



Informal Caregivers in Canada: A Snapshot

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Executive Summary

In the January 2001 Speech from the Throne, the Government of Canada made a laudable promise to take steps to enable parents to provide care to a gravely ill child without fear of sudden income or job loss. However, parents caring for gravely ill children represent a small minority of Canadians who care for relatives or friends with a long-term health or physical limitation. Furthermore, income and job loss are not the only costs caregivers commonly experience.

In 1996, 2.85 million Canadians provided care to at least one person with a chronic health problem or disability. Most caregivers were:

- middle-aged women
- employed full time
- caring for more than one person
- caring for a parent (but significant proportions cared for distant kin or friends)
- caring for more than two years
- not living with the person for whom they cared
- not primary caregivers

Caregiving has significant implications for caregivers' lives:

- more than half made adjustments to their employment at an estimated cost to each employed caregiver of more than \$1.2 million in lost current and future income
- more than 40% incurred extra expenses, estimated at \$30,630 per employed caregiver, because of their caring responsibilities
- men and women averaged between 3 and 5 hours per week on eldercare tasks; it would have taken 276,509 full time employees, at a cost of \$5 - 6 billion, to replace the work of the 2.1 million Canadians who cared for seniors in 1996
- caregivers' physical, social and psychological health also were affected

Few Canadian public policies are designed to reduce the economic costs of informal care. That said, there is no need to "go back to the drawing board" in order to improve caregivers' situation: existing programs provide the basic structure. Recommended reforms in the labour, income security, and health policy sectors include:

- providing 'family responsibility leave' legislation that protects employed caregivers, recognizes the chronic nature of caregiving, and respects the diversity in relationships between informal caregivers and care receivers
- amending EI and CPP/QPP programs so that taking a temporary leave of absence, or retiring early, from the paid labour force because of heavy care responsibilities does not substantially jeopardize carers' current or future income
- assuring a guaranteed minimum income for seniors that takes into account regional economic differences in determining amount of financial support provided
- using eligibility criteria for caregiver tax credits that apply to informal caregivers who experience high consequences, regardless of residency, relationship, or income of the care receiver
- offering a comprehensive program that subsidizes the cumulative cost of health-related services, equipment, and supplies for seniors, regardless of jurisdiction, and sets a

maximum cost-sharing limit that is affordable to most seniors and waived for those who are impoverished

- providing direct financial compensation to unemployed informal caregivers for their caring work
- providing a core set of home care services that would be universal, accessible, and affordable, regardless of jurisdiction
- targeting respite needs of caregivers to sustain informal care by developing services based on caregiver needs, and eliminating fees for short-term replacement services

For maximum effect, comprehensive and integrated solutions are better than sectoral ones.

Informal Caregivers in Canada: A Snapshot Implications and Recommendations

Introduction

In the January 2001 Speech from the Throne, the Government of Canada promised to take steps to enable parents to provide care to a gravely ill child without fear of sudden income or job loss (Prime Minister of Canada, 2001). While this is a laudable objective, parents caring for a gravely ill child represent a small minority of Canadians who provide care to relatives or friends with a long-term health or physical limitation. The majority of informal caregivers are caring for parents, followed by friends, extended family, spouses, siblings and, finally, children (see Table 1). Further, while caregiving has been shown to have significant implications for caregivers' employment opportunities and, in turn, for their income, increased out-of-pocket expenses, unpaid labour costs, and social, emotional, and physical consequences are equally common.

Table 1: The Minority of Canadian Caregivers are Caring for Children

Care Receiver	Instrumental care ¹	Personal care ²
Parents	47%	46%
Friends	24%	13%
Extended family	13%	11%
Spouse	5%	16%
Sibling	6%	5%
Child	3%	5%
Source: Cranswick, K. (1997). Canada's caregivers. <i>Canadian Social Trends, Winter, 2-6</i> .		

¹ Instrumental care includes meal preparation and cleanup; housekeeping, laundry, and sewing; house maintenance and outside work; shopping for groceries and other necessities; transportation; banking and bill paying.

² Personal care includes bathing, dressing, toileting, etc.

In this paper we describe the informal caregiver labour force, the range of consequences they experience as a result of their care responsibilities, and the ways in which current public policies might be adapted to mitigate the costs experienced by Canada's carers. While every attempt is made to provide information about the full range of caregivers and their consequences, available empirical evidence describes most comprehensively the situation of those caring for seniors. This group of caregivers is worth examining separately in any case since it represents the vast majority of caregivers and since seniors with long-term health or physical limitations are among the most disabled and so most in need of care.

Who are the Caregivers?

In 1996, Statistics Canada conducted a General Social Survey (GSS) of almost 13,000 Canadians to learn about their participation in providing support to others. At that time, 2.85 million Canadians were found to be providing care to at least one person with a chronic health problem or physical limitation.

Carers for people of all ages were more commonly women: 10% of all men and 14% of all women in Canada provided care to family or friends. Informal caregiving was more common among the middle-aged: 19% of women and 11% of men between the ages of 45 and 64 were informal care providers in 1996. Neither family status nor employment deterred Canadians from providing care: approximately the same proportion of those with and without spouses, with and

without children, and those who were employed and not employed provided care (Cranswick, 1997).

In the following paragraphs we provide information from the same survey of caregivers who provided care to someone over age 65. Unless otherwise stated, information in this section is from *Eldercare in Canada* (Keating, Fast, Frederick, Cranswick, & Perrier, 1999).

In 1996, nearly 11% of the population 15 years of age and over, or 2.1 million people, provided informal care to one or more seniors with a long-term health problem. We expect that the number of caregivers is underestimated since the number represents only those caring for a senior at the time of the survey. Many more people have taken or will take on eldercare responsibilities at some time during their lives (Evandrou, Glaser, & Henz, 2001).

Women have been identified as the predominant caregivers and this survey confirmed that they do indeed constitute the majority of eldercare providers (61%). Nevertheless, men represented a substantial group (39%) of caregivers. Because relatively little is known about men's characteristics as caregivers, or about the amount and type of care they provide, separate profiles for women and men caregivers are presented (see Table 2).

Table 2: Caregivers to Canadian Seniors are Diverse

Caregiver Characteristics	Women %	Men %	Total %
Age group			
15-29	12.5	18.6	14.9
30-44	33.1	33.9	33.4
45-59	36.6	31.0	34.4
60-74	14.8	12.6	13.9
75+	2.9	3.9	3.3
Highest level of education attained			
<High school	22.4	23.4	22.8
High school	14.3	9.8	12.6
Some postsecondary	19.2	15.7	17.8
Trade school/community college	30.3	26.6	28.9
University degree(s)	13.8	24.6	18.0
Urban/rural residence			
Urban	72.7	79.1	75.2
Rural	27.3	20.9	24.8
Marital status			
Married/common-law	65.9	74.0	69.1
Separated/divorced	8.0	3.5	6.3
Widowed	7.9	1.5	5.4
Single	18.2	21.0	19.3
Labour force status			
Not in labour force	37.9	22.2	31.7
Employed part time	15.3	7.4	12.2
Employed full time	46.8	70.5	56.1
Number of children under 15			
No children under 15	74.8	67.8	72.0
Children under 15	25.2	32.2	28.0

Caregiver Characteristics	Women %	Men %	Total %
Number of people cared for			
1	27.8	33.1	29.9
2	30.7	33.4	31.8
3	21.2	15.2	18.8
4	11.5	12.8	12.0
5+	8.8	5.5	7.5
Length of time caregiving			
<6 months	13.5	12.9	13.3
6<12 months	10.2	11.5	10.7
1<2 years	16.1	15.1	15.7
2+ years	60.2	60.5	60.3
Relationship of caregiver to care recipient			
Spouse/partner	4.9	4.2	4.6
Adult child	56.6	53.5	55.4
Sibling	3.7	3.4	3.6
Extended family	15.6	17.2	16.2
Friend	18.2	21.3	19.4
Proximity			
Same household/building	15.8	10.7	13.8
Same neighbourhood/community	49.6	50.6	50.0
Surrounding area	21.8	22.8	22.2
<1/2 day away	9.3	11.9	10.3
>1/2 day away	3.6	4.0	3.8
Caregiver status			
Primary caregiver	39.0	27.0	34.3
Secondary caregiver	61.0	73.0	65.7

These findings challenge assumptions about the identities of Canada's caregivers.

- **Assumption 1:** *"Most caregivers are middle aged."*
While it is true that the average age of caregivers is about 45, a substantial minority (about one-third) is either under 30 or over 60 years of age.
- **Assumption 2:** *"People in rural areas are more caring."*
Rural women caregivers are somewhat over-represented in comparison with the general population of rural women, while urban women caregivers are under-represented. Rural men are no more likely to provide care than urban males.
- **Assumption 3:** *"People with other demands in their lives, such as jobs, spouses, young children, and other caregiving responsibilities, are less likely to provide care."*
The majority of caregivers are married. Indeed, somewhat higher proportions of married men and married women are caregivers. Most also are in the labour force and most of these are employed full-time. While the existence of a "sandwich generation" has been challenged, more than 25% of eldercare providers also have children under age 15. Most are also caring for more than one person. Although the average is two care recipients, women reported caring for as many as nine people and men cared for up to seven.

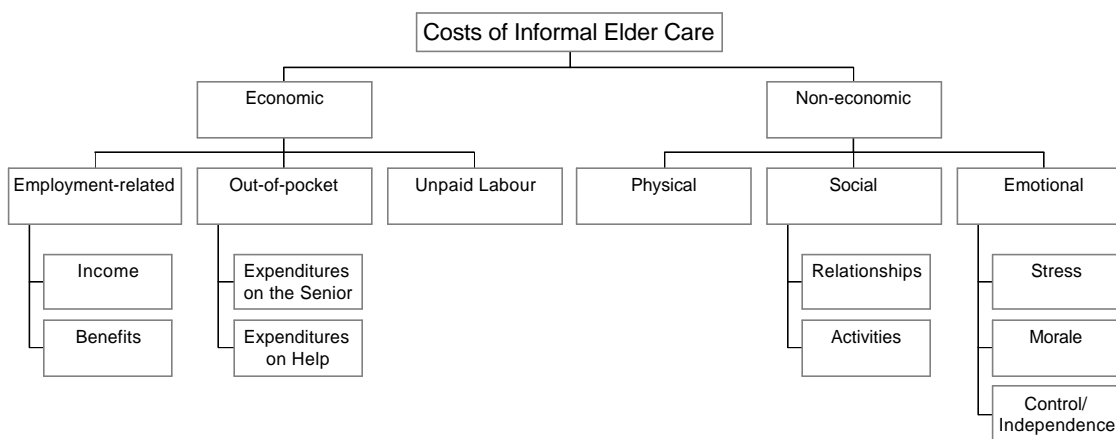
- **Assumption 4:** *“People aren’t committed to caring any more.”*
Most caregivers (about 60%) have been providing assistance for at least two years, illustrating the long-term commitment of those providing eldercare.
- **Assumption 5:** *“Only close kin care.”*
While more than half of women and men caregivers are adult children caring for their parents, less than 5% care for a spouse. In fact, after adult children, the largest proportions of caregivers are providing assistance to friends or to extended family members such as grandparents, aunts, and uncles.
- **Assumption 6:** *“Most carers live with the person for whom they care.”*
Only a small minority of women (16%) and men (11%) caregivers live with the senior for whom they are caring.
- **Assumption 7:** *“Only primary caregivers matter.”*
In 1996, almost two-thirds of caregivers said they are not the senior’s primary caregiver but are actively involved in providing care.

The tendency in policymaking is to base eligibility criteria for programs and services on a limited set of characteristics that is assumed to represent the majority of caregivers. Data presented here, and echoed in other research, demonstrate the diversity among caregivers that must be taken into account in policy development and reform.

What are the Consequences of Caregiving?

Caregivers have been found to experience a range of consequences resulting from their caregiving responsibilities. These consequences are illustrated in Figure 1 below (Fast, Williamson, & Keating, 1999).

Figure 1: A Taxonomy of the Hidden Costs of Eldercare



A limited amount of information about the incidence of many of these consequences is available for those caring for friends and family of any age. More detail is available for eldercare providers. In each of the following sections, we first summarize what is known about consequences experienced by all caregivers and then provide a more detailed analysis of the consequences of eldercare.

1. Economic consequences

Economic consequences are those that involve money or money equivalents and that affect one's standard of living. These are differentiated further into employment-related, out-of-pocket, and unpaid labour costs.

Helping others has been shown to cause employed **caregivers to make adjustments to their paid work**. Almost half of men and women respondents to the 1996 GSS reported that their caregiving responsibilities affected their employment in some way (Table 3). Missing full or part days of work was the most common job adjustment reported (Cranswick, 1997). Much less commonly reported was postponement of educational and employment opportunities. However, for the small proportion that did report these consequences, the implications are serious. Further, women were more likely than men to make adjustments to their paid work and to postpone economic opportunities.

Table 3: Unpaid Care Work Interferes with Carers' Paid Work

Helping others caused caregivers to:	% responding affirmatively	
	Women	Men
• experience repercussions at work	55	45
• postpone education/training	7	5

Source: Cranswick, K. (1997). Canada's caregivers. *Canadian Social Trends*, Winter, 2-6.

Data on employment impacts of eldercare are reported in Table 4. Consistent with the findings on all caregivers, the most common job adjustments reported by eldercare providers were missing full or part days of work. Estimates of the amount of work missed because of eldercare demands range from 5 to 12 days in the previous year (Gibeau & Anastas, 1989; Scharlach, 1994). Employees often are forced to use sick days, vacation, and personal leave when they miss work in order to fulfill eldercare tasks.

Table 4: Unpaid Care Work Interferes with Eldercare Providers' Paid Work

Helping others caused caregivers to:	% responding affirmatively		
	Women	Men	Total
• change hours of work	17.7	21.9	19.6
• come late to work or leave early	35.9	37.2	36.4
• miss a day or more of work	31.7	27.8	30.0
• have their job performance affected	17.1	16.1	16.6
• postpone education/training	8.3	6.0	7.3
• decline a job transfer or promotion	6.2	2.4	4.5
• turn down a job offer	4.2	1.8	3.1

Source: Keating, N. C. et al. (1999). *Eldercare in Canada: Context, content and consequences*. Ottawa, ON: Statistics Canada

Respondents to the 1996 GSS from which the data in Tables 3 and 4 were derived were not asked about the "job adjustment" that is likely to have the most profound effect on caregivers' economic well-being: giving up a job entirely. However, results of one Canadian study showed that between 9 and 11% of employed eldercare providers relinquished employment (Martin Matthews & Campbell, 1995). A more recent U.S. study showed even higher proportions leaving

the labour force because of eldercare demands: 16% had quit a job and another 13% had retired early (Mature Market Institute, 1999).

When informal caregiving interferes with caregivers' employment, current and future income and employment-related benefits are affected. In their 1999 study, the Mature Market Institute made a rare attempt to monetize some of the economic consequences of eldercare. Almost all employed caregivers reported that they had made some sort of adjustment to their work schedule, including reducing their hours of work (33%), changing from full- to part-time work (20%), and taking leaves of absence (22%). Forty percent reported that their caregiving responsibilities had limited their advancement opportunities and two-thirds indicated that there had been a direct impact on their earnings. For a small sample of 55 respondents who provided enough detailed information to support accurate calculations, the Mature Market Institute was able to estimate that, aggregated over their lifetimes, each caregiver's monetary losses amounted to an average of \$1,034,117 (see Table 5).

Table 5: Employed Caregivers Experience Lost Wages and Benefits

Type of income loss	Average CDN\$ value per caregiver
Lost wages (over remainder of working years)	888,685
Lost Social Security benefits (over retirement years)	39,997
Lost private pension benefits (over retirement years)	105,433
Aggregate lost income	1,034,117
Source: Mature Market Institute (1999). <i>The MetLife juggling act study: Balancing caregiving with work and the costs involved</i> . New York, NY: Metropolitan Life Insurance.	

Out-of-pocket costs are expenditures that would not have been made had informal care not been provided. They include expenditures on goods and services purchased by the caregiver for the care recipient, expenditures by the caregiver on assistance for the care recipient or for themselves, and money transfers to the recipient. The incidence of extra out-of-pocket expenses reported by respondents to the 1996 GSS was similar for those caring for people of any age and for those caring for seniors. More than 40% reported that they had **incurred extra expenses** because of their caregiving responsibilities in the 12 months immediately preceding the survey.

The Mature Market Institute (1999) also was able to estimate average out-of-pocket expenses incurred by employed eldercare providers over the duration of caregiving. The three most common expenditure categories were food, transportation, and medications. However, the highest average amounts expended were for assistance with rent or mortgage and expenses for home care professionals. The estimated average amount spent over their typical 5 to 7 years of caregiving was \$30,630 per caregiver. Over the same time period they reported reducing their savings by an average of \$39,267 and their Investment Retirement Account contributions by a further \$5,664.

Informal care involves unpaid work similar to that of unpaid household work, which increasingly is acknowledged as productive and economically valuable. By definition, **all care providers incur some direct labour costs**. The best metric for these costs is the time spent on care activities. Participation rates and average time spent on individual care tasks by those participating in each task and average time spent on all types of care for caregivers to seniors are reported in Table 6.

Table 6: Eldercare is Time Consuming

Caregiving Task	% of caregivers responding affirmatively		Average hours/week for those doing the task	
	Women	Men	Women	Men
Meal Preparation	40.2	19.0	5.0	4.0
Housekeeping	35.7	15.3	1.7	1.8
Maintenance/repair	18.5	42.8	1.5	1.0
Grocery shopping	48.8	40.9	0.9	0.8
Transportation	47.9	47.5	1.0	1.1
Bills and banking	27.1	24.2	0.3	0.2
Personal care	33.9	18.3	4.1	4.5
Checking up	57.3	50.0	*	*
Emotional support	32.9	22.9	*	*
All care tasks			5.0	3.0
Source: Statistics Canada, General Social Survey, 1996				
*data on time spent on checking up and emotional support were not collected				

It would have taken 276,509 full-time employees at a cost of between \$5 billion and \$6 billion to replace the work of the 2.1 million Canadian caregivers (Fast & Frederick, 1999).

Women who spent more time caring for a senior were primary caregivers, provided palliative care, lived with the senior for whom they were caring, and had a close relationship with the senior. As indicated in the previous section, few Canadian carers live with the person for whom they are caring. However, when they do, they spend between 8 and 10 hours more each week on care tasks than those who care from a distance. Providing palliative care increased the care work by 4 hours per week and being a primary caregiver increased it by 3.6 hours per week (Keating et al., 1999).

Men who were more intensely involved in care for a senior were primary caregivers, cared for more people, did palliative care, had been caring for the senior between 1 and 2 years, and were caring for a spouse or were widowers. Men caring for a spouse spent between 11 and 13 hours more on care tasks each week than men caring for another relative or a friend. Widowers, most of whom were caring for friends, also spent an average of 4 hours per week more on care tasks than married men (Keating et al., 1999).

2. Non-economic consequences

Non-economic consequences arise from declines in certain aspects of the carer's quality of life, such as physical, social, and emotional well-being. Physical well-being refers to physical health. Social well-being refers to interpersonal relationships, the quality of those relationships, and carers' abilities to participate in social activities. Costs related to emotional well-being are described in the literature as psychological stress, poor morale, and loss of control and independence.

It has been shown that **caregiving responsibilities affect caregivers' physical well-being**. Data presented in Tables 7 and 8 indicate that the stress arising from the time and energy demands of caregiving result in significant health problems for those providing care to family and friends of any age. These data also confirm what has been reported in other literature, that eldercare providers experience sleep deprivation and/or changes in sleep patterns (CARNET:

The Canadian Aging Research Network, 1993). Employees with caregiving responsibilities have been found to experience more stress and more physical ailments such as headaches, loss of energy, gastro-intestinal disturbances, and fatigue than employees without eldercare demands, which, if persistent, can negatively affect their health (Duxbury & Higgins, 1999; Mature Market Institute, 1999).

These data also indicate that caregiving responsibilities interfere with caregivers' social and recreational activities. This is consistent with findings from earlier studies in which caregivers have been found to forego leisure, social activities, and personal development in order to fulfill their caregiving responsibilities (CARNET: The Canadian Aging Research Network, 1993; Killeen, 1990; White-Means & Chang, 1994). Eldercare providers have little time or energy left for social and recreational activities after attending to their caregiving responsibilities which lead to increased emotional and physical stress and decreased life satisfaction (Blieszner & Alley, 1990; White-Means & Chang, 1994).

Table 7: Caring Affects Carers' Health and Social Lives

Helping others caused caregivers to:	% responding affirmatively	
	Women	Men
• change sleep patterns	31	26
• experience changes in health	27	12
• change social activities	47	44
• change holiday plans	26	25

Source: Cranswick, K. (1997). Canada's caregivers. *Canadian Social Trends*, Winter, 2-6.

Table 8: Caring Affects Eldercare Providers' Health and Social Lives

Helping others caused eldercare providers to:	% responding affirmatively		
	Women	Men	Total
• change sleep patterns	31.1	25.0	28.7
• experience changes in health	27.5	10.6	20.8
• change social activities	46.7	44.7	45.9
• change your holiday plans	26.5	25.8	26.2

Source: Keating, N. C. et al. (1999). *Eldercare in Canada: Context, content and consequences*. Ottawa, ON: Statistics Canada.

Perhaps the most pervasive findings from research relate to the **psychological impact of caregiving**. Depression, guilt, worry/anxiety, loneliness, and, more generally, emotional stress, strain, or burden have all been attributed to caregiving (Duxbury & Higgins, 1999; Parker, 1990; Parks & Pilisuk, 1991).

As indicated in Tables 9 and 10, high proportions of respondents to the 1996 GSS who were caring for people with long-term health or physical limitations reported stress related to competing demands and a lack of personal time. Fourteen percent of men and 22% of women caring for people of any age also reported feeling angry around the person for whom they were caring (see Table 9), raising concerns about risk of abuse; a slightly higher proportion of those caring for seniors felt this way (see Table 10). Often, caregivers feel guilty because the competing pressures of a job and family do not allow them to do more. Many feel guilty because they do not have the essential skills to do a better job. The majority of eldercare providers also reported feeling guilty about the amount or quality of care they were providing. Thirty-six percent wished someone would take over their caring responsibilities.

Table 9: Carers Feel Guilt and Burden

Helping others caused caregivers to:	% responding affirmatively	
	Women	Men
• experience a lack of personal time	45	35
• experience stress due to multiple demands	59	45
• feel angry around the person they're helping	22	14

Source: Cranswick, K. (1997). Canada's caregivers. *Canadian Social Trends*, Winter, 2-6.

Table 10: Eldercare Providers Feel Guilt and Burden

Helping others caused eldercare providers to:	% responding affirmatively		
	Women	Men	Total
• experience a lack of personal time	45.1	35.5	41.3
• experience stress due to multiple demands	59.4	44.7	53.6
• feel angry around the person they're helping	25.2	19.4	22.9
• think they should be doing more for those they help	60.9	66.7	63.2
• think they could be doing a better job of helping	52.5	66.9	58.2
• wish that someone else would take over caregiving responsibilities	37.3	34.0	36.0
• feel burdened in helping others	18.9	17.0	18.2

Source: Keating, N. C. et al. (1999). *Eldercare in Canada: Context, content and consequences*. Ottawa, ON: Statistics Canada.

Family and friends provide the vast majority of care to chronically ill or disabled adults. Clearly they are doing this time-consuming and stressful work at great financial and personal cost. The increasing care burden arising from demographic, health, retirement, and other socioeconomic and policy trends, coupled with changes in family size, mobility, and structure is raising concerns about the sustainability of the informal sector. Evidence suggests that a little support goes a long way with informal carers, enabling them to continue to care longer (Penning & Keating, 2000). In the following section we assess the potential for public policy to provide that support.

How Can Public Policies Better Support Caregivers?

Evaluation of the impact of public policies on caregivers is rare. In fact, while there is a large body of literature examining such concepts as caregiver burden, to our knowledge there are no comprehensive evaluations of the impact of public policies on non-economic consequences of care. Where evaluations do exist, they tend to be focussed on a limited set of costs and a limited set of public programs or services. A comprehensive evaluation of how policies affect the non-economic consequences of care could benefit policy decision-makers enormously because the social, psychological, and physical well-being of individual caregivers is critical to the sustainability of the informal care sector.

There are, however, three recent studies that provide detailed analyses of the impact of federal, provincial/territorial, and regional programs and services on the economic consequences experienced by those caring for seniors (Eales, Keating, & Fast, 2001; Fast, Eales, & Keating, 2001; Keating, Eales, & Fast, 2001). These analyses encompassed three policy sectors judged to have the greatest potential impact: labour, income security, and health.

The key conclusion from these analyses was that **relatively few current Canadian public policies are designed to support informal caregivers by reducing their economic costs.**

In the following sections we first summarize the conclusions that flow from these analyses as they relate to each of the three types of economic costs. Table 11 summarizes the programs within the policy sectors of labour, income security, and health that were evaluated and indicates the potential of each to affect the three types of economic costs: employment-related, out-of-pocket, and labour. We make recommendations about how policies in these sectors might be amended to reduce these costs thereby sustaining the informal care sector.

Table 11. Potential Impact of Policy Instruments on Informal Caregivers' Economic Costs

Policy Instrument	Employment-Related Costs	Out-of-Pocket Costs	Unpaid Labour
Labour policies			
Employment Standards, Family Responsibility Leave	✓	✓	✓
Income security policies			
Employment Insurance	✓	✓	✓
Social Assistance Programs	✓		✓
Old Age Security		✓	
Canada Pension Plan / Quebec Pension Plan	✓	✓	
Veterans Affairs Canada (VAC) Disability Pension		✓	
VAC Attendance Allowance		✓	✓
Guaranteed Annual Income Programs for Seniors		✓	
VAC War Veterans Allowance		✓	
Attendant Care Expense Tax Deduction		✓	
Caregiver Tax Credit (Tax credit respecting the housing of a parent in PQ)		✓	
Amount for Infirm Dependants Age 18 years and older (Amount respecting other dependants in PQ)		✓	
Disability Tax Credit (Amount respecting a severe and prolonged mental or physical impairment in PQ)		✓	
Medical Expense Tax Credit (Refundable tax credit for medical expenses in PQ)		✓	
Tax Credit for Home Support Services (available only in PQ)		✓	

Policy Instrument	Employment-Related Costs	Out-of-Pocket Costs	Unpaid Labour
Health policies			
Physician and Hospital Services		✓	
Prescription Drugs		✓	
Home Care Programs		✓	
VAC Veterans Independence Program		✓	
Adult Day Programs	✓	✓	
Health-Related Equipment and Supplies		✓	
Rehabilitation Services			✓
VAC Health Care Treatment Benefits		✓	

* There is no indication here of the direction of the impact, either positive or negative. For more information, see Eales, J., Keating, N., & Fast, J. (2001). Analyzing the impact of federal, provincial and regional policies on the economic well-being of informal caregivers of frail seniors. (Final report submitted to the Federal/Provincial/Territorial Committee of Officials (Seniors), Contract #219660-UAAlberta-00-2). Edmonton, AB: Author.

Employment-related costs, while often significant and long-lasting, have remained largely outside of public policy. While the majority of Canadian caregivers are in the labour force, few provinces have ‘family responsibility leave’ provisions in their employment standards legislation, leaving most Canadian caregivers at risk of losing their jobs when care responsibilities interfere with employment responsibilities.

While both the Employment Insurance and Canada/Quebec Pension Plan programs protect the incomes of those who must leave the labour force for child bearing and rearing, they lack parallel clauses to protect the incomes of those whose employment is interrupted by adult care responsibilities. Further, social assistance programs are moving from “welfare” to “work” models, intended to encourage people to become more self-reliant by requiring them to seek employment and/or training. In most jurisdictions informal care is discounted as work. Thus most informal caregivers are ineligible for social assistance benefits.

Policy reforms in the labour and income security policy sectors that would reduce caregivers’ employment-related costs include:

- providing family responsibility leave legislation that protects employed caregivers, recognizes the chronic nature of caregiving, and respects the diversity in relationships between informal caregivers and care receivers
- amending EI and CPP/QPP programs so that taking a temporary leave of absence, or retiring early, from the paid labour force because of heavy care responsibilities does not substantially jeopardize carers’ current or future income

Out-of-pocket costs have been incurred by almost half of all caregivers in Canada because of their caregiving responsibilities. The cumulative magnitude of these extra expenses has not been well-documented in Canada. However, our prior analyses suggest that most programs in the policy domains of income security and health have the potential to affect out-of-pocket

expenditures either indirectly through the income of the care receiver, or directly through user fees.

Out-of-pocket expenses related to caregiving are most likely assumed by caregivers of poor seniors. OAS and GIS provide the basic structure to support poor seniors. Eligibility for guaranteed income programs need to be reconsidered given that almost half of unattached women over 65 years and one-third of unattached men over 65 years were living in poverty (Ross, Scott, & Smith, 2000). Programs such as Veterans Affairs Canada's (VAC) disability pension and war veterans' allowance provide veteran clients with an adequate income, thereby enabling them to afford needed supplies and services.

User fees and cost sharing arrangements for home care, homemaker and other home support services, prescription medications, and health-related equipment and supplies, lead to out-of-pocket expenses. However, some programs such as VAC's Veteran's Independence Program and Health Care Treatment Benefit Program, subsidize, in full or in part, the costs of services, medications, medical supplies, and equipment for veteran clients. The VAC Attendance Allowance provides money to hire extra assistance. As a result, the downloading of out-of-pocket costs to informal caregivers of veteran clients is minimized (Keating et al., 2001).

Income tax credits and deductions for medical and disability-related expenses are provided for under federal and provincial income tax legislation. In addition, a caregiver tax credit was introduced in the 1998 federal budget to provide tax assistance to individuals providing in-home care for elderly or infirm family members. Unfortunately, tax credits and deductions have little impact on the out-of-pocket expenses since few caregivers profiled in our previous analyses meet the strict eligibility criteria. It is difficult to ascertain the cumulative impact of tax credits and deductions given the indirect nature and complexity of the tax and transfer system. In general, these appear to be poor vehicles with which to reduce the out-of-pocket expenses of informal caregivers.

Policy reforms in the income security and health policy domains, that would reduce the impact of caregivers' out-of-pocket expenditures, include:

- assuring a guaranteed minimum income for seniors that takes into account regional economic differences in determining amount of financial support provided
- offering a comprehensive program that subsidizes the cumulative cost of health-related services, equipment, and supplies for seniors, and sets a maximum cost-sharing limit that is affordable to most seniors and waived for those who are impoverished
- using eligibility criteria for caregiver tax credits that apply to informal caregivers who experience high consequences, regardless of residency, relationship, or income of the care receiver

The **unpaid labour** of informal caregivers is productive and economically valuable. However, unpaid work often is marginalized in existing Canadian policy. In contrast to other developed countries, Canada has chosen not to directly compensate informal caregivers for their caring work (Fast & Mayan, 1998; Jenson & Jacobzone, 2000). An exception is the VAC Attendance Allowance that provides cash transfers based on assessed need to veteran clients for the purposes of hiring assistance (Keating et al., 2001). Policies that require unemployed caregivers to seek paid employment or for any caregiver to pay for their own respite, also ignore the economic contributions of informal carers. As a result, programs that may influence the unpaid labour costs of informal caregivers fall almost exclusively within the health policy domain. The

two main programs in this area are home care and adult day care. These programs are seen as the mainstay of what has become known as respite services for caregivers. Yet recent research findings show that caregivers often are reluctant to use such services (Chappell & Dow, 2000). Further, when these services are used, they do not reduce the amount of labour of informal caregivers, but divert it to tasks that have remained undone when the caregiver's attention is focussed on the care recipient (Strang, 2000). Thus, such programs do not appear to reduce significantly informal caregivers' unpaid labour costs.

Policy reform in the health and income security policy domains, that would help sustain the unpaid labour provided by informal caregivers, include:

- providing direct financial compensation to unemployed informal caregivers for their caring work
- providing a core set of home care services that would be universal, accessible, and affordable, regardless of jurisdiction
- targeting respite needs of caregivers to sustain informal care by developing services based on caregiver needs, and eliminating fees for short-term replacement services

There is no need to "go back to the drawing board" in order to positively affect the economic and non-economic consequences experienced by caregivers. Existing programs provide the basic structure. The policy reforms recommended above illustrate how existing federal, provincial/territorial, and regional policies can be strengthened so that they better support and maintain the informal care sector. For maximum effect, comprehensive and integrated solutions are better than sectoral ones.

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