinship networks and lead to ambiguity about who is willing and expected to provide support (Fast & Keating, 2000).

It should be noted that while caregiving occurs largely within the context of the family, it is not the entire family unit that is struggling to provide this care, but more commonly a woman within the family who takes primary responsibility for family care (Guberman, 1999; Guberman, Maheu, & Maille, 1992; Penrod, Kane, Kane, & Finch, 1995). The pressures on women to provide care come from many places. While there is evidence that women are socialized to have the appropriate skills and to feel responsible for caregiving, there is much more going on. One must also look at the context in which women are providing care work. “Caring can be understood only as women’s work within unequal relationships, structures and processes that help create women as carers and undervalue this caring work”, argue Armstrong and Armstrong (2004, p. 11). It is also important to understand that not all women think about care work the same way. Some will not feel that it is their responsibility. Others will believe they should provide the care, struggle with inadequate times, skills or other resources to properly take on the caring role. Others are providing care such as meal preparation, cleaning and running errands without seeing this as care work, but rather as a regular part of daily life (Armstrong & Armstrong, 2004).

Not only are women taking responsibility for much of the care provided within families, women also more commonly find themselves taking on multiple caregiving roles. As adult children remain in the parental home longer or return home after leaving the nest, women in particular may find themselves caring for more than one generation, juggling roles of mother, sister, daughter, wife and employee (Fast & Keating, 2000; Keefe, 2003). Changing family structures, and in particular the reduced availability of caregiving by adult children, means that women may end up providing care throughout their lives. Where once they might have only cared for their children and then their parents, these new realities mean that women might also be called on to care for their siblings, extended kin, neighbours and friends (Keefe, 2003). Men are also assuming more involvement in care work (Guberman, 1999).

In addition to the changes in family structure and family life, there has also been a significant change in the relationship between women and the market place. Over the past few decades the number of women in the labour market has dramatically increased (Jenson, 2004b). Women’s participation in the labour force increased from 24% in 1951 to 60% in 2001. This rate rose to 81% for women with a school-aged child under the age of 15 (Jenson, 2004b).

The involvement of women in the workforce has not meant a reduction in women’s caregiving role. It has been shown that when women increase their paid work time, there is not an equal

reduction in unpaid work (MacDonald & Phipps, 2004; Phipps, MacDonald & Lethbridge, n.d.). Additionally, the burden of taking on these extra responsibilities seems to fall disproportionately on women. Phipps, MacDonald, and Lethbridge (n.d.) found that men have not increased their share of unpaid work at the same rate that women have increased their share of paid work. Women are left doing double, triple or quadruple duty.

Alongside the involvement of women in the labour force has been a decline in the traditional male-breadwinner family model and an increase in two earner families (Jenson, 2004b). In order for families to secure well-being through the market place, it is increasingly essential to have 2 income earners in the household. In 1994, in 7 out of 10 married or common-law couples under the age of 65 had both partners involved in paid work. This marks a significant increase from 30 years earlier when approximately 1/3 of couples were dual earner (Canadian Council on Social Development, 1999; Vanier Institute of the Family, 1997). Women's economic contributions to the family have also become more important. In 1995, women's earnings accounted for between 25% and 49% of family income for almost 1/2 of families (46%) and in 1/4 of families women contributed half or more of the family's income (Canadian Council on Social Development, 1999; Vanier Institute of the Family, 1997). Given this new economic reality, families with caregiving responsibilities are left in a precarious place. If more care is required than can be provided around the constraints of paid work, one earner, usually the woman due to lower income and traditional roles, may be forced to leave the labour market (Armstrong & Armstrong, 2004). However, as women's income has become increasingly important to the well-being of families, reduction or loss of labour market income in order to provide care can have significant consequences for families. The consequences are even greater for single parent families. Jenson notes that as the relationship between the market and the well-being of families is currently constructed, Canadians are not only left to "strive to earn enough for their families, they must also ensure that they can care enough for them" (Jenson, 2004a, p. 17).

Despite these profound changes in family life, there has been notably little response to these changes from the state. The greater diversity in family relationships and the increasingly complex situations in which families are asked to provide care have not been matched by a shift in the thinking behind public policy. Policy continues to be based on "homogeneity among families and clear lines of family obligations" (Fast & Keating, 2000, p. 7).

There has, however, been a change in thinking about the role of the state. Armstrong and Armstrong (2004) argue that from the end of World War II until the 1970s Canadian social programs were in their most comprehensive and universal form. This period was marked by discourse and action based on shared risk and collective rights that meant the state took responsibility for the welfare of citizens and for limiting the negative impact of the market place. The "state played a more active and visible role in the redistribution of income, power and other resources, and in the delivery of services", write Armstrong and Armstrong (2004). This redistribution of resources was particularly significant for women because women have historically had fewer resources than men (Armstrong & Armstrong, 2004).

The 1970s saw a move away from this model to one focused on individual responsibility and on markets rather than states as the mechanism for redistribution (Armstrong & Armstrong, 2004).

Fast and Keating (2000) identify a number of changes in public policy associated with this shift in discourse that changed the caregiving context:

- 1) “Reduced government expenditure on health, income security and social services” (Fast & Keating 2000, p.10). The consequences of reduced spending have fallen disproportionately on women as they must fill the gaps left in the system and find themselves with fewer supports (Freiler, Stairs, Kitchen, & Cerny, 2001).
- 2) “Push toward the privatization of health and continuing care” (Fast & Keating, 2000, p.10). Publicly paid services are being provided by private organizations and eligibility for public supports is being narrowed, leaving caregivers and care receivers to cover the costs of private services, or caregivers to fill the gap by providing additional care.
- 3) “Shift from institutional to community-based health and continuing care” (Fast & Keating, 2000, p. 10) resulting in increased demands on informal caregivers as they strive to maintain the care receiver in the community.
- 4) “Increased geographic inequity in health and social service delivery” (Fast & Keating, 2000, p. 10). Caregivers in one area of Canada may have available to them a different range of supports, with different eligibility criteria and co-payments, than other areas of Canada, resulting in a varied distribution of costs among informal caregivers. Armstrong and Armstrong note that “Care still needs to be done, but less is done for pay in the public sector or provided without direct financial cost to citizens” (Armstrong & Armstrong, 2004, p. 18).

While all four of these shifts have had an impact on caregivers, further mention must be made about the shift to community care, and the state’s assumptions behind this move, as the consequences to caregivers have been tremendous.

This shift has been facilitated by new medical techniques, technology and drugs that have made it possible to relegate more procedures as day surgery or on an outpatient basis, and to shorten hospital stays. Additionally, these technologies have meant increased longevity, and increased rates of survival after serious illness and injury. As a result more frail, ill and disabled people are being cared for at home. It also means that these people suffer from more severe disabilities and illnesses which, in turn, means more intense and complex care needs. Thus, not only is there more care, but also more complex care, being done within the community (Fast & Keating, 2000). Armstrong and Kits (2001) notes that “our grandmother never cleaned catheters or checked intravenous tubes; they did not examine incisions or do much wound care” (p. 26). Caregivers are also incurring additional financial costs as a result of this shift because drugs and equipment provided as insured services within the hospital may only be provided through means-tested programs in the community. If the care receiver is deemed ineligible, either the caregiver or care receiver will have to pay for these services when care is provided at home (Stadnyk, 2002).

The shift to community care is revealed in the discourse that care receivers want and will be better cared for in the community. However, this shift also has economic motivations for

government, since costs for publicly funded programs can be reduced by shifting care into the community. As well, one should not be quick to conclude that community-based care is more cost effective than hospital stays and long term facility placement (Keefe, 2002). The cost effectiveness of this shift needs to be understood in a broader context. In particular, the substantial amount of unpaid care provided by family and friends in the community, and the financial and other costs that they incur, is not included in this accounting (Keefe, 2002). Keefe (2002) notes that “critics of community care policy highlight that care *in* the community, in terms of location, is admirable. But care *by* the community sets up expectations of the role of family members, particularly women, and exploits their unpaid labour” (p. 126).

Not only does the discourse around cost savings under community care need to be reconsidered, but the discourse of “community care” itself is suspect. Guberman (2004) writes:

...when we talk about community care we are talking about care in the home, supplemented occasionally by day centers. And when we talk about care in the home, more often than not we are talking about care provided mainly by family and friends, supplemented by some homemaking, personal care, nursing support and perhaps Meals-on-Wheels or volunteer transportation services. And among family and friends we are most often talking about women. So again, more often than not, what is called community care is in fact care by women in the family with little or no support from the community. (p. 75)

There has not only been a shift to care in the community, but also a shift in approach to home care. Three general approaches to home care can be identified:

- 1) Long Term Care Model: Home care services are provided to keep people in the community and out of a long term care facility;
- 2) Maintenance-preventative Model: Home care services are provided to those with health or functional needs to enable independence, prevent further deterioration, and prevent or delay institutionalization; and
- 3) Acute Care Substitution Model: Services are delivered through home care to enable people to return home sooner or avoid admittance to an acute care facility (Keefe, 2002).

Manning (2004) notes that most provincial and territorial publicly funded home care programs were initiated with the goal of assisting the frail elderly with personal care and homemaking tasks; services that could be seen as supporting the Maintenance-preventative Model. However, in recent years there has been a significant shift toward the Acute Care Substitution Model. Funding has been diverted to home nursing services, while the availability of home support and personal care services has been reduced in many jurisdictions (Manning, 2004).

While caregivers are being called on to fill the gaps, community organizations are also being asked to take on a greater role in providing these services. Increasing demands have raised serious concerns about lack of funding leading to instability in service provision and difficulty

recruiting and training volunteers. Concern has been voiced about the quality and the sustainability of services provided through community organizations (Guberman, 1999). There seems to be an assumption that the voluntary and community sector can replace parts of formal care services without consultation or additional resources. For example, a publicly provided meal program will be cut when a Meals-on-Wheels service is available without determining if the organization can accommodate the increased demand (Guberman, 1999). These challenges within the community sector to provide services have numerous consequences for caregivers. First, caregivers may find that they cannot count on community services to be available as wait lists are long and volunteer turnover can be high. Additionally, caregivers are left to negotiate their way through a complex and uncoordinated network of services. Caregivers must try to piece together adequate services from public, not-for-profit and private sources within the community, and as availability and origin of delivery change, caregivers must renegotiate these relationships.

All of these changes mean that informal caregivers are doing more, whether it be more hours of care and work, more juggling of multiple responsibilities, more managing of multiple care providers, more negotiating and advocating for services, or more complex care provision. In the next section we will look at who these caregivers are, what kinds of care they are providing and what are the costs and consequences of providing this care.

2.0 Profile of Caregivers and Caregiving in Canada

As a first step in identifying caregivers' needs and where there might be policy gaps, we need to paint a picture of caregiving in Canada. This section describes the people who are providing care, what they are doing, and some of the hidden costs incurred by caregivers, as well as the diverse social, economic, and cultural contexts in which caregiving occurs.

This section is based largely on data from Cycle 16 of Statistics Canada's *General Social Survey* (GSS), "Aging and Social Support". The GSS is an annual telephone survey carried out in all 10 provinces involving 25,000 randomly selected respondents living in private homes. The survey collects information on the characteristics of family and friends who provide care to seniors. The data were collected between February and December 2002. Two key points must be raised about this survey: 1) Only caregivers aged 45 and older are included in the sample. 2) Only caregivers caring for someone age 65 and older with a long term health problem are included in the sample. Unfortunately this means that the data does not tell us about younger caregivers and caregivers supporting disabled adults under age 65 (Stobert & Cranswick, 2004). One should not assume that the types of care work or the needs and challenges faced by young caregivers or caregivers of young care receivers are identical to those represented in the 2002 GSS, although there are likely similarities.

The work of Gahagan et al. (2004), based on focus groups with caregivers in the province of Nova Scotia, is also featured in this section. This research complements the 2002 GSS findings by providing an overview of the challenges, costs and consequences caregivers identify when describing their caregiving experience. This research is also helpful in demonstrating the diversity of caregiving because the participants came from a wide range of communities (African Nova Scotian, Aboriginal, disability community, immigrant community, low-income women and rural women) and caregiving situations (lone parents, caregivers of persons with HIV/AIDs, caregivers of elderly persons, caregivers of adults with disabilities, male caregivers, etc.).

2.1 Who Provides Care?

According to results from the 2002 GSS, there were over 1.7 million adults between the ages of 45 and 64 who were caring for 2.3 million seniors with a long term disability (Stobert & Cranswick, 2004). Of all of those people providing care to a senior in 12 months prior to the survey, 54.4% were women and 45.6% were men. The simple answer to the question "who provides care?" is that many Canadians provide care, but women in particular are caregivers. Given that women are more often caregivers than men, it seems pertinent to use gender to breakdown the 2002 GSS data on the characteristics of caregivers in order to gain a clearer understanding of the gendered nature of care work.

Age is seen as a characteristic that plays a role in determining who becomes a caregiver. For both men and women approximately 42-43% of caregivers are between the ages of 45 and 59. Slightly higher proportions of caregivers (47.7% of women and 48.8% of men) are between the ages of 60 and 74. Guberman (1999) identifies the aging of caregivers as a new trend; accompanying the increase in life expectancy has been an increase in the age of both those who receive and those who give care. With age comes different caregiving challenges. For example,

women in their 60s and 70s may be asked to care for parents while also caring for a spouse with care needs (Guberman, 1999). We are also seeing increases in the number of older parents caring for an aging child with a life long disability (MacLellan, Norris, Flowerdew, & MacPherson, 2002), and caregivers in their 80s and 90s who look after a disabled spouse. Data from the 2002 GSS indicates that almost 10% of women and more than 8% of men caregivers are 75 years of age or older. Clearly, older people are not only care receivers but also caregivers (Keating et al., 1999). These caregivers may also be dealing with their own disabilities or chronic illnesses and have their own care needs.

Family structure, such as presence of children and marital status have also been examined. Among women, 9.9% reported having a child under 15 years of age, while 15.4% of men reported having a child under 15 year of age. In previous research Keating et al. (1999) found that in comparison to the general population, women caregivers with children were underrepresented. This may be because the demands of childcare make it more difficult give time to eldercare, or there is less demand for eldercare because the parents of caregivers with young children are likely to be younger (Keating et al., 1999). According to the 2002 GSS, most caregivers were married, but the rates of married men and women caregivers differed somewhat. Among women providing care 70.6% reported that they were married or in a common-law relationship, while 83.1% of men indicated they were married or in a common-law relationships.

One should also consider the role played by employment status and whether caregiving shapes the relationships caregivers have with the labour market. Data from the 2002 GSS indicate that higher proportions of men than women caregivers were in the labour force. Among women, 36.4% were not in the labour force, and 25.4% of men were not in the labour force. A greater proportion of men (67.4%) were employed in full-time work than women (44.8%), while a greater proportion of women (18.6%) than men (7.0%) were employed in part-time work. There is some indication that women's caregiving responsibilities may be having an impact on the types of employment women are doing. Armstrong and Kits (2001) note that in 1999, 41% of employed women aged 15-64 worked in a non-standard employment situation, compared to 35% in 1989. They argue that instead of having to take time off from work or quit work to provide care, women are taking jobs with shorter hours or that can be done at home in order to balance work and caregiving. As will be discussed in greater detail below, there are costs to these kinds of choices, as non-standard work is less likely to have benefits and pensions, leaving these women to rely on public pensions in old age (Armstrong & Kits, 2001; Townson, 2000).

Related to employment is education. Keating et al. (1999) point out that there is a common hypothesis that those with higher levels of education will have less time for caregiving. This is based on the assumption that those who are highly educated are more likely to be employed and dedicated to full-time positions, whereas less educated people are less likely to think of their work as a career and as a result are more likely to leave work to provide care. However, results of recent studies do not fully support these assumptions (Keating et al., 1999).

While family structure, age, and labour market status are important characteristics shaping caregiving, geography also plays a role. Most caregivers live in urban areas (76.9% of women and 74.8% of men), but approximately 3 live in a rural area. Past research found that the proportion of male caregivers living in rural areas was similar to that of the general population, but that rural women caregivers were somewhat over-represented, and women caregivers in

urban areas were underrepresented (Keating et al., 1999). The rural/urban issue is an important one to consider as caregivers in rural areas face different challenges than those in urban areas. Long term disability and chronic illness rates are higher in rural communities, in part because nearly 1/3 of elderly Canadians live in rural communities. Additionally, as seniors have remained or moved into rural areas and young people have left those communities, there are fewer sources of unpaid care within those communities. Furthermore, both public and private services are often limited or unavailable in rural or isolated communities. Those caring in rural communities tend to turn to informal networks for support (Fast & Keating, 2000; Guberman, 1999).

The 2002 GSS provides us with information not only on the characteristics of caregivers, but also on caregiving relationships. Caring for a close relative was the most common caregiving relationship with more than half of women (59.4%) and men (64.6%) caregivers being adult children caring for a parent. Interestingly, 22.5% of women and 28% of men indicated that the person they were caring for was a friend or neighbour, supporting the claim that a great deal of care is being provided outside of the traditional family structure.

It is also important to note that most caregivers had been providing care for a substantial length of time. Most women (73.4%) and men (80.9%) have been caregiving for two years or more. This finding may not be surprising given that caregiving is defined in the survey as providing assistance to someone with a health problem lasting six months or more (Keating et al., 1999), and thus, those providing short term care would not be included as caregivers in the data. However, this does suggest that caregiving occurs of long periods of time in many cases, and following this, that the costs and consequences of caregiving can also be long term. Among the 98 participants in Gahagan et al.'s (2004) focus group research, the average number of years spent caregiving was 10 with a maximum of 71 years, although this is not restricted to eldercare. As has been mentioned elsewhere in this report, caregivers, and women in particular, may be asked to care for more than one person during the course of their lives. Additionally, their responsibilities may ebb and flow as the needs of the care receivers change, or other circumstances in the caregivers' lives alter the ability to provide care. Unfortunately there is a lack of longitudinal studies on caregiving (Guberman, 1999) that could illuminate such issues as the long term health, financial, and social consequences of caregivers, or provide insight into the unpaid care careers of caregivers.

Table 2.1**Characteristics of women and men caregivers aged 45 and older caring for a care receiver age 65 and older¹**

	Women n=2729	Men n=1892
Caregivers	54.4%	45.6%
Marital Status		
Married/common-law	70.6	83.1
Divorced/Separated	14.3	8.5
Widowed	8.2	1.8
Single	7.0	6.9
Age		
45-59	42.4	42.8
60-74	47.7	48.8
75+	9.9	8.4
Residency		
Urban	76.9	74.8
Rural	23.2	25.2
Have 1 or more children (<15 years)	9.9	15.4
Income		
<\$15,000	6.4	4.3
\$15,000-\$29,999	16.7	10.7
\$30,000-\$49,999	27.3	18.5
\$50,000-\$79,999	24.5	30.9
\$80,000+	25.2	35.5
Employment Status		
Part-time	18.6	7.0
Full-time (>30hrs)	44.8	67.4
Not employed	36.4	25.4
Length of relationship		
< 2 years	23.0	19.1
>2 years	73.4	80.9
Care receiver: Close relative (spouse, partner, parent)	59.4	64.6
Care receiver: Distant Relative	9.1	7.4
Care receiver: No relation	22.5	28.0
Care Receiver Age: 65-74	16.1	23.8
Care Receiver Age: 75-84	43.8	46
Care Receiver Age: 85+	26.9	26.6
Care Receiver: Deceased	6.6	6.7
Move near care receiver	3.8	2.3
Care receiver moves near them	9.3	7.6
Live in same house as CR	14.4	11.6
Live in surrounding area of CR	18.3	19.3
Live in same community as CR	42.8	51.8
Live less than 2 day away from CR	9.3	9
Live more than 2 day away from CR	6.9	7.1

Source: Statistics Canada, General Social Survey, 2002

¹ Missing responses are not included.

Other characteristics of caregivers, such as culture, ethnicity, disability, and personal qualities and circumstances also shape the caregiving experience. These factors play a role not only in when and why they care, but also what kinds of care work they do and what access they have to supports (Unpaid Caregiving Forum, 2003).

For example, immigrant women in Gahagan et al.'s (1999) focus group research identified tension between their own cultural caregiving practices and Canadian customs. Additionally, those who are themselves immigrants or caring for recent immigrants to Canada may experience unique barriers to accessing support and services. For example, translation services may be needed for those who do not speak English (Keefe, 2003). Furthermore, sponsored immigrants are ineligible for government paid assistance including hospitalization, home care services and institutionalization, placing a great deal of burden on their caregivers (Guberman, 1999).

Aboriginal communities also face different caregiving contexts as disease and disability rates are twice as prevalent as in other communities, meaning increased need for care (Keefe, 2003). Caregiving networks are also different. In Aboriginal communities extended kinship networks may mean that caregivers are involved in more diverse and complex caregiving arrangements (Gahagan et al., 2004). It has also been noted that supports to Aboriginal caregivers on and off reserve can be quite different (Gahagan et al., 2004).

Gahagan et al. (2004) found that African Nova Scotian caregivers identify some unique caregiving issues. They identified strong kinship and community ties, particularly through the "church community". They also identified inadequate and culturally inappropriate support as barriers to getting help with caregiving. Socio-economic status was also identified as a barrier to accessing support (Gahagan et al., 2004).

It must also be remembered that caregiving is not a one way relationship. Many of those that need assistance also provide assistance. Additionally, caregivers may have a chronic illnesses or disabilities that they can manage on their own, while they also provide care for someone else. Gahagan et al. (2004) note that the issues these caregivers face may not be different from those of other caregivers, but may be heightened. Disabled caregivers identify fatigue as being a central concern originating both from their own disability and as a result of caregiving. Support has been identified as being of particular importance to this group of caregivers (Gahagan et al. 2004).

Caregivers also bring with them different beliefs about caring, diverse personal goals and interests, and unique life histories. For example, participants in Gahagan et al (2004) found that identified past experience in paid care work and personal qualities such as being nurturing or having personal strength have played a role in taking on caregiving. We must be mindful of this diversity and the way it shapes the caregiving experience as we consider the data on caregiver characteristics and begin to think about policy needs for caregivers.

2.2 What are Caregivers Doing?

Caregivers provide a broad range of services. Armstrong and Kits (2001) identify 4 broad, overlapping categories:

- 1) Instrumental Activities of Daily Living: Help with chores such as cooking, shopping, housework and home maintenance.
- 2) Assistance with the Activities of Daily Living: Help with personal care needs such as bathing, dressing, using the toilet and grooming. Helping with medications, giving needles, and other health care needs.
- 3) Management of Care: Most caregivers do some work of this kind, but this is the prime role of many caregivers. Care management involves finding out about, arranging for, and ensuring delivery of formal and informal services.
- 4) Social and Emotional Support.

While the 2002 GSS provides detailed data on caregiving activities in the first two categories, less detailed information is available on categories three and four.

Table 2.2

Average time spent on caregiving activities by caregivers (hours per month).

	Women		Men	
	45-64	65+	45-64	65+
Total hours	29.6	32.9	16.1	20.9
Inside Activities (housekeeping, etc.)	19.9	20.8	6.4	9.4
Outside Activities (home maintenance, etc.)	2.3	.3	5.3	2.3
Transportation	2.6	5.2	3.1	6.1
Personal care	4.8	6.6	1.3	3.1

Source: Stobert & Cranswick, 2004, Statistics Canada, General Social Survey, 2002.

According to data from the 2002 GSS, women caregivers aged 45-64 spent almost twice the amount of time (29.6 hours per month) on caregiving tasks as their male counterparts (16.1 hours per month). Stobert and Cranswick (2004) found that these amounts are not greatly reduced when looking at caregivers who are employed. Women continue to spend 26.4 hours a month and men spend 14.5 hours per month when employed. Stobert and Cranswick (2004) argue that the disparities between the amounts of care provided by men and women are due to the kinds of care work being done. Women take 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 home maintenance and transportation. Care work is clearly divided by gender.

Women aged 65 and older also spend more time caregiving than men in the same age group. Men in this age group do spend more time caregiving than men aged 45-64, as they are likely to be retired and have more time. Men in this group also do spend more time on inside activities and less on outside work than middle-aged men, perhaps because of reduced physical capacity to do tasks such as home maintenance. Older women still spend most of their caregiving time on

inside domestic activities and personal care (Stobert & Cranswick, 2004).

Gahagan et al. (1999) note that there are numerous additional tasks that caregivers take on such as “advocating on behalf of themselves and the recipients, ensuring that recipients are treated with respect and dignity, and that as far as possible, recipients have input into decisions concerning their care. They also have to take care of themselves so they can continue providing care to others” (p. ix). Caregivers are left to try to juggle all of these competing responsibilities.

2.3 Costs and Consequences of Caring

When individuals take on the role of caregiver, they are faced with many challenges such as making adjustments to social and work life, reconsidering future plans, and dealing with the physical demands of caregiving as well as concerns about immediate and long term financial security, and how to cope with the illness, disability or potential death of the caregiver (Guberman, 1999).

Keating et al.(1999) note that caregivers identify both positive and negative outcomes of caregiving. Positive outcomes include satisfaction, increased knowledge and self-confidence, as well as increased tolerance and understanding of others (Fast, Williamson, Keating, 1999, p. 306). According to data from the 2000 GSS, the majority of both men (70.9%) and women (71.7%) caregivers reported that they nearly always felt that their relationship with the care receiver was strengthened.

However, the negative consequences can have significant costs to caregivers. In order to determine how to better support caregivers, this section will address the negative consequences in greater detail.

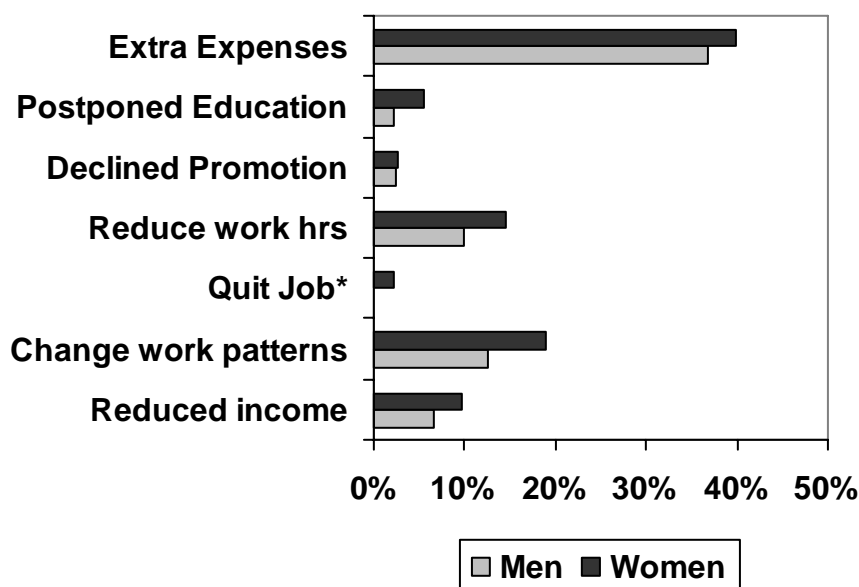
The 2002 GSS includes many questions that attempt to uncover the potential costs of caregiving. A taxonomy of costs developed by Fast, Williamson, and Keating (1999), will be used to structure this discussion. As outlined in the taxonomy, costs can be grouped into two categories. The first category is economic costs, which involve money or money equivalents, such as out-of-pocket costs, employment-related costs, and unpaid labour. The other category is non-economic costs, which “result from declines in certain aspects of ones life” (Fast et al. 1999, p. 304) including social, emotional, and physical well-being.

Economic Costs

Economic costs not only include expenditures on services, equipment or supplies, but also include costs related to lost current and future employment income and benefits. Caregivers may make changes to their work patterns or reduce hours to provide care. Taking days off, arriving late or leaving early, or taking longer leaves from work can all have economic costs, not only in terms of reduced immediate earning, but also future earnings, as these employees may be turned down for raises and promotions. Caregivers may also turn down career-related opportunities such as additional training, extra projects, and promotions because they cannot take on the additional time or responsibilities due to their care work. This has economic consequences as these opportunities might have led to salary increases and promotions. If a caregiver has to reduce hours or quit a job to provide care, she may also lose many employment-related benefits,

such as extended health care, life and long term disability insurance, and private and public pension benefits (Fast et al., 2001). The economic consequences for women are of particular concern. Kerr (1992 in Guberman, 1999) has suggested that a 35 year old women who leaves the labour market for 2 years can expect a future earnings loss of \$15,000, with \$50,000 after a 5 year absence, and \$94,000 after a 15 year absence from the workforce. This does not include lost earnings while out of the labour market or reduction to pensions. Furthermore, women who do not participate in the labour market to provide unpaid care must rely on their spouse or social assistance. Not only does this have an impact on their economic autonomy within the household, or leave them with the challenges of low income, but as they age they may also be dependent on their spouse's pension, or government programs such as OAS and GIS (Townson, 2000).

Chart 2.1
Economic costs of caregiving



* The data from men is too small to be expressed.
Source: Statistics Canada, General Social Survey, 2002

Of all economic costs, incurring extra expenses as a result of caregiving was the most commonly reported cost. This cost was experienced by 39.9% of women and 36.7% of men. Guberman (1999) notes that these out-of pocket costs do not only include the kinds of expenses commonly thought of, such as payment for care services, adaptive equipment, medication, and home modifications, but that care-related expenses can also be less easy to identify or calculate. For example, in order to save time or because they cannot leave the care receiver alone, caregivers may use services such a fast food or grocery delivery. The additional costs associated with these services contribute to the financial strain placed on caregivers.

Many caregivers, and women in particular, also identified costs associated with employment. Reduced work hours were reported by 10% of men and 14.5% of women, while 12.6% of men and 19.0% of women caregivers noted that they had changed their work patterns as a result of caregiving. A higher proportion of women than men reported all of these economic costs of

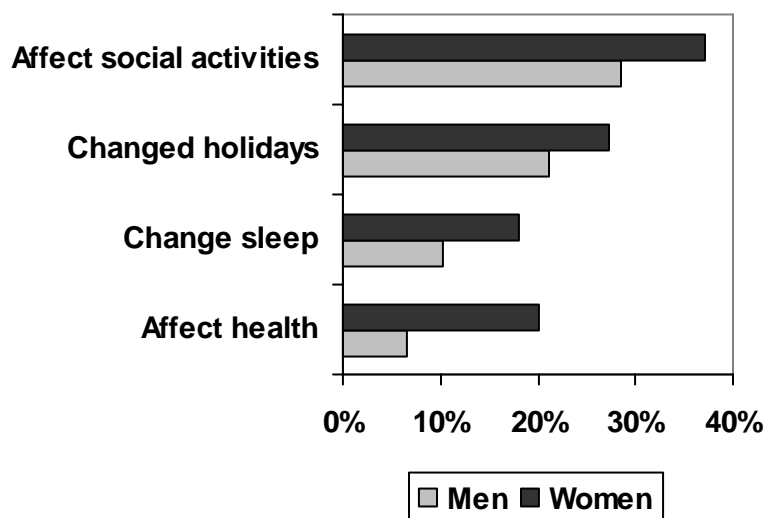
caregiving. There may also be a relationship between the types of care being provided and employment-related economic costs. Walker's (2005) analysis of data from the 2002 GSS found that caregivers who reported providing more personal care also were more likely to change their work patterns. Women who provided personal care also were more likely to quit their jobs.

Non-economic Costs

Caregivers also face social, physical, and psychological costs. Caregivers often give up social activities and leisure in order to provide care (Keating et al., 1999). This can happen for a number of reasons such as difficulty finding a substitute caregiver, fatigue due to care work and juggling multiple responsibilities, as well as "reluctance to have friends and extended family interact with the care recipient because of the latter's behaviour and the stigmas and taboos associated with mental retardation, mental illness and other such conditions" (Guberman, 1999, p. 38). Gahagan et al. (2004) found that caregivers' social lives were altered in significant ways due to the heavy workload of caregiving. They had difficulty maintaining social networks and lost friendships either because they did not have the time or energy to maintain friendships or friends stopped visiting. Data from the 2002 GSS indicate that 37.1% of women and 28.5% of men report that caregiving has affected their social activities and 27.2% of women and 21.2% of men have changed holidays due to caregiving responsibilities.

Caregivers, particularly women, also identify physical consequences of caregiving. Changes in sleep were identified by 18.1% women, but only 10.3% of men reported changes in sleep. Higher proportions of women (20.2%) than men (6.5%) said that caregiving had affected their health. As with economic costs, we consistently see a larger proportion of women than men reporting non-economic consequences of caregiving.

Chart 2.2
Non-economic costs of caregiving: Social and physical



Source: Statistics Canada, General Social Survey, 2002

Caregivers also express a range of emotions, concerns and desires about their caregiving responsibilities. An examination of these reveals more about the caregiving experience and

hidden costs. While more than 70% of both men and women caregivers report that they nearly always felt that caregiving has strengthened their relationship with the care receiver, many caregivers also report negative feelings. Stress has been identified as a prime concern for caregivers. Among men, 24.9% said they sometimes feel stressed, and 6.5% said they nearly always feel stressed. These rates were higher for women: 35.7% said they sometimes feel stressed, and 14.2% said they nearly always feel stressed.

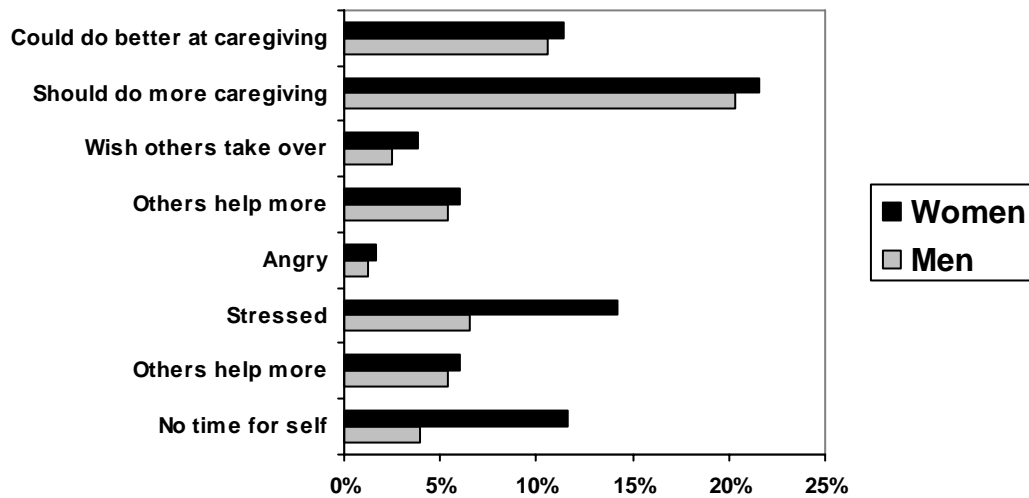
Walker (2005) found that among employed caregivers, women with high incomes reported being stressed more often than women with low incomes, suggesting that the demands of high paying work is linked to work-life conflict for women. On the other hand, Walker (2005) found that men with high incomes reported being more satisfied with work-life balance than men with low incomes. Walker (2005) suggests that this may be because these men recruit paid help, allowing them to meet both caregiving and employment responsibilities, whereas women are being asked to provide more care and more complex care, and it may not be felt that it is appropriate for them to purchase care services.

Experience of guilt is another cost for caregivers. Caregivers feel guilty because they cannot do as much as they think they should because of competing demands on their time and energy. Keating et al. (1999) argue that many caregivers feel they should be doing more, should be more efficient, or have better caregiving skills. More than 10% of both men and women nearly always felt that they could be doing better, and more than 20% nearly always felt they should be doing more. When those that said they sometimes have these feelings are included, we see that the majority of caregivers experience these feelings of guilt. Caregivers reported wishing others would take over caring or help more; as well, many had feelings of anger. A larger proportion of women than men reported that they nearly always feel they have no time for themselves. Stobert and Cranswick (2004) found that among caregivers age 45-64, less than one in five (17%) reported that they received help when they needed a break. Assistance that is provided comes largely from other family members (82%), while 16% relied on paid help from private or government sources.

Chart 2.3

Non-economic costs: Emotional

Proportion of caregiver who responded that they nearly always felt the following:



Source: Statistics Canada, General Social Survey, 2002

2.4 Summary

The data from the 2002 GSS reveals that many Canadians are providing care to seniors. Among those aged 45 to 64, 16% reported providing eldercare for disabilities (Stobert & Cranswick, 2004). While this represents a substantial proportion of the population, it is crucial to remember that there are many outside of this age group who are providing eldercare and many across all ages that care for someone younger with a disability or illness, but are not included in the 2002 GSS data on caregiving. The circumstances and needs of these caregivers should be further researched and need to be considered in the development of policy.

This portrait tells us not only that more women are caregivers than men, but that women are also spending more time on caregiving, and report incurring greater economic and non-economic costs from caregiving than men do. There are also changes occurring around who provides care. For example, men are becoming more involved in care work. We also find that seniors are not only the receivers of care but are also becoming the providers of care in greater numbers, and are providing care into old age. 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.

3.0 Canadian Programs and Policies Supporting Caregivers

We have seen that caregivers incur significant costs as a result of caregiving, whether they be financial, physical, emotional or social, or of a long or short-term nature. Currently, the Canadian government has no comprehensive strategy in place to support caregivers. Rather, there is a mix of programs and policies in place at the federal and provincial levels that are either directly targeted to help caregivers, or provide some support to caregivers indirectly through services provided to care receivers. These program and policies fall under two main categories: 1) Home care services provided through provincial continuing care programs; and 2) Policies that provide financial compensation. This section provides an overview of current policies and programs, and examines issues around accessibility and impact of available supports on caregivers.

3.1 Home Care in Canada

One the main ways support is provided 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. In Canada, these programs fall largely under the responsibility of provincial departments of health or social services, and more specifically are included in continuing care programs that cover a range of services provided to care receivers residing both within communities and in residential long term care facilities. While all of the services offered under the umbrella of continuing care may provide some support to caregivers, we are particularly interested here in those services that are provided within the community, where caregivers are taking on particularly heavy care loads. Home care can be defined as “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, & Eustic, 1994). This definition can also be expanded to include services to caregivers, and additional services such as home adaptations, transportation services, and meal delivery program, to name a few (Kane et al. 1994). Home care programs across Canada are diverse. By looking at the historical development of home care in Canada it will be possible to shed light on the sources of this diversity and the ensuing complexity of programs within which care receivers and caregivers are currently operating.

Accounting for Diversity in Home Care Programs in Canada

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 (Keefe & Fancey, 1998). The *Canada Health Act*, the central guide for the provision of health care services in this country, outlines two major categories of services (Hollander et al., 2000). These are Insured Health Services and Extended Health Care Services. Insured Health Services include hospital based services and physician-provided services. Extended Health Care Services include nursing home and long term residential care, some home care services, adult residential care and ambulatory health care services. These services are not insured services under the *Canada Health Act*. Other types of home care services such homemaker services and adult day programs are also not covered by the *Canada Health*

Act. In order to receive federal funding for Insured Health Care, provinces and territories must abide by the principles and regulations of the *Act*. However, Extended Health Care services and those not outlined in the *Act* are not subject to the principles of the *Act*. Instead they fall under provincial/territorial jurisdiction (Hollander et al., 2000). Given the lack of federal responsibility for home care, these programs have been left to develop in very different ways in the provinces, with the result that different provincial programs offer different kinds of services, with diverse assessment and eligibility criteria, approaches to payment, and so on.

While the absence of national policy on the provision of home care is largely responsible for the unique historical developments of home care in each province and territory, other policy shifts have contributed to the diversity of home care programs.

The shift from the Canadian Assistance Plan (CAP) to Canadian Health and Social Transfer (CHST) as a mechanism for providing federal funding for health care had a significant impact on the development of home care in the provinces. Under the CAP, enacted in 1966, the federal government provided funds to the provinces to cover 50% of the costs on long-term support for disabled persons (Keefe, 2002). In 1996, the federal government moved to a new funding model. The CHST provides block funding rather than cost sharing. Under the CHST the provinces can determine independently how much of the funding from the federal government to allot to home care programs (Keefe, 2002). Amounts allocated to home care for the fiscal year 1997-98, including national funding sources for First Nations, veterans, and provincial and municipal home care services, ranged across jurisdictions between 2% to 6% of public health expenditures. In this year the Yukon had the lowest rate and New Brunswick the highest rate of public funding for home care (Keefe, 2002). With greater independence for decision-makers within jurisdictions, provincial and territorial home care services have developed and changed independently of trends in other jurisdictions, in accordance with the agenda of provincial and territorial governments of the day.

The regionalization trend further complicated the home care picture. Under the financial constraints of the 1990s, all provincial and territorial governments except Ontario moved to a regional model of health care delivery (Manning, 2004). Until the early 1990s Ministries of Health worked in partnership with service providers (Hollander et al., 2000). Under the regional model, ministries of health provide health care funds to the regions. The amount of funding is usually determined by use of a population based funding model. The region is then responsible for dividing the available funds among major budget items, including home care (Hollander et al., 2000). Greater decision making powers at the regional level, coupled with concerns about inadequate health care funding, have resulted in significant variation in the type and extent of home care services offered not only between provinces, but also within provinces (Keefe, 2002; Canadian Association of Retired Persons, 1999). These disparities are most noticeable between rural and urban areas. Professional services such as nursing and rehabilitation services tend to be more readily available in urban areas, and are often non-existent in isolated and rural communities (Keefe, 2002).

Home Care Services and Availability

Despite the conditions that have contributed to variations in home care from jurisdiction to jurisdiction, there is a central core of programs that are available in most provinces in some form. All jurisdictions have single entry access in which case managers are responsible for the assessment, determination of eligibility, and coordination of home care services for clients (Keefe, 2002). In each jurisdiction there are also two categories of home care services provided: professional services, such as nursing, rehabilitation services (physical therapy/occupation therapy) and social work; and home support services, such as homemaking (including tasks such as cleaning, cooking, laundry) and personal care (including tasks such as bathing, dressing) (Canadian Association of Retired Persons, 1999). A wide range of other services are also included under the umbrella of home care. Adult day programs provide opportunities for socialization and provide respite to caregivers. Access to additional professional services such as dietitians and speech language pathologists may also be provided by home care programs. Equipment and supply programs provide assistance with the cost of equipment required by people with physical disabilities. Home oxygen programs, available in a few jurisdictions, provide equipment and supplies to individuals needing technological assistance to properly oxygenate their blood. Other services include transportation, meal programs and home repair and maintenance (Fast, Eales, & Keating, 2001).

Of particular interest when examining supports for caregivers are respite services. Respite can be defined as “a caregiving service that provides planned intermittent breaks from the on-going responsibility of caring for a chronically disabled individual who is managed at home” (Guberman, 1999, p. 45). There are three common types of respite: 1) In-home respite: Care is provided in the care recipient’s home by volunteers or paid workers. This kind of respite may not be offered as a separate service for caregivers. Home support workers may be in the home to provide needed services to the care receiver or additional hours may be provided to relieve the caregiver (Fast, Eales, & Keating, 2001). This kind of respite may offer a break of a few hours a day or week; 2) Day care programs: Care recipient spends part of the day or week at a day program, providing the caregiver time away from care responsibilities; 3) Institutional respite: care receiver is temporarily placed in a long term care facility or hospital. This type of respite enables caregivers to take a longer break of several days or a week or more from caregiving responsibilities (Guberman, 1999).

While it is more an approach to service delivery than a service itself, many jurisdictions also offer self-managed care in which clients are allocated funding to make decisions about the purchasing and delivery of their own care. These types of programs evolved from the independent living movement, which is rooted in a philosophy enabling disabled persons to participate fully, control, and make decisions about all aspects of their lives (Canadian Association of Independent Living Centres, 2003). In Canada, younger adults with disabilities are the more likely users of these programs (Keefe, 2002). It should be noted that while these programs are available in several jurisdictions, levels of use vary. In 2003 Saskatchewan reported only 11 individuals utilizing this service, while 70% of home support services are provided through self managed care in Newfoundland (Canadian Home Care Association, 2003).

When considering how this type of program supports caregivers it should be noted that while these kinds of programs in other countries often allow the client to use the funds to pay a family caregiver, (as will be seen in Section 4.0), this is not generally the case in Canada (Keefe & Fancey, 1998).

The chart below drawn from work by Hollander et al. (2000) provides an overview of where various types of home care services are available across Canada.

Table 3.1
Services included in Continuing Care by type of service and jurisdiction

<i>Type of Service</i>	<i>NF</i>	<i>NS</i>	<i>PE</i>	<i>NB</i>	<i>ON</i>	<i>MB</i>	<i>SK</i>	<i>AB</i>	<i>BC</i>	<i>NT</i>	<i>YT</i>
<i>Assessment and Case Management</i>	X	X	X	X	X	X	X	X	X	X	X
<i>Homemaker/Personal Care</i>	X	X	X	X	X	X	X	X	X	X	X
<i>Home Care Nursing</i>	X	X	X	X	X	X	X	X	X	X	X
<i>Community Rehab (PT/OT)</i>	X	X	X	X	X	X	X	X	X	X	X
<i>Meal Programs</i>	X			X	X	X	X	X	X	X	X
<i>Adult Day Programs</i>	X		X	X	X	X	X	X	X	X	X
<i>Group Homes</i>	X			X		X	X	X	X	X	
<i>Equipment & Supplies</i>	X	X		X	X	X	X	X		X	X
<i>Transportation Services</i>	X			X	X	X	X				
<i>Home Maintenance and Repair</i>	X				X		X			X	
<i>Self Managed Care</i>	X				X	X		X	X	X	
<i>Palliative Care</i>	X	X	X	X	X	X	X	X	X	X	X
<i>Respite Care</i>	X	X	X	X	X	X	X	X	X	X	X

Source: Hollander et al., 2000.

When looking at the availability of services across jurisdictions reported by Hollander et al. (2000) there are three issues to consider:

- 1) Provinces and regions are continually reviewing home care services and making changes to programs. It is likely that changes have been made since this scan was completed (Hollander et al., 2000);
- 2) Even within service types there may be variation. For example, while nursing services are provided in all provincial and territorial home care programs, what is included under nursing services varies. Some jurisdictions include complex clinical care, while others only provide monitoring support (Canadian Home Care Association, 2003); and

3) This table tells us about the availability of programs but does not tell us about access
Rajnovich, Keefe & Fast (2005)

to the program, adequacy of the funding for the program, or the volume of clients using the services. For example, while all jurisdictions have home support and home nursing programs, there has been a trend to shift funding toward home nursing. This move means that access to nursing services may be improved while reducing access to home support services.

Federal Government Involvement in Home Care

While home care largely falls under the domain of provinces and territories, the federal government does play a role in home care beyond the transfer of funds through the CHST. The federal government operates home care programs for two distinct populations: First Nations and veterans.

Veterans Affairs Canada (2005) provides home care through its Veterans Independence Program. This national program is aimed at helping eligible clients “remain healthy and independent in their home or community for as long as possible” (Veterans Affairs Canada, 2005). The program provides funding for services such as grounds maintenance, housekeeping, personal care services, nutritional services, and health and support services. Other services such as home modification, nursing care, and transportation may also be available. The program may also continue to provide some of these services, such as lawn care or housekeeping, to spouses, partners, or another primary caregiver after death of the veteran under certain circumstances (Veterans Affairs Canada, 2005).

The First Nations and Inuit Home and Community Care Program, under the Department of Indian Affairs and Northern Development and Health Canada, provide home care services within First Nations and Inuit communities. Home care services offered under this program include nursing, personal care and homemaking services. These services are provided by trained and certified personal care and home health aid workers at the community level and are supervised by a registered nurse. Services under this program are to be equitable to that available to other Canadians, culturally sensitive, and “responsive to the unique health and social needs of First Nations and Inuit” (Health Canada, 2005).

How are services delivered?

There are not only differences in the types of services provided under Home Care programs but also how they are provided. While there are variations from jurisdiction to jurisdiction, it is possible to identify 4 models of home care delivery that cover the general practices of provinces and territories:

- 1) **Public provider model:** Under this model all home care services are provided by public employees including single entry access services (assessment, case management and discharge planning), professional nursing services and home support services. This model is used in Saskatchewan, PEI, Yukon and the North West Territories.
- 2) **Public professionals and private home support model:** Under this model single entry access

and all professional services are provided by public employees. Paraprofessional services are provided by private agencies. This model is used in New Brunswick, Newfoundland, Quebec, British Columbia and Alberta.

- 3) **Mixed public-private model:** Under this model single entry access services plus some professional services are delivered by public employees, while some nursing and all home support are contracted out depending on the region of the province. This model is typical of Nova Scotia and Manitoba.
- 4) **Contractual model:** Under this model only single entry access services are provided by public employees. All other services are contracted out. This model is used in Ontario (Keefe, 2002).

We see from these models that home care may be provided by public employees, but that in many areas home support services are contracted out, and in some jurisdictions professional services are also contracted out. Contracted providers may be for-profit or not-for profit. In order to save administrative costs, there has been an increase in contracting with non-government agencies to provide services and a move to making the procurement process more competitive. Ontario is the prime example of this move, as a managed competition model is being used for procurement of both professional and paraprofessional services (Keefe, 2002).

Additional Jurisdictional Differences

As has been outlined, there is variation between jurisdictions both in terms of the types of services offered and also how they are provided. The differences do not end there; assessment tools, eligibility criteria, entitlement and fees also vary significantly (Canadian Home Care Association, 2003).

Assessment Tools

Assessment tools are used in all jurisdictions to enable determination of a care receiver's needs. Various provincial and international data collection tools are used across Canada. The Canadian Home Care Association (2003) notes that one tool that is currently being used, or is planned to be adopted for use in a number of jurisdictions, is the Resident Assessment Instrument for Home Care (RAI-HC) which is "designed to identify client needs, using the Minimum Data Set for Home Care (MDS-HC) which is the screening component to assess multiple areas of function, health, social support and services use" (p. 3). It is important to note that while the tools used differ across jurisdictions, they have at least one feature in common - the focus is on assessment of the care receiver's needs. There may be an attempt to assess the capacity of family and friends to provide care, but the caregiver's needs are commonly not taken into account. While tools to assess the needs of caregivers have been developed and shown to be of value for understanding the needs of caregivers (Guberman, Keefe, Fancey, Nahmiash, & Barylak, 2001), implementation of caregiver assessment by home care organizations has been limited to date.

Eligibility

Most provinces use resident, landed immigrant or citizen status as basic eligibility criteria. Home Care is available to persons of all ages in all jurisdictions except British Columbia, where home support for those under 18 is funded separately (Canadian Home Care Association, 2003). In 2003, 6 provinces and territories had no income testing. Income testing was present in the other jurisdictions but commonly only for some services such as personal care and homemaking. For example, British Columbia has a standard income test used across the province, while New Brunswick has both income and asset testing for long term supportive care, and Nunavut has no income testing (Canadian Home Care Association, 2003).

Entitlement

The amount of service provided also varies greatly, as do approaches to determining upper services limits: 1) Home care costs approach the cost for institutional care; 2) Home care costs cannot exceed a particular amount per month; 3) Limits on the number of hours per week or month per client for home support, professional services, or total services (Canadian Home Care Association, 2003). For example, Saskatchewan has no provincial policy that limits service levels, but regions often operate under the guideline that when the cost of care reaches the cost of nursing home care, home care clients should be reassessed and provided alternative options. Ontario uses limits on the number of hours of services. For example, personal support and homemaking services are provided based on assessed needs up to 60 hours per month (Canadian Home Care Association, 2003).

Fees

There are generally no or low co-payment for rehabilitation services. In a few jurisdictions, home support services are provided without co-payments, but in many there is an income test such that in some jurisdictions the care receiver may be responsible for the full cost of services. Most other home and community services such as adult day care, meal delivery and respite have some form of co-payment in most jurisdictions (Hollander et al., 2000). For example, in Nova Scotia, clients may be required to pay a fee for homemaking, personal care and home oxygen services where the cost is based on net income and family size. In Alberta there are no charges for nursing, rehabilitation, personal care, assessment and case coordination, but a client may be required to pay \$5 an hour for home support to a maximum of \$300 per month based on a sliding fee scale (Canadian Home Care Association, 2003).

How is Home Care Supporting Informal Caregivers?

The services offered through home care programs can be invaluable supports to caregivers. Home supports can take some burden off caregivers and may offer periods of respite. Meal programs, transportation services, home nursing, and home modification programs can enable care receivers to remain at home and supplement care from family/friend caregivers or provide services that caregivers are unable to perform. Despite the potential for home care programs to support caregiving relationships, it has been highly criticized by caregivers and their advocates on a number of grounds.

As part of cost saving measures, governments have been tightening eligibility criteria and

entitlements to home care (Guberman, 1999). Those in need of care may be deemed ineligible for the program due to income or assessed level of need. Those that are deemed eligible may not receive adequate levels of services. Additionally, eligibility criteria are frequently revised and care receivers re-assessed as local and provincial economic conditions change (Guberman, 1999). This leaves caregivers in the precarious situation of providing care or purchasing care privately when the care receivers resources are exhausted.

Caregivers have also criticized this system for its piecemeal approach. As governments increasingly contract out services to for-profit and non-for profit suppliers, clients may be shifted from one organization to another as contracts change. Caregivers are faced with having to adjust to new approaches, educating new personnel about the care receiver's needs, and re-negotiating how and when care is provided (Guberman, 1999).

Home care services have also been criticized for being homogenous. Caregivers note that while the services they provide are responsive to the unique needs, likes and dislikes of the care receiver, home care services do not offer personalized services under the guise of rationalization, universality and equity. This approach leaves many care receivers unsatisfied and uninterested in relying on formal services. Caregivers are left to negotiate with care providers about how services should be provided, or to step in and provide the appropriate services (Guberman, 1999). Instead of home care decreasing their burden, caregivers find themselves not only providing care, but also acting as care managers.

Concern has also been raised about low levels of public awareness about home care programs. It has been suggested that home care programs within provinces are not adequately advertised and promoted. There are also low levels of awareness about how home care is structured and delivered. The difficulty caregivers experience navigating the system only adds to their burden. It has been suggested that those who best advocate for the care receiver and themselves receive better services than those who are not able to take on this role. Additionally, caregivers sometimes hesitate to complain about amounts or quality of services provided for fear of having already inadequate service levels further reduced (Canadian Association of Retired Persons, 1999).

The challenges caregivers face when dealing with the home care system are compounded by the ambiguous status of caregivers in relation to public policy and programs. Caregivers are not official clients of the health and social service system and generally are not entitled to services in their own right, but rather only indirectly through the care receiver (Guberman, 1999). Assessments look at the needs of care receivers but give at best little attention to caregivers' needs. Furthermore, when determining needs and entitlement, the underlying premise of many home care programs is that families, and specifically women, are responsible for providing care. Guberman (1999) notes that services "are often provided in a minimal, stigmatizing and rationed manner according to the availability of female kin" (p. 56). Services are provided not to support or ease the burden of caregivers, but only as a last option to fill gaps not being met by family (Guberman, 1999).

3.2 Financial Compensation for Caregivers

Alongside home care services, another policy option for supporting caregivers is financial compensation. As seen in Section 2.0, caregivers often incur financial costs as a result of their caregiving responsibilities, be it through out-of-pocket expenses for medical supplies, purchasing services such as homemaking and respite, employment-related costs due to missed time or loss of employment opportunities, and long term financial sacrifices with regards to savings and pensions. As will be discussed in Section 4.0, many countries have chosen to provide financial support to caregivers, whether to acknowledge the financial sacrifices made by them, to acknowledge the social importance of the work they do, as economic motivation, or to reduce health care and institutional costs by shifting care into the communities and onto family and friends. As will be discussed in greater detail in Section 4.0, 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 to provide care (Keefe & Fancey, 1998). The focus of this section will be financial compensation policies offered at the national level in Canada.

Supporting Caregivers through the Canadian Tax System

While other countries have embraced financial compensation as an approach to support caregivers and have implemented multiple programs targeting different groups of caregivers with different objectives (see Section 4.0), in Canada there has been no such strategy. Rather, the emphasis 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.

Caregiver Tax Credit

The Caregiver Tax Credit is intended for caregivers of an adult dependent or elderly relative. To be eligible the caregiver must have lived with the care receiver at some time during the tax year. The care receiver must be a child or grandchild, the caregiver's or caregiver's spouse or common-law partner's sibling, niece, nephew, aunt, uncle, parent or grandparent. Care receivers under 65 must be dependent due to mental or physical disability. This credit cannot be claimed if anyone is claiming the Eligible Dependent amount for the care receiver. For 2004, the maximum credit was \$605. The credit is reduced when the care receiver's income exceeds \$12,921 and is phased out when the care receiver's income reaches \$16,705. This is a non-refundable tax credit (Canada Customs and Revenue Agency, 2003; Technical Advisory Committee on Tax Measures for Persons with Disabilities, 2004).

Infirm Dependent Age 18 and Older Credit

The Infirm Dependent Credit is available to caregivers of a dependent adult relative. The caregiver must be supporting their parent, grandchild, sibling, aunt, uncle, nephew, neice, or adult child or grandchild of the caregiver or the caregiver's spouse or partner. Unlike under the Caregiver Tax Credit, the care receiver does not have to live with the caregiver for the caregiver to be eligible to claim this amount. However, the caregiver cannot claim this amount if someone else is claiming the Eligible Dependent Tax Credit or the Caregiver Tax Credit for the care

receiver. For 2004, the maximum credit was \$605. The credits is reduced when the care receiver's income exceeds \$5,368, and is not available if the care receiver's income is greater than \$9,152. This is a non-refundable credit (Canada Customs and Revenue Agency, 2003; Technical Advisory Committee on Tax Measures for Persons with Disabilities, 2004).

Eligible Dependent Tax Credit

This credit is available to caregivers who either do not have or are not living with or being supported by a spouse or common-law partner and who are caring for a dependent relative. The dependent relative must have lived with the caregiver in a home maintained by the caregiver during the tax year. This credit has much narrower eligibility criteria with regards to the relationship between the caregiver and care receiver than the Caregiver and Infirm Dependent Credits. The care receiver must be the caregiver's parent or grandparent, or child, grandchild, or sibling who is under the age of 18 and who has a mental or physical disability. Only one person can claim this amount for a given care receiver. For 2003 the maximum credit was \$1053. The care receiver's income must be less than \$659 to claim a full amount, and between \$659 and \$7,245 to claim a partial amount. This is a non-refundable credit (Canada Customs and Revenue Agency, 2003).

Disability Tax Credit Transferred from a Dependent

This credit is available to caregivers who are caring for a dependent relative who is eligible for the Disability Tax Credit. To be eligible the care receiver must be the caregiver's or caregiver's spouse or common-law partner's parent, grandparent, child, grandchild, brother, sister, aunt, uncle, nephew, or niece. This credit cannot be claimed if the spouse or common-law partner of the person with the disability is already claiming the disability amount or any other non-refundable tax credit (other than medical expenses) for the person with a disability. For 2004, the maximum credit was \$1,038. This is a non-refundable credit (Canada Customs and Revenue Agency, 2003; Technical Advisory Committee on Tax Measures for Persons with Disabilities, 2004).

Medical Expenses Tax Credit

This credit is available to caregivers of a dependent adult or child relative. The care receiver must be the caregiver's spouse or common-law partner or the caregiver's or their spouse or common law partner's dependent child or grandchild, or their dependent parent, grandparent, sibling, uncle, aunt, niece or nephew. Caregivers can claim medical expenses incurred by themselves or their spouse/common law partner for an eligible care receiver. In 2003, expenses must have been more than 3% of net income or \$1,755, whichever is less, to claim any credit. The credit equals 16% of qualifying medical expenses. However, if you claim medical expenses for a dependent other than a spouse or partner with a net income of more than \$7,756, the caregiver must reduce their claim (Canada Customs and Revenue Agency, 2003; Technical Advisory Committee on Tax Measures for Persons with Disabilities, 2004).

Amounts paid for a medical practitioner, dentist, or nurse are eligible expenses, as is the purchase price or rental charge of needed equipment. Eligible devices must be listed in the

regulations and prescribed by a medical practitioner. Eligible devices include artificial limbs, wheelchairs, crutches, hearing aids, and prescription eyeglasses. The cost of traveling to receive treatments not available locally may be claimed. Home renovation or alteration expenses that enable the care receiver to access or be mobile or function within the dwelling can also be claimed. Expenditures on paid care providers may be claimed if a doctor or other medical practitioner certifies that the care receiver is dependent on others for care (Fast, Eales, & Keating, 2001).

Problems with Using the Tax System for Supporting Caregivers

A central criticism of the Canadian tax relief measures for caregivers is that these credits are least useful to those who are mostly likely to be providing care, most likely to face serious consequences due to the financial cost of caregiving, and most in need of financial support. Data from the 2000 tax year indicate that only 39% of claimants of the Caregiver Credit were women, despite research demonstrating that women form the majority of family/friend caregivers. This is likely in part because many women caregivers do not have sufficient income to benefit from this non-refundable credit (Shillington, 2004; Young, 2000). For example, a single woman caring for her elderly parent, who cannot work or works a few hours in order to provide care, will not be able to benefit (Young, 2000). While tax measures do not directly discriminate against women, they do not take into account the different social and economic circumstances in women's lives that affect their access to these programs (Freiler et al., 2001).

Similar problems have been noted with respect to the Medical Expenses Tax Credit (METC). Data on the use of this credit reveals that the average amount claimed increases with income. Lower income claimants cannot benefit from this tax measure if they do not have the necessary income to purchase drugs, equipment or care (Shillington, 2004). In-kind-contributions, which may be the only means of providing care-related services for low and middle income caregivers, cannot be claimed. Additionally, as with the Caregiver Credit, one must have taxable income to benefit. Shillington (2004) notes that "about \$1 billion of medical expenses are reported for income taxes by persons with no taxable income; about 66% of these futile claims were made by women" (p. 70). Clearly many people, particularly women, who have expenses are not able to access financial compensation for care costs through this credit.

The care receiver income test attached to many of the federal tax credits also prevents or substantially reduces the support many caregivers can access through the tax system. Fast, Eales, and Keating (2001), argue that the cut off is so low that only those caring for the most severely impoverished seniors would benefit.

Additionally, while many caregivers meet some of the eligibility criteria for most tax deductions and tax credits, they rarely meet all of them (Fast et al., 2001). For example, since spousal caregivers are ineligible for the Caregiver Tax Credit and few other caregivers live with the person for whom they care, this credit is not available to many caregivers. Fast et al., (2001) note that, in the 1996 General Social Survey, relatives other than a spouse who lived with the care receiver accounted for only 6% of caregivers. Nor are caregivers to non-kin, who represented 20% of all eldercare providers in 1996 (Keating et al., 1999), eligible for these credits. While the nature of families and caregiving relationships have changed, the government has not altered its

understanding of family to accommodate these new realities, thus leaving many caregivers without any compensation for the costs they incur.

It has also been noted that the complexity of the eligibility criteria and calculations deter many from claiming these credits. While those with higher incomes have the financial resources to access expert tax services to make sense of the tangle of criteria involved in determining eligibility, many caregivers, and women in particular, will not have access to expert advice and as a result may not be aware of these credits or may not be able to determine their eligibility (Shillington, 2004; Young, 2000). Furthermore, for those that are able to determine that they are eligible, the benefit amounts of these taxes to the caregiver are minimal when compared to the costs associated with caregiving (Fast et al., 2001; Young, 2000).

Compassionate Care Benefit

Outside of tax credits, there is only one other national program that offers financial compensation to caregivers in Canada. This is the new Compassionate Care Benefit, a new element of the Employment Insurance (EI) program. The Compassionate Care Benefit came into effect in January 2004. It 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 6 months. 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. To be eligible the caregiver must have worked 600 hours in the last 52 weeks or since the start of a previous claim and be able to demonstrate that their regular weekly earnings from work have decreased by more than 40%. A certificate is required from a medical practitioner indicating that the family member for whom they are caring is at a significant risk of death in the next 26 weeks and requires support from one or more family members. For the purposes of this program care is defined as "providing or participating in the care of the patient, or arranging for the care of the patient by the third-party care provider, or providing psychological or emotional support to the patient" (Human Resources and Skills Development Canada, 2005). The benefit can be shared among two or more EI-eligible family members. As with other EI benefits there is a two week waiting period before payment of benefits begins. To coincide with the implementation of this program the Canadian Labour Code was amended so that employees' jobs will be protected when they take up to eight weeks compassionate care leave. A caregiver's access to this program cannot be taken into account when deciding to promote or train an employee and the employee must be reinstated in their former position or a comparable position in the same location with the same wages and benefits. The basic benefit amount is 55% of the caregiver's average insured earnings, to a maximum of \$413 per week. The benefit is taxable. A family supplement is available to those in a low-income family with children (Human Resources and Skills Development Canada, 2005).

While the introduction of the Compassionate Care Benefit marks a shift in the approach to policy from relying on tax credits to support caregivers, it does not help many groups of caregivers. Those providing long term care, or short-term non-palliative care, cannot access financial support for lost earning or work absence through this program. Additionally, caregivers may not be able to access this program if they cannot afford the substantial reduction in income. As women have lower wages than men, and women make up the majority of minimum wage

workers, many women are already struggling. A cut to 55% of their income may be unmanageable. Many caregivers are not eligible for the program such as those who work on contract or are self-employed. Those who work part time may not have accrued the 600 hours needed to be eligible (Shillington, 2004). Additionally, the definition of family is very narrow and do not reflect the diverse relationships between caregivers and care receivers. For example, in many minority ethnic communities, women are expected to care for members of their extended family. Caregivers of persons living with HIV/AIDS, especially those who are gay men, may not fall within the eligibility criteria for this program, but may be a friend, partner, sibling, or more distant relative (Unpaid Caregiving Forum, 2003). Under the current eligibility someone providing end-of-life care to a parent-in-law is not eligible for this program. As women are more likely to provide care within families than men, this exclusion will have a significant impact on women caregivers.

Provincial and Territorial Approaches to Financial Compensation

As at the federal level, the provinces and territories have focused on the use of the tax system to provide financial assistance to caregivers (Armstrong & Kits ,2001). The 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. Some jurisdictions have different or additional tax credits. For example, Quebec offers several tax credits to cover the costs of purchasing formal services. These tax relief measures are subject to the same criticisms as federal tax measures.

While direct compensation does not exist at the federal level and is mostly non-existent at the provincial and territorial level, there has been some use of this approach in Canada. Nova Scotia provided compensation to caregivers between 1984 and 1994. Recipients were mostly young women living in rural areas. This was a means-tested program and paid less than minimum wage, leading Armstrong and Kits (2001) to argue that the program merely served to reinforce caregiving as undervalued women's work. The Ministry of Children and Family Development in British Columbia introduced a direct payment to family caregivers in June 2000. This program allows some family members to be paid to provide care or support to a relative who has been deemed eligible to receive care from the government. Clients can pay family members that do not live with them. However, the program does not allow payment to the care receiver's parents, children or spouse regardless of where they live, except where there is no other qualified caregiver available and one of the following conditions are met: rural or remote location, cultural barriers, language barriers, behavioral problems (Ministry of Health Services, British Columbia, 2002).

4.0 International Approaches for Compensating Caregivers

It is clear that caregivers incur considerable costs as a result of their caregiving role. While Canada has yet to develop a strategy for supporting caregivers, other countries have taken a more active approach to meeting the needs of caregivers. One commonly used approach is financial compensation for caregivers. These policies have multiple purposes; some are intended to replace lost income, some are intended to provide long term financial security, while others are intended to acknowledge the social value of caregiving (Keefe & Fancey, 1998). These policies provide some support for the financial costs of caregiving, but they can also indirectly reduce the other costs of caregiving.

This section will provide an overview of policies in place in 9 other countries (Australia, France, Germany, Israel, Netherlands, Norway, Sweden, United Kingdom, and the United States). These countries were selected for examination as part of the Hidden Costs/Invisible Contributions project because they represent a mix of welfare and health systems as well as approaches to supporting caregivers. A review of international approaches can provide decision makers not only with policy alternatives, but also information on the strengths and weaknesses of these approaches. For the purpose of this report we have identified three types of compensation policies available in other countries: direct compensation, indirect compensation and labour policies.

4.1 Direct Compensation

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. While some provide hourly wages equivalent to that which formal care provides, 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 & Fancey, 1998).

Both Sweden and Norway offer a wage to caregivers. In Norway, a Care Wage is available to caregivers who are providing burdensome levels of care to severely disabled persons. The amount paid depends on the care receiver's needs, but the average amount is NOK 4,600 (\$878 CAD) per month (Lingebretsen & Erikson, 2004). Sweden's Carers' Allowance is available to caregivers under the age of 65 who are providing care to an elderly dependent. As policy is implemented at the municipal level in Sweden, eligibility criteria vary by municipality. What is significant about this program is that it provides caregivers with a salary equal to that of a formal home help service provider employed by the municipality and also provides similar social security protection (Johansson, 2004).

While the above programs provide compensation based on the amount of care provided, other countries have chosen to focus compensation programs on caregivers who are low income because of their caregiving. Australia has a Carer Payment for caregivers who are not able to support themselves through the labour market due to caregiving responsibilities for a child or adult. To be eligible the caregiver must not work in the labour market for more than 20 hours per

week. The adult care receiver must have a severe disability as determined by an assessment and must be eligible for social security benefits. There is no co-residency requirement, but the care must be provided in the care receiver's home. To determine eligibility, both caregiver and care receiver are subject to income and asset tests. Cut off levels are based on a number of factors including household composition and whether one owns a home. For those that are deemed eligible the maximum payment is \$464 AUD (\$459 CAD) biweekly for a single person and \$387 AUD (\$351 CAD) biweekly per person for couples. This amount is payable for up to 63 days in a calendar year during a period of respite or while the care receiver is in hospital. Recipients of the Carer Payment may also be able to access a number of additional benefits and payments such as Education Entry Payment, Employment Entry Payment and Rent Assistance (Centrelink, Australia, 2004).

While the above programs are intended to substitute for lost labour market income, direct payments can also be intended to help meet the non-economic needs of the caregiver incurred as a result of caregiving. The United Kingdom has introduced a Direct Payment program that offers both caregivers and care receivers funds to purchase services. It is available to caregivers aged 16 and over who is caring for someone aged 18 and over. Local councils conduct an assessment of the caregiver's needs to determine that amount of payment. The amount of the payment must cover the cost of securing the needed services. Caregivers can determine how to spend the funds, but must use them to purchase services for their own needs, not the needs of the care receiver. The payment is not taxable (Department of Works and Pensions, United Kingdom, 2004).

Another option for supporting caregivers is the use of care allowances. These types of programs are not intended to replace labour market participation, but provide a small sum to acknowledge the social value of caregiving or to provide some assistance with out-of-pocket costs (Keefe & Fancey 1998). The United Kingdom's Carer's Allowance is an example of this type of program. The Carer's Allowance is available to the caregiver of a disabled child or adult who is a relative, neighbour or friend. For the caregiver to be eligible, the care receiver must qualify for one of several disability-related benefits. The caregiver must provide at least 35 hours of care per week and must not earn more than £79 (\$182 CAD) after various exclusions such as monies paid for income tax, national insurance and half of pension contributions. There is no asset test. Those deemed eligible are entitled to approximately £44 per week (\$108 CAD). The payment is taxable. It continues for up to 12 weeks if the caregiver or care receiver is in hospital or respite care, and for up to 8 weeks after death of the care receiver (Department of Works and Pension, United Kingdom, 2004). Australia's Carer Allowance is somewhat different. It is available to caregivers who are either living with the care receiver or who provide personal care on a daily basis for a minimum of 20 hours per week in the care receiver's home. As of June 2004 the amount of the allowance was \$90 AUD (\$89 CAD) biweekly. The payment is nontaxable (Centrelink, Australia, 2004; Montgomery & Friss Feinberg, 2003).

Another direct compensation approach provides monies to the care receiver to arrange for services. This approach allows caregivers to purchase services from a formal care provider or pay an informal caregiver. Norway, Sweden and the Netherlands offer similar programs. Norway offers an Attendance Allowance to disabled or ill care receivers in need of nursing care. The amount depends on needs but the maximum is NOK 5,862 (\$119 CAD) per month and is not taxable (Lingebreetsen & Erikson, 2004). The Netherlands offers a Personal Budget to the care

receiver. The amount is based on an assessment and is paid at a standard national rate per hour of care needed (Brodsky, Habib, & Mizrahi, 2000; National Board of Health and Welfare, n.d.).

Sweden offers two programs of this type: one for elderly persons and one for those with disabilities under age 65. Sweden's Attendance Allowance is for elderly persons who require assistance from a family member. Eligibility criteria vary by municipality, but many municipalities have 17 hours of caregiving per week as a cut-off criteria. Entitlement is based on the care receiver needs, but the maximum payment is about SEK 5000 (\$860) per month and is not taxable. The money is to be used to pay the family member providing care. The Assistance Allowance is available to those under age 65 who have a disability and require assistance from a family member. To be eligible the care receiver must require an average of more than 20 hours of personal assistance per week. The amount is based on the number of hours of care received and it is taxable (Johansson 2004).

France has taken a similar approach to Sweden. France offers a Compensatory Allocation for Third Person Benefits (ACTP) for persons with disability between 20 and 60 years old. To be eligible the care receiver has to have a disability assessed at 80% or higher. There is an income test based on household composition. Payment amounts are between 378 €(\$605 CAD) and 756 €(\$1210 CAD) per month and are based on the amount of care needed. The funds can be used to purchase formal care services or to compensate a relative, neighbour or friends as caregivers. However, spouses cannot be paid under this program. Those over 60 years of age can assess the Personalized Allowance of Autonomy (APA). Under this program the care receiver's needs are assessed and classified into one of six categories; only those in the four highest categories of dependency are eligible. A care plan is then developed by the assessment team. While no one is excluded from receiving funding from the APA because of income, the care receiver's income is taken into account when determining the amount of the allowance. Amounts allocated based on care needs range from 1125 €(\$1787 CAD) for those in the highest category, to 482 €(\$766 CAD) for those in the lowest category. Those with higher incomes may be expected to cover part of the cost of the care plan. The allowance is paid in cash but is treated as a voucher to pay for help received at home. The care receiver must declare who has been hired to provide care services. As with the ACTP, the money can be used to pay a relative (but not a spouse), neighbour, or friend caregiver (Service-Public.fr, France, 2004).

Israel has also opted to provide different programs to these two age groups. While non-elderly adults with disabilities have access to an attendance allowance that can be used to pay family members, elderly care receivers are provided with formal services through Israel's Long Term Care Insurance program (Brodsky, Habib, & Mizhari, 2000; Gal, 2001). Caregivers of the elderly have no access to direct compensation in Israel.

Germany instituted direct payments to care receivers to pay caregivers through its Long Term Care Insurance program (LTCI) implemented in 1995. Under the LTCI system persons with disabilities are entitled to the same benefits as the elderly. Home care is provided through this program. Users can receive care through professionals or through unrestricted payments that may be used to pay caregivers. For those that choose the payment, there are three different amounts allocated based on daily care needs. Level 1 pays 205 €per month (\$318 CAD), Level 2 pays 410 €per month (\$637 CAD), and Level 3 pays 665 €per month (\$1033 CAD). This

program also provides money to cover respite for caregivers; care receivers are able to access an additional month of payment to pay a stand-in caregiver while also paying their regular caregiver. Another important component of Germany's approach is that caregivers are able to register for a new employment category of "Informal Caregivers" which provides additional rights and recognition (Brodsky, Habib, & Mizrahi 2000; Evers, 1998; Meyer, 2004; Montgomery & Friss Feinberg, 2003).

4.2 Indirect Compensation

Indirect compensation programs are non-direct cash payments. These programs take two principle forms: tax relief and pension security.

Tax relief includes measures such as tax credits, tax deductions and tax exemptions. Tax deductions are an amount of money the claimant is able to deduct before the calculation of tax liability and it lowers the tax payer's taxable income. Tax credits are amounts of money that can be claimed against taxable income. These are usually pre-determined amounts and may be either refundable or non-refundable. Tax exemptions are a specific amount of earnings or type of earning (e.g. allowance, stipend) that a claimant is able to exempt from their taxable income or does not have to be declared at tax time. The purpose of these programs may be to recognize the contribution of time or the out-of-pocket expenses incurred by caregivers (Keefe & Fancey, 1998).

A number of countries offer tax relief to caregivers. The United Kingdom offers a Council Tax Discount for Cares. Caregivers who are providing care to someone with a disability in their home for at least 35 hours a week are eligible for a discount on their council taxes (Department of Works and Pensions, United Kingdom, 2004). France offers a tax deduction for expenses linked to caregiving of an elderly parent (A.Grand, personal communication 2004). The Netherlands offers a tax deduction to caregivers caring for parents or siblings with a serious disability who are 27 years of age or older and living with the caregivers. Caregivers can deduct medical expenses and other extraordinary expenditures relating to caregiving that exceed 11.2% of income (National Alliance for Caregiving, 2004).

The United States (US) is similar to Canada in its reliance on using the tax system to help caregivers at the national level. The United States offers three tax relief measures. The Child and Dependent Care Tax Credit (CDCTC) is offered to employed caregivers of children or dependent adults. To be eligible the caregiver must have purchased care for a child under 13 or a spouse or dependent of any age who has a physical or mental disability that prevents self-care. The caregiver must also have earned income in the tax year. If the caregiver is married, both parties must have earned income, unless one was a full-time student or the care receiver. Additionally, the care receiver must live with the caregiver. The credit is a percentage (20% to 35%) of the amount of work-related care expenses paid to a care provider based on income. For 2003, this credit provided up to \$2,100 USD (\$2,700 CAD) for families with incomes under \$15,000 USD (\$18,995 CAD) and two or more dependents, and up to \$1,200 USD (\$1520 CAD) for families with incomes under \$43,000 USD (\$54,458 CAD) with two or more dependents (Internal Revenue Services, United States Department of the Treasury, 2004).

Another program offered in the US is the Dependent Care Assistance Program. This program
Rajnovich, Keefe & Fast (2005)
Supporting Caregivers of Dependent Adults

targets caregivers who paid for care services in order to continue working. The eligibility criteria are similar to the CDCTC. Under this program employers can provide an employee with up to \$5,000 USD (\$6,333 CAD) each year in child and dependent care benefits tax free. Benefits may take several forms including cash reimbursements, vouchers or free or subsidized care. If the caregiver receives benefits through this program, the amount must be subtracted from expenses used to calculate the CDCTC (Internal Revenue Services, United States Department of the Treasury, 2004).

The US also offers a medical expenses tax deduction which allows caregivers who spend more than 7.5% of their income on medical expenses, either for themselves or the person they are caring for, to deduct these expenses (Internal Revenue Services, United States Department of the Treasury, 2004).

It should be noted that while only tax relief is available to caregivers at the national level in the United States, at the state level a wide range of financial compensation programs and other services for caregivers are available. Most notably, a “Cash and Counseling” demonstration project has been underway for many years in three states (Friss Feinberg, Newman, Gray, & Kolh, 2004; Montgomery & Friss Feinberg, 2003; University of Maryland Center on Aging, 2004). Many of these programs have been funded by the federal government through the National Family Caregiver Support Program (Montgomery & Friss Feinberg, 2003).

Another form of indirect compensation, pension security, involves third party payment of pension credit or insurance premiums, or a drop out clause for periods while caregiving. The purpose of these programs is to acknowledge the financial sacrifices made by caregivers and provide long term financial security (Colepaugh, 2004; Keefe & Fancey, 1998).

Germany offers pension security to caregivers through its Long Term Care Insurance program in the form of pension insurance. The program is available to caregivers who provide at least 14 hours of unpaid home care a week and are employed in paid work for less than 30 hours a week. Under this program the insurance fund pays contributions toward the caregivers statutory pension insurance. As with direct payments under the program, pension contributions are based on the level of dependency of the care receiver and the amount of time spent caregiving. For 2004, the maximum contribution amount was 376 €per month (\$584 CAD) (Brodsky, Habib, & Mizrahi, 2000; Evers, 1998; Meyer, 2004; Montgomery & Friss Feinberg, 2003).

Norway also offers pension security in the form of pension credits. Under this program, caregivers in receipt of Care Wage automatically receive pension credits. Other caregivers must apply every year. To be eligible they must provide at least 22 hours of care a week (including travel time), and must have been caregiving for at least 6 months. Caregivers are given three pension credits per year, which corresponds to a below average wage (Lingebretsen & Erikson, 2004). Sweden’s approach is similar, with caregivers in receipt of Carers’ Allowance or Care Leave (see below) accruing credits alongside credits from other kinds of income (Johansson, 2004). France has recently introduced a program that provides pension benefits to caregivers of someone assessed as having at least an 80% permanent disability, and who has income under a ceiling that varies based on the number of income earners and number of children in the household. Those who are deemed eligible have contributions made to the old age insurance

program by the state during the period they are providing care (Service-Public.fr, France, 2004).

The United Kingdom offers multiple approaches to pension security for caregivers. Basic pension protection is offered to caregivers who do not work or have low incomes. Caregivers in receipt of the Carer's Allowance are entitled to pension protection through that program. They receive a National Insurance contribution for each week they receive the Carer's Allowance. Other caregivers can receive pension protection through the Home Responsibilities Protection (HRP) program. To be eligible the caregiver must be caring for someone at home, be in receipt of income support and not be required to register for work due to caring responsibilities, or spend at least 35 hours a week looking after someone who is getting benefits related to a disability and does not work or has very low earnings. This program provides protection for the basic state pension whereby years in receipt of HRP are taken away from the number of qualifying years needed to calculate pension entitlement.

Recently, the United Kingdom has instituted a program to further ensure long term financial security for caregivers. This program acknowledges that financial sacrifices made by caregivers and the long term implications of those financial sacrifices. The program offers a State Second Pension for Carers. This pension is a supplement to the regular state pension covered under the other programs. It is available to caregivers who do not work or are low income earning. To qualify, the caregiver must be eligible for either the HRP or be under State Pension age and entitled to the Carer's Allowance. Under the program the caregiver is treated as if his or her earnings are at a low earnings threshold of ,11,600 (\$26,050 CAD) for 2004/2005. At present details around amounts that will be available to caregivers upon retirement are still being determined (Department of Works and Pensions, United Kingdom, 2004; Montgomery & Friss Feinberg, 2003). It should also be noted that while caregivers began to accrue credits under this scheme in 2002, State Second Pension for Carers will not be payable until 2050 (P. Tihanyi, personal communication 2004).

4.3 Labour Policies

Labour policies provide paid leave from work to provide care, or provide access to employment benefits if the caregiver must leave work to provide care. Paid leave programs range from days to several months leave. 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.

Sweden has had a labour policy to support caregivers in place since 1989 in the form of the *Care Leave Act*. This *Act* provides caregivers under age 65 caring for a close relative who is terminally ill a paid absence of up to 60 days depending on the needs of the care receiver. Payment level is 80% of income and is made by the National Social Insurance program (Johansson, 2004). Benefits are taxable. Norway offers two programs. Nursing Care Leave provides up to 20 days leave paid at full wages to care for a permanently ill or terminally ill family member. The payment is taxable. Norway also offers a Care Leave program that provides full wages for a period of up to 10 days leave (J. Erikson, personal communication, 2004; Lingbretsen & Erikson 2004).

The Netherlands offers three labour policies covering a range of caregiving situations. Care Leave is available to employed caregivers who need time off to care for their child, partner or parent. It provides up to 10 days leave per year. Employers are required to pay at least 70% of wages and the employer receives compensation for this amount from the government. The Netherlands also offers paid leave to care for someone who is terminally ill. Under this program the care receiver must be a close relation, though this does not include only family members, who is in the last phase of life. Leave is for least 1/3 of normal working hours and between at least 1 to 6 months. In some situations the period of leave can be extended up to 18 months. Benefits under this program are 490 € (\$762 CAD) per month, paid from public funds. It is important to note that there is no legal right to this program; employers must agree to grant the caregiver leave. The third program offered in the Netherlands, Career Interruption, is available to employed caregivers who must leave work to provide care. To be eligible, the caregiver must have worked for at least one year, and as with the program described above, the employer must agree to the leave. Under this program the leave will only be paid if the employer replaces the caregiver with someone who is unemployed or otherwise out of the labour market. Under this program the caregiver can take leave for between two to six months, although the leave period can be extended to 18 months under certain situations. It is paid at the same rate as the above program - 490 € per month (\$762 CAD) from public funds (National Board of Health and Welfare, Sweden, n.d.).

Israel has taken a different approach to labour policies for caregivers. Israel instituted a *Sick Leave Act* in 1993 available to employed caregivers to care for an elderly parent or in-law. The parent receiving care must be aged 65 and older, and must be ill; defined as dependent upon the help of others for daily functioning. The *Act* allows caregivers to take up to six days of paid leave from their own allotment of sick days. Israel has also had a *Severance Compensation Act* in place since 1963, which provides a means for caregivers to access financial compensation if they must leave employment to provide care. To be eligible the care receiver must be the employed caregiver's spouse or partner, child, parent, grandchild, grandparent, or live-in parent-in-law who is financially supported by the caregiver. Caregivers are only eligible if changes to work conditions cannot be made to enable the employee to continue working while providing care. Under the *Act*, resignation from work is considered as a dismissal, and the caregiver is entitled to full severance compensation and all rights of a worker who has been dismissed including unemployment benefits without delay of deducted days (Doron & Linchiz, 2002; National Alliance for Caregiving, 2004).

4.4 Caregiver Case Studies

Clearly, other countries have taken a wide range of approaches to supporting caregivers. Some focus on the care receiver and allow monies to be transferred to the caregivers, other pay the caregiver directly. Some are interested in supporting employed caregivers, while others have programs in place to help low-income caregivers. Many of these countries have implemented multiple programs recognizing that caregivers are a diverse group with different needs and life circumstances. By looking at what other countries are doing we can see what policy alternatives are available for Canadian decision-makers to consider. An examination of how the structure of these policies and programs would shape access and impact on caregivers in diverse caregiving situations will provide further information for determining what policy approaches will best meet

the needs of Canada's caregivers.

What follows are "caregiver portraits": fictional portraits based on caregiver portraits prepared by Fast et al. (2001) to examine the economic impact of health, income security and labour policies of diverse caregivers, and on information collected through in-depth qualitative interviews and focus groups with caregivers representing "equity reference groups" - Aboriginal Canadian women, African Canadian women, immigrants, and women with disabilities - conducted as part of the Healthy Balance Research Program (Gahagan et al., 2004). While they are not based on individual caregivers or caregiving situations, they do reflect the diverse and complex situations in which care is provided. These portraits will provide the basis for an examination of international policy approaches. The focus of this analysis will be on the criteria within the policies that shape access to and impact of the policies for the caregivers in our portraits.

Helen: Spousal Caregiver

Helen is in her early 70s. She immigrated to Canada in her late 50s with her husband following two of her three children, one of whom had been living in Canada for a few years. She is the primary caregiver for her husband who is in his late 70s. He has developed both physical and cognitive impairments over the last few years. Helen also has minor chronic health problems. They live in an apartment near their youngest son in a large urban centre. Their other son lives in a city a few hours away. While she has learned to speak some English, she sometimes finds it difficult to communicate with first language English speakers, and has found it difficult to find out about supports and services available to her and her husband. Helen wants to do as much for herself and her husband on her own as she can. She helps her husband with personal care and is involved in the management of his health care. She does much of the housework, and gets help from her son and his wife, and occasionally from neighbours in her building, but some tasks are left undone. Her husband can no longer drive and Helen has never learned to drive. Her daughter-in-law, Mary, who works full time and cares for her children, will drive her to appointments when needed and brings over food from time to time. Mary would like to help her mother-in-law more, but she finds her current workload difficult to manage. Helen's son arranged for homemaking support to help with cooking and other household chores Helen finds difficult, but Helen's husband did not like the food they prepared, so Helen discontinued the service. Helen feels increasingly isolated and finds caring for her husband to be lonely. She would like to participate in events organized by the local seniors' centre, but she does not want to leave her husband alone. Her own health is deteriorating and she is under increasing stress. She is also starting to worry about the financial costs associated with her husband's increasing care needs.

Richard: Adult Son Caregiver of His Widowed Mother

Richard is in his 50s. He is married to Colleen. His children are over 18 but one still lives at home. John and Colleen are middle income earners. Richard is employed full time at a job that demands long hours on a regular basis. His mother, Sarah, is in her 80s and was widowed five years ago. Her health has deteriorated since that time. She still lives in her own home, but Richard worries about this living arrangement. Richard has been her primary caregiver for the

last five years. Richard has been helping Sarah with running errands, taking her to appointments, organizing her finances, and making decisions about her care. John visits Sarah three to four times a week on his way home from work. He is not hesitant about asking for supportive service from the formal sector and usually gets help, but has found the amounts to be inadequate to meet his mother's needs. Richard and Colleen have decided to purchase additional home support services for Sarah. Sarah does not feel comfortable about her son spending money on her care. Richard is also concerned about the escalating costs, and finds that he is putting in a great deal of time into negotiating with care providers about how to care for her mother, as there is significant worker turnover both in the public and privately provided support services. Colleen is also providing care to her own father who recently had a stroke and has moved into a long-term care facility. To this point, Richard's employment has not been significantly affected by his caregiving responsibilities, but he finds that the long hours he puts in at work combined with the time he spends with his mother has left him little time for his own interests, and he wonders what consequences the stress will have on his health.

Kim: Mother Caregiver of an Adult Son with Disabilities

Kim is in her late 40s. She is divorced and lives in a small apartment along with her 2 children. She has been on a disability pension for the last two years as a result of chronic pain that has prevented her from working. Her younger child is 16 and in high school. Her older child, Greg, is 20 and has developmental and physical impairments that require intensive care. Kim provides all personal care to her son and does most of the housework with some help from her teenage daughter. Their apartment is not well designed to accommodate Greg's wheelchair but it was the only one Kim could afford on her current income. Kim also takes Greg to physiotherapy appointments twice per week. This is a real struggle as her apartment is on a bus route with limited accessible bus service. She is sometimes able to use the Access-A-Bus service but because Greg's appointment times change regularly, this service is sometimes full. In these cases she must decide whether to skip the appointment or pay for the one accessible taxi available in her city. Not only is this costly, but she has also heard rumors that this service will be eliminated and she wonders what she will do if that happens. Kim receives some respite services every week, but she finds that she must use these hours to do such tasks as grocery shopping and go to her own appointments. Kim feels that Greg is not getting appropriate medical attention. Kim spends a great deal of time advocating on behalf of her son and finds that to be quite stressful and exacerbates her own health problems. Kim also feels that her case worker is pushing her to put her son in a long-term care facility and to return to work.

Sharon: Friend Caregiver of an Adult Friend with a Disability

Sharon is in her late 30s, married to Todd, and a mother of two children, aged 10 and 8. She lives in a small rural community about 2 hours away from a major urban centre. Until her younger child started school she was not involved in the labour market. For the last three years she has been working in temporary, part-time positions. She has found it difficult to find steady work in her community. Her husband's job is seasonal and in the off season he works odd jobs. They own a house and have two cars because they both need to get to work and there is no public transportation in their community. Financially they are getting by, but there are times when money is tight. For the past two years Sharon has been caring for a 52 year old woman, Sophie,

who attends her church and lives nearby. Sophie has a chronic illness that has reduced her mobility over the period of a few years. Sophie has required the use of a wheelchair for the past two years. She has also lost much of her fine motor skills and requires help with many activities such as dressing and housework, including cooking. Sophie no longer works and receives disability benefits. She continues to live on her own in her own home. Sharon has become increasingly involved in caring for Sophie. She helps Sophie with chores like laundry, cooking, and runs errands for her. She also provides transportation for Sophie to doctors' appointments, church and other outings about once a week. Sophie receives formal services for personal care and homemaking, but these do not cover all of her needs, and there is no help with transportation or home maintenance. From time to time Sharon, her husband Todd, and other members of the church help with heavy outdoor work at Sophie's home. Sharon would like to return to work full-time to improve the financial situation for her family, but also wishes to continue to care for Sophie, and is concerned about her ability to juggle these multiple responsibilities.

4.5 Access and Impact on Costs of Compensation Policy Approaches

The international compensation programs described above are quite diverse, yet it is possible to identify key aspects of the policies that shape who can access the policy and how much impact it will have on the costs incurred by caregivers. Five key areas have been identified: recipient of direct payment, assessment of needs, caregiver's labour force status, the relationship between caregiver and care receiver, and benefit amounts.

Recipient of Direct Payments

One of the principal differences among the various direct compensation policies is whether the money goes directly to the caregiver or to the care receiver who then pays the caregiver. For example, while Australia's Carer Allowance and Carer Payments are paid directly to the caregiver, funds allocated through Germany's Long Term Care Insurance Program go to the care receiver. There are strengths and weakness to either approach for each party involved. When payments are made directly to the caregiver, the caregiver will be ensured to receive the funds and will have more control over the conditions of caregiving. The result is greater personal autonomy for the caregiver (Keefe & Fancey, 1998). Additionally this provides some recognition of the social value of the work being done by the caregiver. On the other hand this approach can jeopardize the autonomy of the care receiver. Direct compensation policies providing payments to care receivers, often categorized as consumer directed or self managed care, have been praised by the independent living movement praised because they allow care receivers to have more control over who and how their care is provided (Keefe & Fancy, 1998). Commonly, receivers can use the funds to purchase services or pay family or friend caregivers. The caregiver, however, may be in a difficult position when this approach is used. The care receiver may not transfer the money to the caregiver or may not transfer adequate amounts to the caregivers (Colepaugh, 2004). Caregivers that rely on these funds may become dependent on the care receiver, and may have little control over the amount of payment and conditions under which they provide care. Ungerson (1997) notes there is concern that policy of this type will lead to relatively unregulated arrangements in which caregivers will have no employment rights. For example, Sophie may choose to pay Sharon a minimal amount for her care work, knowing that Sharon is committed to providing the care, and instead use the funds to purchase additional

formal services. This problem has been noted in the German Long Term Care Insurance Program, which pays directly to the care receiver. There is no information available about how much of this money gets transferred to caregivers, and no monitoring in place to ensure that this happens (Glendinning, personal communication, 2004). For Sharon, this program may end up having little impact on her costs from caregiving if she does not receive appropriate funds from Sophie. Alternatively, should the money go directly to Sharon, Sophie may not have as much control on determining the types of services she needs. These problems could be minimized by implementing payment standards and monitoring mechanisms.

Assessment of Needs

Eligibility and entitlement for almost all of the programs are based to some extent on assessment of the care receiver's level of disability or needs. As with Canada's Compassionate Care Benefit, it is common for labour policies to provide leave only for care receivers assessed as needing terminal care. Australia's Carer Payment is only payable when the care receiver is assessed as having needs of a certain level. Both of France's direct compensation programs involve an assessment of the care receiver's level of disability and pay amounts on a sliding scale to the care receiver based on the amount of care needed and the financial situation of the care receiver. Germany's Long Term Care program had taken a similar approach. While there is no financial assessment, payments are made at three levels based on care needs measured in time per day. France's and Germany's programs are better able to reduce the costs of caregivers than those that provide one set amount (which are often low) because the caregiver can be compensated based on the amount of care they provide. While a program like Australia's Carer Allowance which offers a small set amount to all caregivers who provide at least 20 hours of care per week might be helpful to someone like Helen because it would enable her to purchase a few hours or respite per week, this approach is unlikely to improve Kim's situation as the amount is minimal and her financial situation is already strained. Kim would be better helped by a program that recognizes the high level of care she is providing and compensates her accordingly.

It should be noted that few programs assess the needs of the caregiver. Indeed the Netherlands' Personal Budget program under the *Exceptional Medical Expenses Act* has been criticized by caregivers because assessors commonly assume that family will provide a significant amount of care (National Board of Health and Welfare, Sweden, n.d.). The United Kingdom's Direct Payments program is an exception to this trend because it assesses the caregiver's needs and provides monies directly to caregivers to purchase services to meet their identified needs. Helen would likely benefit greatly from this program because she could purchase transportation and respite and thus could participate in her community and reduce her sense of isolation.

Employment Status

The employment status of the caregiver has an impact on the access to compensation policies in a number of ways. Some programs have maximum hours of employment per week, such as Australia's Carer Payment, or use low employment income cut-offs to determine access. For example, for a caregiver to be eligible for either the Home Responsibilities Protection program or the State Second Pension for Carers Pension protection programs in the United Kingdom, the caregiver must have low earnings. Kim would be helped by this program because she is not in

the labour market. It would provide her with some long-term financial security. Richard would not benefit from this program because he is employed full time. But due to his employment and income he likely is not in need of pension security. Sharon, on the other hand, may be in need of this program, but may not be eligible. Her part-time work will not allow her to accrue significant pension under the Canada Pension Plan, particularly because her work is often temporary or of a short-term nature, but because she does work, her income might exceed the upper limits for the pension security programs in the United Kingdom. Sharon would be better off under Germany's Pension Insurance program that makes contributions to state pension based on the amount of time spent caring.

Some programs also have minimum hours of care provided as an eligibility criteria. To be eligible for Australia's Care Allowance the caregiver must provide at least 20 hours of care per week if not co-residing. Someone like Richard who works full time, or Sharon who is working part time and caring for children, may not be able to provide that much care given their other responsibilities (Colepaugh, 2004). Kim may be eligible for Carer's Allowance in the United Kingdom because she provides continuous care for her son and would meet the minimum 35 hours of care required per week, and she is in receipt of social assistance for her disability.

Eligibility for many of these programs depends on being employed. Caregivers can only access all of the labour policies if they are employed. The Netherlands Career Interruption program requires the caregiver to have worked for at least a year. Richard may be the only one of the caregivers who can access these programs because he works full time. The labour policies that are only available for terminal care (Netherlands's Leave to Care for a Dying Person, Sweden's *Care Leave Act*) would be of little value to Richard at this point in his mother's caregiving needs, but those offered for non-terminal care (Israel's *Sick Leave Act*, Norway's Care Leave) may help Richard take time away from work for several days if his mother needed a higher level of care for a shorter time.

Richard is also the most likely to be able to benefit from tax relief because he has more disposable income than the other caregivers. The tax relief measures available in the United States can only be accessed by employed caregivers. They are intended to support the caregiver to remain employed by providing tax relief for monies paid out for formal care services. Helen, Kim and Sharon, who are not employed or have little employment income, would not be able to access these programs despite the financial costs they incur as a result of their caregiving roles.

Relationship Between Caregiver and Care Receiver

The relationship between the caregiver and care receiver can have an impact on who can access these programs. It is not uncommon for the policies to specify a family caregiver. Sweden's Attendance Allowance and Assistance Allowance can only be paid to a family caregiver. This is also true of the tax deduction and Care Leave program available in the Netherlands. Sharon would not be able to access these programs because she is not a relative of Sophie's. Such an approach does not reflect the current nature of caregiving in Canada where neighbours and friends are being called on to provide care in the absence of family and community supports.

As in Canada, where there are restrictions on which family relationships qualify under tax relief

measures, France's two direct payment programs allow payments to relatives, neighbours and friends, but exclude spouses and partners from this list. Helen would not be able to be paid by her husband for the care she provides. As many spouses, particularly elderly women, are providing intensive levels of care for their partners, this exclusion is troublesome. France has been considering removing this exclusion for the ACTP, but not the APA, which is for elderly care receivers (A. Grand, personal communication, 2004). Helen would not benefit from this change. However, Helen may receive some help under this program as the funds could be used to purchase respite or other services from someone her husband knows who could provide more individualized care. It should be noted, however, that many international programs do not place restrictions on the relationship between caregiver and care receiver. Friends, neighbours, and family can be eligible for most direct payments to caregivers.

Connected to the relationship between the caregiver and care receiver are criteria around living arrangements. Co-residency is used as an eligibility criterion for some Canadian tax measures, and is also used internationally, although in limited cases. The Netherlands tax deduction for caregivers requires that the care receiver live with the caregiver. This is the same for the United States Child and Dependent Care Tax Credit. Sharon and Richard would not be able to benefit from these tax measures because they do not live with the care receiver, while Helen and Kim might. However, they may not meet the other eligibility criteria. Co-residency is not generally used as an eligibility criterion for direct compensation, pension security or labour policies. Australia's Carer Allowance was once restricted to those living together but the eligibility criteria were recently expanded to include caregivers that are not living with the care receiver but provide at least 20 hours of care per week. Eliminating co-residency is an important step because living together is often not the preferred choice of either the caregiver or care receiver and it would be a more stressful kind of caregiving relationship (Linsk et al., 1995 in Guberman, 1999).

Benefit Amounts

The amount of payments and whether or not they are taxed also influences accessibility and how much they help the caregiver. The amount available through tax relief measures is often minimal and does not reflect the real costs of caregiving. While labour policies may be beneficial to someone like Richard, the amounts they pay out may limit his ability to access these programs. For example, while the Netherlands's Career Interruption provides leave for between 2 and 18 months, Richard may not be able to sustain his family on the monthly payment of approximately \$762 CAD per month. Sweden's *Care Leave Act* provides 80% replacement of income, which might be more manageable for Richard's family than what is currently provided in Canada, as it would provide him with more than the 55% of income (up to a maximum of \$413 weekly) available under the Compassionate Care Benefit.

The benefit of direct payments is limited by how much funding is made available to the caregiver. Programs like Sweden's Carers' Allowance, which pays caregivers at the same rate as formal service providers, and the Netherlands Personal Budget, which provides a standard hourly rate, or France's direct payments which pay over \$1000 a month for high level care needs, are likely to be most beneficial to caregivers. Kim and Sharon would be helped the most by these programs. Sharon would be able to continue caring for Sophie while also increasing her income. Kim would be most helped by Sweden and the Netherlands' programs as they would allow her

to bring in a sustainable level of employment income to support her family instead receiving social assistance.

Programs that provide lesser amounts may have less benefit to caregivers. The United Kingdom's Carer's Allowance pays approximately \$108 per week to caregivers providing at least 35 hours of care per week. This amount would not sustain someone who is caregiving full time, particularly as eligibility requires very low income. The benefit is made even less useful for caregivers because it is taxable.

4.6 Summary

Examining the details of these policies reveals that caregivers' access is affected by policies differently based on a number of criteria including recipient of the payment, the amount of compensation offered, whether the amount is based on needs or is a set amount, and the relationship between caregiver and care receiver. These criteria may relate to targeting of the program to a particular population (employed caregivers, low income caregivers), or to the intent of the program (to help caregivers continue to work, to reduce government costs, to provide care where formal services are unavailable or inappropriate). The ability of caregivers to access these programs is shaped also by the complexities of their own lives and the caregiving situations.

5.0 Policy Recommendations to Support Caregivers

This report has set the stage for discussion on how to better support Canadian caregivers. We have provided an overview of the changing realities within Canadian society that have increased the burden on caregivers, painted a picture of who caregivers are, what they do, and the consequences of caregiving. We have examined current policy to support caregivers, and looked at the ways other countries are supporting caregivers.

It must be acknowledged that despite social and policy change and the resulting consequences, caregivers continue to give generously of themselves. Downloading of home care responsibilities onto family and friends is not without costs for individual caregivers, communities, or society as a whole. The welfare diamond has become unbalanced with families and communities being required to take on levels and types of care that put caregivers at risk and are potentially unsustainable without additional supports from the state. Given the discourse of cost containment that is guiding so much policy today, Jenson notes that “any cost-benefit calculation must include the short- and long-term cost of the continuing pressure on family members to provide care” (Jenson, 2004a, p. 42). When this approach is taken, what emerges is awareness of the need to rebalance the welfare diamond, and in particular a call for the state to take an increased role in supporting caregiving.

This section does not provide answers on what should be done, but rather provides an overview of the types of policies that have been suggested by researchers and caregiver advocates and puts forward issues and questions for consideration when developing policy and programs for caregivers.

5.1 Suggested Policy Options

Caregivers need many things to facilitate a “healthy balance” in caregiving: information about available supports; support from family, employers and health care providers; training and skill development; respite and help with day to day chores; emotional support and financial support (Gahagan et al., 2004). Numerous approaches for state action to better support caregivers have been suggested. These suggestions include 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 calls to alter provincial drug and health plans to cover necessary drugs and supplies used in the home. Increases to amounts and access to home care and respite care for caregivers (Guberman, 1999), as well as reductions to user fees for low income care receivers (Fast et al., 2001), have also been discussed. Other suggestions have been loftier, calling for significant policy shifts and development of new programs. For example, discussion at the Unpaid Caregiving Forum (2003) led to calls for development of a list of core services, guiding principles, and indicators of supportive home and community care for Federal/Provincial/Territorial discussion. Guberman et al. (2001) have suggested that caregivers should be viewed as partners within the home care system and/or a caregiver needs assessment should be implemented as part of intake into the system. It has also been suggested 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).

Improvements to or development of new financial compensation policies for caregivers have also been popular recommendations. We highlight four suggestions here.

Suggestion 1: Improvements to Tax Credits

As discussed in Section 3.0, current tax measures are of limited value to caregivers and many caregivers are not able to access these credits. Numerous suggestions have been made to improve tax relief measures. Suggestions include:

- Make credits refundable. This would increase their benefit to women and low income caregivers, and ensure that all those who meet the eligibility criteria receive some assistance (Shillington, 2004; Young, 2000).
- Remove co-residency criteria as this eliminates many caregivers and is often not preferred or the most beneficial living arrangement for either the care receiver or caregiver (Guberman, 1999).
- Increase income ceilings on means tests for tax credits (Fast et al., 2001).
- Recognize that not all caregivers are family members (Unpaid Caregiving Forum, 2003).
- Simplify the system to improve accessibility (Fast et al., 2001).
- Increase credit amounts to provide meaningful financial relief (Fast et al., 2001).
- Pay on a monthly basis (Unpaid Caregiving Forum, 2003) like the Child Tax Benefit.
- Change Medical Expenses Tax Credit to recognize in-kind contributions (Shillington, 2004).

Suggestion 2: Improvements to the Compassionate Care Benefit

It has also been recommended that the Compassionate Care Benefit be altered to improve accessibility and helpfulness to employed caregivers. The report from Unpaid Caregiving Forum (2003) suggests the following:

- Expanding the eligibility to “those providing significant levels of unpaid care to a person deemed to be eligible for the Disability Tax Credit (recognizing that ‘significant’ will have to be determined) and persons needing medical care upon the authorization of an accredited health professional” (p. 13).

Other options based on limitations of the program identified at the Unpaid Caregiving Forum (2003) include:

- Increase the benefit amount. The current provision of 55% of income may make the benefit inaccessible to low income workers who are already struggling to make ends meet. An increase would be particularly important to women as they make up the majority of minimum wage. Care leave policies in other countries provide up to 100% of wages.
- Extend eligible caregiving relationships to include such family members as in-laws, aunts and uncles, and friends and neighbours.

- Expand the program to provide access to contract, temporary and self-employed workers, and part-time workers who are currently not eligible.
- Extend the amount of paid leave time available. In Canada, up to 52 weeks leave is available for parental caregiving but there is no similar provision for other caregiving relationships. International programs provide up to several months of leave to care for seniors and adults with disabilities or illnesses.

Suggestion 3: Develop a Direct Compensation Program

Direct compensation was addressed as early as 1998 in a report commissioned by Health Canada on the issue of financial compensation (Keefe & Fancey, 1998). Options considered include:

- Introducing a caregiver allowance similar to the Australian Carer Allowance. This approach would provide a small payment (i.e., \$100 biweekly) to caregivers who provide a certain level of care (i.e., 20 hours per week or more).
- Introducing a caregiver wage similar to the one found in Sweden that pays an hourly rate equivalent to that paid to formal home help workers.
- Expanding consumer directed care programs to allow hiring of family members.

Keefe and Fancey (1998) identify basic features to consider if developing this kind of policy. These include:

- Benefits should not interfere with eligibility for other income supports or deter involvement in part-time employment.
- Benefits should not be taxed to increase the value of the payment.
- Direct compensation should not be offered to replace services, but should be offered as part of a range of supports to caregivers.

Suggestion 4: Provide Pension Security

It has also been noted that policy is needed to address the long term costs of caregiving. If caregivers make decisions that reduce their current income, for example by reducing hours of paid employment or postponing or declining job training and promotion, this will have an effect on future income/retirement income. Pension security, available to caregivers in many other countries, has been suggested as an option for supporting Canadian Caregivers. Currently caregivers of adults and seniors are not able to access the Canada Pension Plan (CPP) drop out provisions available for caring for children. They cannot make contributions to CPP while out of the labour market providing care. Additionally, those who reduce their paid work hours will face the consequences of lower CPP amounts upon retirement, having made lower CPP contributions amounts while working (Unpaid Caregiving Forum, 2003). The report from the Unpaid Caregiving Forum (2003) includes the following suggestions for improving CPP for caregivers:

- Expand the childcare drop out provision to those providing other types of unpaid care.
- Enable caregivers providing support to a family member with a “severe” disability as determined by eligibility for the Disability Tax Credit to drop out of some or all of the

- years spent caregiving when determining eligible contributory years under CPP.
- Enable caregivers to have contributions made to CPP based on their unpaid caregiving contributions.
- Allow contributions to CPP to be made by caregivers, as is currently available to the self-employed, or by another individual on behalf of the caregiver, or by the government for low income caregivers.

Similar recommendations have been made by Shillington (2004). Whatever approach is used, it should be flexible enough to ensure assistance not only to those that have left the labour market but also to those that have made significant cuts to paid work to provide care.

5. 2 Considering Values and Principles When Developing Policy for Caregivers

Researchers have argued that when considering any policy option, there must be an awareness of the underlying objectives or values informing the policy. Keefe and Fancey (1998) argue that objectives of caregiver policies are either economic or social in nature. Policies with a social objective “recognize the contribution of informal care and support the informal care system” (Keefe & Fancey, 1998, p. 4). The focus is on acknowledging that caregiving is valuable and caregivers should be supported. Policies with economic objectives have the goal to “reduce or delay the institutionalization of the person with care needs and thereby decrease the cost to the health care system” (Keefe & Fancey, 1998, p. 4). Discourse around these policies often points out that they are cost-effective.

In the past decade economic objectives have been the focus of caregiving-related policy. The shift to community care and changes within home care programs have been based on concerns around cost effectiveness and economic savings without recognizing the heavy burden being placed on families and communities, and women in particular, as the state offloads some of its responsibility onto these spheres of the welfare diamond.

In order to rebalance the welfare diamond, researchers have argued for policy approaches that make the values which underlay policy transparent, and for the use of principle-based frameworks for evaluating and developing policy. This type of approach calls for a shift away from policy with economic objects to a focus on social objectives. For example, Kenny (2004) argues for a move to seeing public policy “as a moral endeavor that involves decisions about who we are and who we desire to be as a country” (p. 2). Policy should not only be based on empirical evidence but also in an ethical framework. Kenny’s framework is based on an “intergenerational equity” approach to policy development that is “concerned with justice and fairness in the here and now and for future generation.” (p. 2). Kenny (2004) provides several guiding principles, such as respect for persons of all ages, meaningful autonomy, and solidarity, which should be considered in order to promote policy that facilitates intergenerational equity. Policy makers are also called on to examine the impact of policy over the lifespan to ensure fairness across generations and to make certain that policy improves overall well-being of all groups over the long term (Kenny, 2004).

Nussbaum’s (2000) “human capabilities approach” to policy is also rooted in social objectives.

According to Nussbaum's framework, human capabilities include:

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. (p. 245)

Under this framework, the goal of policy should be to promote the ability of individuals to achieve these human capabilities. According to Nussbaum (2000), this is important because "people love best when they are in other respects flourishing, not when they are exhausted, or struggling to make ends meet" (p. 297).

Attempts have been made in Canada to develop values or principle-based frameworks for the evaluation and development of caregiver policy. In November 2001, 55 experts from academic, policy and caregiver communities met to discuss issues around women and home care. The result of these discussions was the "Charlottetown Declaration on the Right to Care". While the central focus of this document is on outlining fundamental principles for home care, many of the principles are useful for thinking about caregiver policy (Pederson & Huggan, 2001).

Based on principles included in the Declaration on the Right to Care, the following can be put forward as guidelines for use when considering any public policy which affects caregivers:

- Care should be provided in an environment that meets the needs of both the care receiver and caregiver. The home should not be assumed to be the appropriate or desirable location for care.
- Caregiving must be voluntary. It cannot be assumed 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.
- Caregivers must have choices. This means that they must be able to make choices about what types of care they want to provide, how much care, and to whom they will provide the care.
- In order for caregiving to be voluntary and for caregivers to have choices, they must have access to and awareness of alternatives and appropriate supports.
- 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.

By using guidelines of this type when considering how to support caregivers it becomes possible to focus attention to the needs, wants, and rights of caregivers and expose the problems with current community care discourse and policy. It also facilitates a shift away from an approach to policy based on cost reduction, to one where caregiving is deemed a worthwhile activity and supporting caregivers is seen as a social responsibility.

5.3 Need for Use of Gender Lens for Policy Analysis

While making transparent the values that underlay current policy and considering what values should guide policy are both crucial to finding better ways to support caregivers, other issues must also be considered. Throughout this report, it has been demonstrated that caregiving is gendered. Given this reality, a gender-based analysis lens has been suggested as a way to ensure equitable and inclusive policy development. A gender-based analysis approach recognizes that roles, responsibilities and access to resources are gendered, and that men and women have different social realities and different socioeconomic positions that might affect their lives (Morris, 2001). This approach also calls for recognition of other forms of diversity and inequality, such as those based on race, ethnicity, level of ability, sexual orientation and so on, when developing and evaluating policy (Health Canada, 2000).

Health Canada has developed a gender-based analysis policy for looking at health policy and programs. Within this policy, gender-based analysis is seen to perform a “challenge function”: “It challenges the assumption that everyone is affected in the same way by policies, programs and legislation... It probes concepts, arguments and language used, and makes underlying assumptions and values transparent and explicit” (Health Canada, 2000, p. 2).

Morris (2001) argues that use of a gender-based approach will facilitate the development of solid, evidence-based policy that is rooted in an awareness of the reality of women's and men's lives and how they are affected by policy.

Possible questions to be addressed when conducting a gender-based policy analysis, based on work by Armstrong and Kits (2004), Health Canada (2000), Morris (2001; 2004), and Pederson and Huggan (2001) include:

1. Does the policy/program consider the socio-economic realities of women's lives?
2. Does it provide women with choices regarding caregiving?
3. Does it appropriately value the work of caregivers?
4. Does it consider the different life circumstances of women and the needs of women across the life span?
5. Does it help to reduce both the immediate and long-term costs and consequences of caregiving?
6. Will it improve the life-long financial security of women?
7. Will it benefit some groups more than others or provide equitable support to all caregivers?
8. Does it promote equity?

These questions can provide orientation for discussion and evaluation of current policy and can be used to guide deliberation on alternatives. While not all of these questions focus on women, Rajnovich, Keefe & Fast (2005)

they are all gender sensitive (Morris, 2001) and help to uncover assumptions about women and caregiving. For example, the question about choice prompts us to consider what role policy plays in women taking on caregiving. Questions that address the long-term consequences of caregiving encourage us to ensure policy does not meet today's needs at the expense of future needs and well-being. Armstrong and Kits (2001) argue, for example, that a caregiver allowance may provide an immediate benefit to a woman providing care, but if it means she leaves work to continue caregiving, she may find herself without appropriate economic security as she ages if no policy is in place that responds to long term needs (Armstrong & Kits, 2001). Questions about diversity lead us to consider the problems with a "one size fits all" approach to policy and how policy can be made flexible and responsive to individual caregiver's needs (Gahagan et al., 2004). The result should be an uncovering of practices that are discriminatory or biased against women or other groups, and development of policies that "reduce rather than exacerbates inequality" (Morris, 2001, p. 3) and are inclusive (Health Canada, 2000).

5.4 Conclusion

This section has focused on raising questions: questions about what policy options might support caregivers; questions about the values and principles that should guide policy; and questions about the role of policy in promoting gender equity. The purpose has been to prompt discussion about how to go about supporting caregivers.

Guberman (1999) has suggested an alternative approach to address these issues that challenges our beliefs about family and state responsibility. Noting that attempts to reduce the costs and consequences of caregiving have to date been fragmented and have had little impact on the well-being of caregivers, Guberman (1999) calls for a more comprehensive approach in the form of a model of social community care. This model calls for viewing caregiving as a social responsibility, putting the public sector rather than the family at the centre of care provision. It also views caregiving as real work and places an emphasis on the facilitation of choice, empowerment, and partnerships between stakeholders.

While adoption of such an approach may be unlikely given our current political and economic environment, Guberman's (1999) approach raises additional questions around how we think about caregiving and what is required to provide real support to caregivers. We conclude, then, with another set of questions that bring the discussion to a broader level and encourage envisioning a new model for care provision and supporting caregivers:

1. What vision should we have for care provision in Canada?
2. What values should underlay care-related policy?
3. Are there limits on what it is fair to ask of caregivers (Kunkel, Applebaum, & Nelson, 2003-2004)?
4. What role should the state play in supporting caregivers?
5. What policy approaches are appropriate for supporting caregivers?

6. What might be the costs and consequences to Canadian society if we do not improve support for caregivers?

These are important questions that call on us to consider what Canadians value; to contemplate what is fair and just for caregivers; to examine how we think responsibilities should be distributed within the welfare diamond; and finally, to reflect on the repercussions of inaction on this important social issue.

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