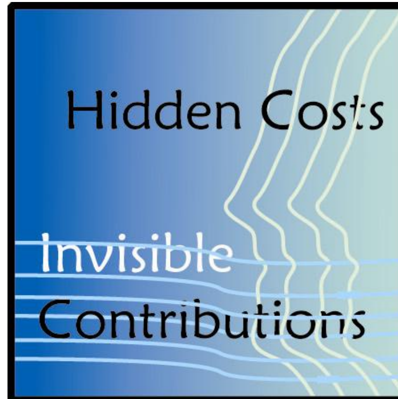

Employed Family/Friend Caregivers to Adults with Disabilities: The Impact of Public Policies on Caregivers' Costs

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Employed Family/Friend Caregivers to Adults with Disabilities: The Impact of Public Policies on Caregiver Costs

Executive Summary

Family/friend caregivers comprise a significant part of the long-term care sector. Most caregivers are employed. There is increasing recognition that while employed caregivers are willing contributors, their involvement in care comes with employment-related and other costs (Fast, Niehaus, Eales, & Keating, 2002). However, little is known about how public policies and programs actually influence the economic and non-economic costs to employed caregivers, particularly those who care for non-senior adults. The purpose of this project was to analyze the impact of federal, provincial/territorial and regional policies in the domains of health, not-for-profit support services, income security, employment, transportation, and housing on the economic and non-economic costs incurred by family/friend caregivers of working age (25-64) who are providing care to adults (aged 25 and older) with disability or chronic illness.

The project involved several steps:

1. Selection of regions and policy domains: Because policy instruments and programs are often delivered regionally, we chose four regions for comparative analysis: Edmonton and Oyen in Alberta, and Halifax and Parrsboro in Nova Scotia. Development of caregiver scenarios: Scenarios were developed to assess how policies would impact employed caregivers in various situations. First, caregiver characteristics were identified that were associated with economic and non-economic consequences of caregiving (from 1996 GSS), and with care receivers' use of family help (from 2001 PALS). Key informants provided additional contextual detail. Proximity of caregiver and care receiver, and disability type of care receiver, were the defining conditions of the scenarios. The resulting scenarios represented: 1) employed caregiver living with her brother with a mental health condition; 2) employed caregiver living with her brother with multiple sclerosis; 3) employed caregiver living at distance from his father with early dementia; 4) employed caregivers living at distance from their daughter with a stroke and 5) employed caregiver living with his wife with cancer.
2. Conducting a scan of federal, provincial, territorial and regional policies and programs in the domains of health, not-for-profit support services, income security, labour/employment, transportation and housing were selected.
3. Conducting the policy impact analysis: The impact analysis used a framework modified from Eales, Keating and Fast (2001). We considered economic (out of pocket, employment, and unpaid labour) and non-economic (emotional and social well-being) costs as described in the cost of care taxonomy developed by Lero, Keating, Fast, Joseph, and Cook (2007).

Policy Scan and Impact Analysis

The policy scan showed that there were policy instruments and programs in place in all regions and domains, although rural regions had less health, transportation and not-for-profit services available. Interprovincial differences were apparent in programs and services for care receivers, such as income support and health (home support and equipment).

All of the caregivers in the scenarios experienced economic and non-economic costs related to caregiving regardless of geographic region.

Employment-related costs (reduced earnings and income benefits, use of vacation or sick leave for caregiving, reduced job security, foregone career advancement) were related to caregivers' employment status (full-time, self-employed, contract employment) and sector employed in, care receivers' disability type and severity and the proximity of caregivers to care receivers. Labour/employment and income security policies and programs only minimally offset caregivers' employment-related costs.

Out of pocket costs (purchases or expenditures for care receivers such as home care, purchases for caregiver such as respite, hotel costs for care receivers, and money transfers) were related to care receivers' disability type and severity; the type and amount of income and health support available to care receivers; geography (rural/urban) and caregiver/care receiver proximity, as well as caregivers' competing demands. Programs that provide services (e.g. for respite, home care, medication, transportation, meals) provided some caregivers with a significant benefit at a nominal fee. However, many of these services are only available to a limited number of caregivers or care receivers and therefore yield no benefit to those who do not meet the eligibility criteria. There are also several programs that provide a financial benefit (e.g. tax credits, funds to purchase assistive devices and transportation to medical appointments) that offset the out-of-pocket expenses incurred by caregivers. However, these benefits tended to be of modest financial value in relation to the cumulative amount of expenditures caregivers typically incur.

Unpaid labour costs (direct care services, supervision, coordination and case management, transportation) were related to care receivers' disability type and severity, caregiver/care receiver's proximity, and geography, which influences the availability of programs and services. While health care programs (particularly home care) had the potential to reduce costs in this area, service limits and eligibility criteria made their effect minimal.

Emotional and social well-being costs (being stressed for time or energy and experiencing worry or depression, social isolation and reduced participation in social and voluntary activities) were related to care receivers' disability type and care needs; presence of competing demands (e.g. employment, care of young children or other dependents); and the caregivers' income and employment status (which affects the extent to which they can purchase supports to reduce the care burden and their access to workplace flexibility). Respite services and not-for-profit sector supports potentially ameliorated some of these costs, however, respite services often had eligibility criteria that precluded their use by people with certain types of disability or illness.

Policy Implications

While policies and programs that may ameliorate caregivers' economic and non-economic costs are in place, many provide minimal benefits to family/friend caregivers. We identified policy and program areas that could be changed to better address employed caregivers' costs in the following areas:

For employed caregivers

- Flexible work arrangements, leave, and earnings replacement
- Home care, respite and day programs that are more responsive to the needs of employed caregivers

For caregivers of adults with disabilities

- Programs that potentially benefit caregivers, such as home care, tax credits, not-for profit support programs, supports for rural caregivers
- Programs that benefit care receivers and therefore indirectly impact caregivers' costs
    - Addressing program eligibility for non-senior adults with cyclical or fluctuating disability (for example, some mental health conditions)
    - Addressing adequacy and regional disparities in income supports, home supports, and equipment funding programs.

Employed Family/Friend Caregivers to Adults with Disabilities: The Impact of Public Policies on Caregiver Costs

Chapter 1. Introduction

A *family/friend caregiver* is a person who provides assistance to a relative, friend or neighbour because of that person's long-term health or physical limitations (Keating, fast, Frederick, Cranswick, & Perrier, 1999). A family/friend caregiver has a personal history with the care receiver (National Advisory Council on Aging, 1990) and is not paid or contracted through a public, private sector or voluntary organization (Eales, Keating, & Fast, 2001). For the purposes of this project, a *care receiver* is a person who receives care from a family member and/or friend because of a long-term illness or disability. Care may take the form of instrumental, emotional, or informational support.

Family/friend caregivers comprise a significant part of the long-term care sector. In Canada, it would cost approximately $24.2 billion to replace the amount of care provided by caregivers aged 45-64 providing care to the older adults (Hollander, Lee & Chappell, 2008). The replacement costs would be considerably higher if the costs to replace the care provided to non-seniors with a health condition were included.

In addition to the economic value, family/friend care also has social value: most care receivers want to live in their community and maintain their connections with family and friends. However, in recent years, family/friend caregivers have been under increasing duress, and strains on the family/friend care sector are becoming obvious (Eales et al., 2001). Population aging, advances in medical technology, and reform in the health and continuing care policy sectors are increasing the demand for unpaid care by family members and friends (Fast & Keating, 2000) while at the same time, concern over public cost containment is prompting policy reforms that further shift responsibility for care from the formal to the family/friend sector (Keating, Fast, Connidis, Penning & Keefe, 1997). As the demand for family/friend caregiving intensifies, additional factors, such as changes in family size, composition, and geographic proximity, may reduce the supply of caregivers, further increasing the pressure on those who remain.

Employed caregivers are particularly vulnerable to these strains. There is increasing recognition that while employed caregivers are willing contributors, their involvement in care comes with employment-related and other costs (Fast, Niehaus, Eales & Keating, 2002). While there are few policy supports in place that are directly targeted to support employed caregivers, there are many public policies, programs and services that have the potential to impact costs that they incur as a part of their care work. However, the net impact of policies on employed caregivers' costs has only begun to be understood. The focus of this project is to contribute to our knowledge of the complexity of costs, and the net impact of public policies and programs on the economic and non-economic costs of employed caregivers.

1.1 Context of this project

This project is part of a Social Science and Humanities Research Council, Major Collaborative Research Initiative entitled *Hidden Costs/Invisible Contributions: The Marginalization of Dependent Adults (HCIC)*). It is part of the HCIC research theme examining the relationship of public policies to the costs and contributions of caregivers and dependent adults.

The purpose of this project was to analyze the impact of federal, provincial/territorial and regional policies in the domains of health, not-for-profit support services, income security, employment/labour, transportation, and housing on the economic and non-economic costs incurred by family/friend caregivers of working age (25-64) who are providing care to adults (aged 25 and older) with disability or chronic illness.

In this project, we built on previous research conducted by the Research on Aging, Policies, and Practice (RAPP) team in the Department of Human Ecology at the University of Alberta, which focused on the economic impact of public policies on caregivers to older adults in the areas of income, labour and health in several regions of Canada. Three reports from these projects provided detailed policy impact analyses of economic costs to caregivers of older adults, with a particular focus on gender as a moderating characteristic of policy impact (Fast, Eales & Keating, 2000); best practices to reduce caregivers' costs (Eales et al., 2001), and policies impacting caregivers of Veterans (Keating, Eales & Fast, 2001). These projects used caregiver profiles (stories) and detailed policy scans to examine the impact of policies on economic costs incurred by caregivers. The research demonstrated the importance of regional differences in programs, as well as several mediating factors such as labour force status, geographic proximity, incomes of caregivers and care receivers, and presence of young children, on the ways in which policies are experienced by caregivers.

Building on methodological and conceptual frameworks developed in the previous studies, this project adds to knowledge gained in previous projects by:

- addressing the complexity of the economic and non-economic costs of caregiving
- focusing on the costs incurred by employed family/friend caregivers aged 25-64
- focusing on those employed caregivers who provide care to younger adults (aged 25 and older) with a disability or chronic illness
- expanding the policy domains examined to include not-for-profit support services, transportation, and housing.

Below, each of these areas is explored as it relates to the focus of this research project.

1.2 The complexity of caregiving costs

The three previous policy impact studies (Eales et al., 2001; Fast et al., 2000; Keating et al., 2001) focused primarily on the economic costs of caregiving. Recently, there has been increasing interest in the non-economic, as well as the economic costs of caregiving. Non-economic consequences include physical, social and emotional costs

such as sleep deprivation, reduced personal time, and strained family and personal relationships. (Fast, Keating & Yacyshyn, 2008; Fast, Yacyshyn & Keating, 2008; Keating et al., 2001).

Lero, Keating, Fast, Joseph and Cook (2007) have developed a taxonomy of economic and non-economic costs of caregiving, depicted in Figure 1.[1] *Economic costs* are costs that use the caregiver's financial resources and include:

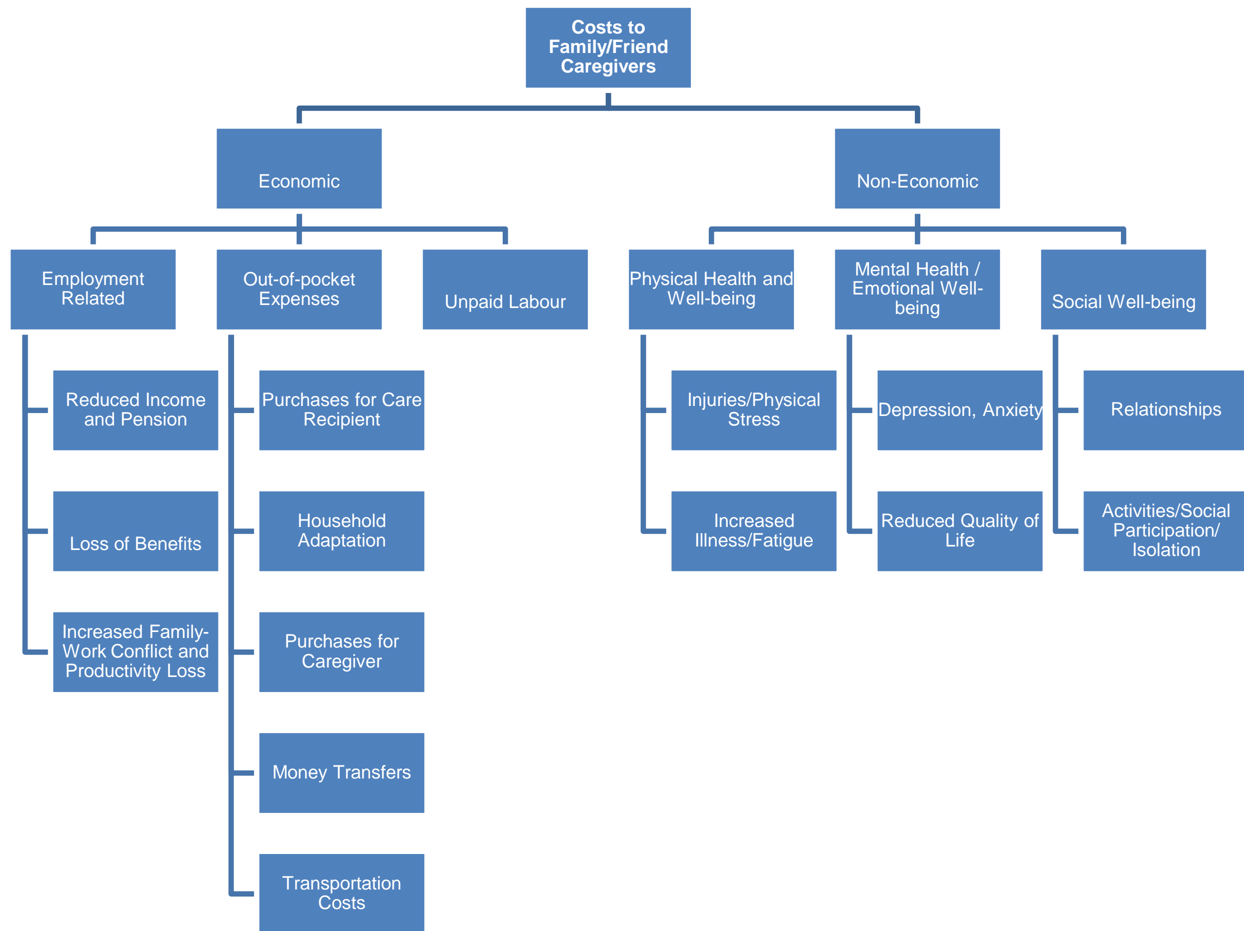
- *Employment-related costs* such as reduced income, lost benefits, and longer-term economic costs due to reduced savings and pension benefits
- *Out-of-pocket expenses* resulting from covering costs for the care recipient and from incurring costs related to the provision of care
- *Unpaid labour costs* resulting from time spent by caregivers in activities such as care management, emotional support and monitoring, and in providing direct services to care receivers. This direct labour, which is increasingly recognized as economically valuable (Hollander et al, 2008), represents an economic cost (Fast et al, 1999).

Non-economic costs are costs that impact well-being and include:

- *Mental health/emotional well-being costs such as depression and anxiety, caregiver strain or distress and reduced sense of quality of life or life satisfaction*
- *Social well-being costs such as social isolation, decreased social activities and disruption of daily routines*
- *Physical well-being costs such as injuries/physical stress related to caregiving tasks, increased illness/fatigue, and decreases in health-promoting behaviours.*

[1] This taxonomy is based on a taxonomy of the costs that may arise from the performance of caregiving tasks originally developed by Fast, Williamson and Keating (1999). The framework identified the set of economic and non-economic costs that family/friend caregivers may experience as a result of providing elder care and builds on Keating and Fast's work on the factors that influence the extent and nature of caregiving provided to seniors in Canada.

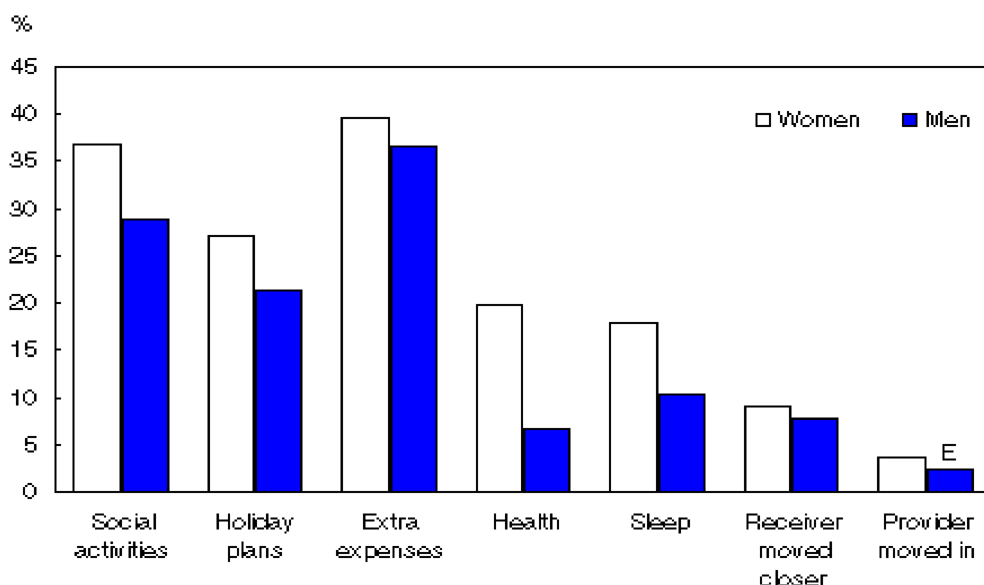
Figure 1. A taxonomy of costs incurred by family/friend caregivers



Source: Adapted from Lero, D.S., Keating, N., Fast, J., Joseph, G., & Cook, L. (2007, March 31). *The interplay of risk factors associated with the negative outcomes among family caregivers: A synthesis of the literature.* (Final report submitted to Human Resources and Skills development Canada (HRSDC) in partial fulfillment of contract #9136-06-0017/00). Guelph, ON: University of Guelph, Centre for Families, Work and Well-being and Edmonton, AB: University of Alberta, Research on Aging, Policy and Practice.

The most recent Canadian national data (limited to caregivers aged 45-64 who provide care to the elderly) illustrates some of the consequences of caregiving outlined by Lero et al. (2007). Figure 2 shows the percentage of caregivers age 45 to 64 reporting economic and non-economic consequences of caregiving in the 2002 General Social Survey. The most frequently reported consequences were had extra expenses and curtailed social activities. A higher percentage of women than men reported costs in all categories. In terms of out of pocket expenses, a substantial proportion of caregivers (44%) incurred significant out of pocket expenses as a result of providing care. Among these caregivers, over two-thirds incurred over $100/month in expenses, with the most common categories of costs being transportation and non-prescription medications (Decima, 2002).

Figure 2. Unpaid caregivers in Canada aged 45-64 who provided eldercare and experienced consequences due to caregiving, 2002



Source: Cranswick, K. (2003). *General Social Survey Cycle 16: Caring for an aging society 2002*. Statistics Canada, Catalogue no. 89-582-XIE. Ottawa: Minister of Industry. Retrieved December 2008 from http://www.statcan.gc.ca/bsolc/english/bsolc?catno=89-582-X

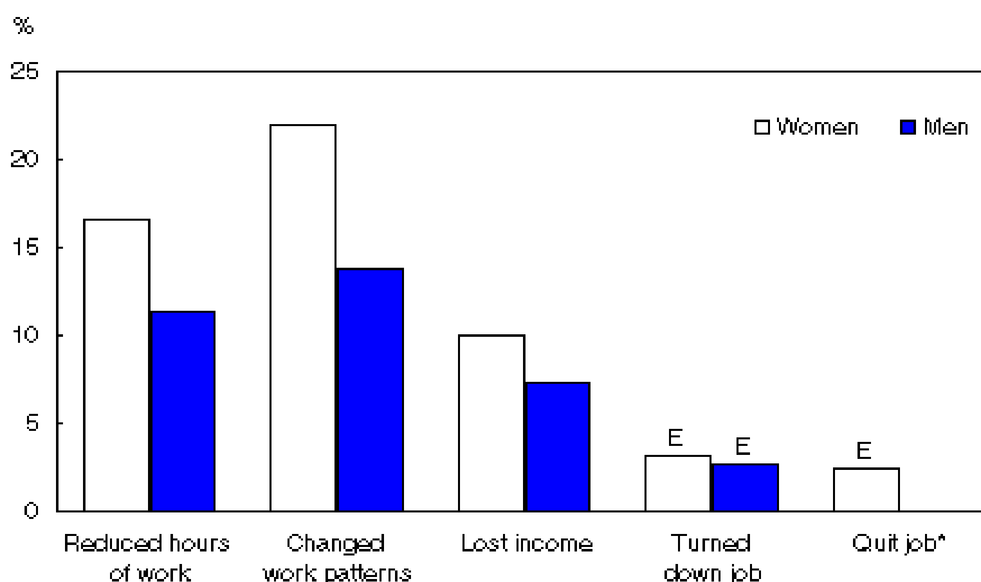
Lero et al's (2007) taxonomy, and the data above, demonstrate the importance of including economic and non-economic costs of caregiving in policy impact analyses. We note that policy impact analysis of economic and non-economic costs of caregiving has an additional layer of complexity besides the consideration of different categories of costs. There is the potential of policy instruments or programs to simultaneously create costs (such as user costs) while alleviating other costs (such as the provision of in-home care, reducing the need for family members and friends to do particular care tasks).

1.3 Employed caregivers' costs

Employed caregivers form the majority of caregivers in Canada (Kemp and Rosenthal, 2001). The three previous policy impact studies ((Eales et al., 2001; Fast et al.,2000; Keating et al., 2001) illustrated the importance of considering labour force status as a factor moderating the way that cost-related policies are experienced.

The most recent Canadian national data (limited to caregivers aged 45-64 who provide care to the elderly) indicated that the most frequently occurring employment adjustments among caregivers are changed work patterns and reduced work hours (see Figure 3).

Figure 3. Unpaid caregivers aged 45-64 who provided eldercare and experienced employment consequences due to caregiving, 2002



Source: Cranswick, K. (2003). General Social Survey Cycle 16: Caring for an aging society 2002. Statistics Canada, Catalogue no. 89-582-XIE. Ottawa: Minister of Industry. Retrieved December 2008 from http://www.statcan.gc.ca/bsolc/english/bsolc?catno=89-582-X

In addition to lost wages, employed caregivers also experience economic costs such as reduced income benefits (e.g. reduced Canada Pension Plan (CPP) or Employment Insurance (EI) entitlements); unavailability of benefits for their intended purpose (e.g. use of vacation or sick leave for caregiving); reduced job security; and forgone career advancement. Employment impacts are important because they affect the short and long term economic situation of the family (Fast, Keating & Yacyshyn 2008, p. ii).

There are few analyses of the monetary value of the lost income and employment-related benefits associated with these adjustments in Canada. The only analysis that has been done on lost wages as a result of eldercare among those aged 20-64 in

Canada (Dosman, Rowe & Fast, 2008) indicated that the annual aggregate lost wages increased from $207 million per year during the period 1997-2001 to $359 million per year during the period 2002-2006. The number of employees experiencing lost wages has nearly doubled in this time period. These results represent lower bound estimates. The figures would be considerably higher if care for non-seniors with a health condition were included, however, data is not available to conduct this analysis.

While employed caregivers incur costs directly related to their employment status, they may actually fare better than their unemployed counterparts, however, since the few benefits that accrue to caregivers in Canada are often tax based. Tax-based initiatives do not address employment or time costs, but may have an impact on out-of-pocket costs. The extent of this impact will be assessed in Chapter 4.

Employed caregivers also incur non-economic costs, stemming from the competing demands of employment and family responsibilities, resulting in time-stress and poorer emotional and social well-being. A survey of Canadian employees in medium to large organizations showed that about one in four employees experiences high levels of caregiver strain as a result of elder care responsibilities (Duxbury & Higgins, 2005). Fast, Niehaus, Eales & Keating (2002) found that employed caregivers reported a higher incidence of health impacts, stress, guilt, out-of-pocket expenses, and social consequences than their non-employed counterparts.

Given the importance of employment status to the economic and non-economic costs experienced by caregivers, this project builds on previous projects by focusing on employed caregivers and considering the impact of particular occupational classifications and status (full time, contract, self-employed) on economic and non-economic costs.

1.4 Caregiving to adult care receivers

While the three previous policy impact studies (Eales et al., 2001; Fast et al., 2000; Keating et al., 2001) examined the costs of caregiving to older adults, this study expands the focus to the costs of caregiving to non-senior adults. Those caring for younger adults with chronic illness/disability may be faced with a lifetime of caregiving and thus experience even more profound consequences for themselves and their families than eldercare providers (Fast, Yacashyn & Keating 2008). Disability characteristics, such as age of onset and type, severity and duration of disability, affect both the likelihood and magnitude of costs experienced and the way policies/programs affect them (Fast, Keating & Yacyshyn, 2008).

An additional context of importance is the caregiver-care receiver relationship. Relationship and proximity of the caregiver to the care receiver may influence the eligibility of each for particular services and programs as well as the nature and magnitude of costs experienced (Lero et al., 2007).

1.5 Policy domains and instruments

Policy domains are broad policy arenas that potentially impact on the costs of caregiving. The 3 previous policy impact studies highlighted the importance of examining direct and indirect policies on caregivers' costs. Direct policies include those initiatives that target a particular group (e.g. caregivers, care receivers, seniors, individuals with disabilities, employees) (Fast et al., 2000). Indirect policies are those that have an unintended positive and/or negative impact on non-targeted, but related, groups. Fewer programs target caregivers than care receivers. Programs for care receivers that indirectly affect caregivers were included because they significantly affect the costs of care for the caregivers in the scenarios.

Previous research demonstrated that labour, income support and health policies were all important to consider for their potential impacts on the economic costs of caregiving. In this project, we expanded the focus to include not-for profit support services, transportation and housing as these programs might directly or indirectly affect the costs that the profiled caregivers incurred.

- *Health* was chosen because of its influence on the types and costs of health services available to care receivers and caregivers.
- *Income security programs were examined because they are often the main source of income for adults with disabilities who need support and are under/unemployed, and therefore impact indirectly on caregiver costs. Income assistance programs, for example, can have an indirect impact on caregivers' economic costs by reducing or eliminating the cost of paying for care receivers' medication, dental care, vision care, etc that care receivers' might need but not be able to afford on their limited income.*
- *Labour/ employment policies were chosen as they impact directly caregivers who may have to adjust their employment in order to provide care. For the purposes of this study, provisions within federal and provincial labour codes were included. Individuals may have additional provisions at their workplace, but these are specific to a workplace or occupation and difficult to gauge.*
- *Transportation and housing were chosen because they may impact on the costs caregivers incur. They are among the most frequently identified unmet needs by persons with disabilities, particularly those with limited income (Statistics Canada, 2003). We limited our exploration of housing policies to those policies that provide for shelter allowances, and those that help to fund renovations to existing dwellings because these are the policies most likely to impact on caregivers.*
- *Not-for-profit sector support services were selected because they are, in some cases, the category of support that most frequently are developed explicitly for caregivers. For the purposes of this study, we focused on five main types of support provided by not-for-profit organizations: information, referral and service navigation; education and training; emotional support or self-help groups; financial assistance for medical travel; and meal programs. It is recognized that other categories of supports are provided by the not-for-profit sector that may*

> *indirectly affect caregivers, such as training or skills development programs for persons with disabilities, but they were not considered in the impact analysis. We limited our scan of these programs and services to those that were primarily targeted to caregivers or respite.*

A *policy instrument* is the technical means of achieving a policy goal (Pal, 2005). The policy instruments examined in this study included legislation, regulations and programs. This project focused on policy instruments in effect in the six policy domains between September 2006 and December 2007.[2]

Many programs are delivered at the regional level. Regional differences in policies and programs have made it difficult for policy makers to understand the impact of policies on caregivers across regions or provinces/territories. Municipal, provincial/territorial, and federal governments have policies and programs that are rarely devised or implemented in partnership. Additionally, the provision of support services by the not-for profit sector (non-government, community organizations) further complicates the ability of policy makers to fully assess policy impacts as these programs exist in an uneven fashion, varying considerably by region and disability/illness type. The end result is a patchwork of government and community initiatives that can have very different impacts, and in some cases no benefit at all, on caregivers depending on their geographic location and the disability/illness of the care receiver.

In this project, we addressed the issue of regional complexity of policy instruments and programs by organizing our policy impact analysis at the regional level. For our purposes, *region* was loosely defined as an area that falls within the boundaries of one province and one health district. We limited the regions in this study to two provinces in order to allow us to conduct an in-depth analysis of policies and their impact. We selected Alberta and Nova Scotia as our two provinces of interest. These two provinces were in different economic situations: Alberta was deficit-free at the time of this study, and rich in opportunities for employment, while Nova Scotia had a provincial deficit of $12.4 billion at the time of this study, had more limited employment opportunities. We wanted to compare urban and rural regions in each province because of our interest in knowing how this context might influence the economic and non-economic costs to caregivers. For example, previous research showed that rural regions often have fewer resources (Dobbs, Swindle, Keating, Eales & Keefe, 2004; Fast et al., 2000) which could impact caregivers' costs because of the need to travel to larger centres for services.

The remainder of this report describes the background, process, and results of our project. In Chapter 2, we describe the methods used in conducting the policy analysis. In Chapter 3, we present our policy scan. In Chapter 4, we report the impact of public policies on caregivers' economic and non-economic costs. Finally, in Chapter 5 we highlight the policy implications of the study.

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[2] It is acknowledged that some programs have changed eligibility criteria and/or benefit levels since December 2007. However, since the latest earnings figures available were from 2007, program criteria and benefit levels from 2007 had to be used so that all information provided was from the same year.

Chapter 2. Methods

The purpose of this project was to analyze the impact of federal, provincial/territorial and regional policies in the domains of health, not-for-profit support services, income security, employment/labour, transportation, and housing on the economic and non-economic costs accrued by family/friend caregivers of working age (25-64) who are providing care to adults (aged 25 and older) with disability or chronic illness.

This chapter describes the method we used to complete the project, including the following steps:

- Developing caregiver/care receiver scenarios
- Choosing and describing regions for the policy impact analysis
- Conducting a scan of federal, provincial and regional policies and programs in the domains of health, income security, labour, transportation, housing, and not-for-profit support services
- Conducting the impact analysis.

2.1 Developing caregiver-care receiver scenarios

Caregiver scenarios were developed so that we could examine the impact of policies on the costs of caregivers in particular contexts or "stories." We planned to develop four to six scenarios of caregivers of employment age who provide care to adults aged 25 and older. We focused on caregivers of employment age (25 to 64) because of the results of previous research (Eales et al., 2001; Fast et al., 2000; Fast et al., 2002) which showed that the policy impact on caregivers' employment-related costs was particularly important. In our scan of policy instruments that indirectly affected caregiver costs through provision of benefits to care receivers, we focused on policy instruments that clearly targeted adult care receivers, rather than youth (age 18-24) care receiver in transition. The task of scanning policies and programs for care receivers transitioning into adulthood would be complex enough to warrant a separate research project, as entitlements and benefits for many programs change once the person turns 18.

2.2.1 Creating skeleton profiles

The first step of creating the scenarios was to develop skeleton profiles based on an analysis of population-based data sets that described caregivers and care receivers.

Analysis of caregiver characteristics

To identify salient characteristics of caregivers for our profiles, we used data from General Social Survey (GSS) 11 (1996). This dataset was selected because it contains information about caregivers and care receivers of age groups of interest to us. More recent GSS datasets have limited sample surveyed to caregivers aged 45 and older providing care to those 65 and older.

We looked at a subset of caregivers, aged 25-64, who have provided care to others in the past year because of long term illness or disability. A total of 863 family/friend caregivers were identified from the 1699 caregivers in the dataset.

Our initial exploration of the dataset revealed that most (71.5 per cent) caregivers gave care to more than one care receiver aged 25 and older with a long term illness or disability. Thus, variables relating to care receivers were collapsed so that each variable represented the proportion of total care receivers with a particular characteristic.

We used CHAID (Chi-squared automatic interaction detection) analysis to identify the characteristics that best distinguished groups of respondents on a dependent variable. The characteristics of interest, or explanatory variables, were selected based on past research projects (Eales et al., 2001; Fast et al., 2000) and were also identified in a literature review by Lero et al. (2007) as important risk factors in experiencing negative consequences of caregiving. The dependent variables we used approximated the costs of caregiving that Lero et al. (2007) describe in their taxonomy: out-of-pocket costs (economic impact), employment costs (work pattern changes, job/education postponements), unpaid labour (amount of time providing care), emotional burden, social consequences, and physical burden. Table 1 describes the dependent variables.

Explanatory variables are listed in Table 2. CHAID analysis looks for the explanatory variable which best differentiates groups of respondents on a given dependent variable. We did a separate CHAID analysis to examine the characteristics that best distinguished respondents experiencing each consequence outlined in Table 1.

Table 1. Dependent variables: Consequences of caregiving

Dependent variable	Definition	Caregivers in sample experiencing consequence
Work pattern changes (n=655)	The extent to which employed respondents made changes to work in order to meet caregiving demands such as changing jobs or leaving work, changing hours of work, coming late or leaving early, missing a day or more, or effects on work performance	51%
Job/education postponements (n=856)	Opportunities delayed or foregone such as having to postpone education or training, turn down a job offer, or decline a job transfer or promotion	15%
Social impact (n=856)	Experience of social impacts of caregiving including changed social activities, changed holiday plans, having to move in with or move closer to the care receiver	57%

Economic consequences (n=856)	Caregiver had expenses related to caregiving	48%
Emotional burden (n=856)	Psychological and emotional hardships arising from caregiving including not enough time for self, wishing someone would take over, feeling angry, feeling stressed in helping others, and overall burden	34%
Physical consequences (n=856)	Experience of physical consequences of caregiving: health or sleep patterns affected	40%
Amount of time providing care	Total minutes per week spent in child care, meal preparation, housework, shopping and errands, personal care for all care receivers	Mean = 305 minutes SD = 857.8

Table 2. Explanatory variables used in CHAID analysis (derived from GSS)

Explanatory variable	Description
Gender of caregiver and care receiver	Male
	Female
Relationship of caregiver to care receiver(s)	Spouse
	Sibling
	Adult child
	Extended family
	Friend
Geographic proximity of caregiver to care receiver(s)	Same household or neighbourhood
	Same community
	Less than half day away
	More than half day away
Caregiver's main activity	Working
	Looking for work
	Going to school
	Keeping house/child care
	Long-term illness
	Retired
Children under age 15	0
	1
	More than one
Children aged 15-24 at home	Yes
	No

Number of care receivers	1-9
Caregiver age	25-44
	45-64
Care receiver age	25-44
	45-64
	65-84
	85+
	Deceased

A matrix of the CHAID analyses results show that different results were obtained for each dependent variable, but that some explanatory variables appeared in multiple analyses.

Table 3. Results of the CHAID analysis

Dependent variable	Strength of the explanatory variable		
Consequences of caregiving	First order variable	Second order variables	Third order variables
Economic consequences	Half a day away	Care receiver deceased or young (25-44)	Further results ambiguous
Job/educational postponements	Female caregiver	Younger caregiver	Further results ambiguous
Emotional burden	Female caregiver	Caregiver has children 15-24 or Caregiver is a day away	Further results ambiguous
Social consequences	Half a day away	If YES - caring for parent or parents If NO - young (25-44) care receivers	Further results ambiguous
Work pattern changes	Caring for multiple parents	Care receiver deceased	Caregiver half a day away
Physical consequences	Caregiver female	Care receiver male	Caregiver half a day away
Amount of time providing care	Care receiver deceased	Caregiver half a day away	Caregiver is homemaker or looking for work

Economic consequences (expenses related to caregiving) seem to be experienced by caregivers providing care from a distance. *Job/educational postponements* were experienced by younger (25-44) women, unless they are caring for parents. *Emotional burden* was experienced by women in a variety of situations. *Social consequences* related to proximity and caring for parents, or to caring for younger care receivers. *Work pattern changes* were experienced by those with multiple caregiving responsibilities, those caring for spouses, or those caring for a terminally ill person. *Physical consequences* were experienced by women, particularly those caring for men. *Amount of time providing care* was highest for caregivers to terminally ill care receivers or those caring at a distance.

The explanatory variables that best distinguished between groups of caregivers, and related to more than one consequence of caregiving, were gender of the caregiver (female) (appearing three times), and the caregiver's proximity to the care receiver (appearing six times)[3]. Proximity was related most strongly to out-of-pocket costs and social consequences, but also to changed work patterns, physical consequences and time spent in care activities. Being female was related to physical and emotional consequences and job/education postponements.

Analyses of care receiver characteristics

To look for the characteristics that best distinguished adults 25 and older with a disability who receive help from friends or family from those who do not receive help from friends or family, we used the Participation and Activity Limitation Survey (PALS) 2001 dataset. PALS is a population-based post-census survey of Canadians with activity limitations. This dataset contained records for 35,000 adults, from whom we selected 17,665 people whose everyday activities were limited because of disabilities and were aged 25 and older.

We used CHAID analysis to identify the variables that best explained receipt of help from friends and family. The explanatory variables selected are listed in Table 4. These variables were chosen because descriptive analyses showed that they distinguished between people with disabilities who received vs. did not receive help from friends and family.

[3] Although "care receiver deceased" also appeared several times in the CHAID analysis, this result should be interpreted with caution. "Care receiver deceased" was actually an age category and thus it is difficult to interpret how it might relate to caregiver consequences. Also, given that most care occurs in the final year of life, the variable may have been functioning as a marker for intensity of care.

Table 4. Explanatory variables used in CHAID analysis of receipt of help from friends and family (derived from PALS)

<table>
<tr><th>Characteristic</th><th>Variables</th><th>Categories of description</th></tr>
<tr><td rowspan="4">Age</td><td rowspan="4"></td><td>25-44</td></tr>
<tr><td>45-64</td></tr>
<tr><td>65-84</td></tr>
<tr><td>85+</td></tr>
<tr><td rowspan="2">Gender</td><td rowspan="2"></td><td>Male</td></tr>
<tr><td>Female</td></tr>
<tr><td rowspan="12">Severity of disability</td><td>Number of underlying conditions</td><td>0-6</td></tr>
<tr><td rowspan="4">Global severity scale (considering all disabilities)</td><td>Mild</td></tr>
<tr><td>Moderate</td></tr>
<tr><td>Severe</td></tr>
<tr><td>Very severe</td></tr>
<tr><td rowspan="5">Duration of limitation</td><td><1 year</td></tr>
<tr><td>1-2 years</td></tr>
<tr><td>3-4 years</td></tr>
<tr><td>5-10 years</td></tr>
<tr><td>11-19 years</td></tr>
<tr><td rowspan="2">Condition existed at birth?</td><td>Yes</td></tr>
<tr><td>No</td></tr>
<tr><td rowspan="9">Type of disability</td><td>Hearing
Seeing
Speech
Mobility
Agility
Pain
Other</td><td>For each disability type:

No disability
Less severe
More severe</td></tr>
<tr><td rowspan="2">Underlying - mental retardation of mental disorder</td><td>Yes</td></tr>
<tr><td>No</td></tr>
<tr><td rowspan="6">Cause of condition</td><td>Disease or illness</td></tr>
<tr><td>Aging</td></tr>
<tr><td>Work conditions</td></tr>
<tr><td>Stress</td></tr>
<tr><td>Accident</td></tr>
<tr><td>Other cause</td></tr>
</table>

Marital status		Divorced
		Married/common-law
		Separated
		Single
		Widowed
Number of children	Number of children	1 child
		2 children
		3 or more children
Respondent's main activity	Labour force status	Employed
		Unemployed
		Not in labour force
	Attending school or university	Yes
		No
		n/a
Equipment use	Use assistive devices	Yes
		No
Economic status	Low income status	Yes
		No
	Employment income	Amount (categories)
	Household income	Amount (categories)
Dwelling type		Owned
		Rented
Decision-making control		All decisions about everyday activities
		Majority of decisions
		Some decisions
		No decisions

The CHAID analysis showed that the characteristics that best differentiated those who received versus did not receive family/friend help were the type of disability (agility/pain, mobility, and other [includes mental illness]), gender, dwelling (owned or rented) and income source (receipt of a public disability pension).

Determination of characteristics to include in skeleton profiles

In order to keep within our goal of developing four to six profiles, the decision was made to present key informants with two characteristics that emerged as the strong explanatory variables from the CHAID analysis: proximity of caregiver to care receiver, and disability of care receiver.

- Caregiver-care receiver proximity: we focused on caregivers who were half a day away because of the importance of this factor in the CHAID analysis. We also

included co-residence as a way show the contrast between living half a day away and cohabitation. Previous research showed that cohabitation is a factor related to employment-related costs such as changing work patterns (Walker, 2005).

- Care receiver's disability: pain/agility and mental health impairments were both included. Mobility was not included as a separate category of disability because it is often occurs concurrently with pain/agility conditions (Canada Council on Disability, 2005).

While gender was a significant explanatory variable in both cases, the effect of gender on caregiving costs and policy impacts costs has been well documented in previous studies (Fast et al, 2000). Thus we decided to focus on caregiver proximity, the most frequently occurring explanatory factor in the CHAID analysis of consequences of caregiving. We decided that all profiles would have caregivers who were employed, given the focus on working age caregivers and our interest in highlighting policy impact on employed caregivers.

The following four skeleton profiles were developed:

- Profile 1. Caregiver is employed and lives with care receiver. The care receiver has a mental health condition.
- Profile 2. Caregiver is employed and lives with care receiver. The care receiver has a pain/agility condition.
- Profile 3. Caregiver is employed and lives a half day's drive from care receiver. The care receiver has a mental health condition.
- Profile 4. The caregiver is employed and lives a half day's drive from care receiver. The care receiver has a pain/agility condition.

2.2.2 Key informant consultation

The next step in developing the scenarios was to consult with key informants in order to develop the skeleton profiles into caregiver scenarios. To do this, we conducted a key informant consultation similar to that done in the previous profile-based policy impact studies (Fast et al., 2000). Key informants drew on their experience with caregivers and persons with disabilities to describe caregiver and care receiver characteristics and contexts for each skeleton profile.

Identification of key informants

Through use of our contacts in RAPP and in each region of the study, we identified key informants who could travel to Edmonton for a two day workshop to assist us in developing the scenarios. Key informants were selected based on their familiarity with caregiver issues and with the regions represented by our project. A total of five key informants were invited: three from Nova Scotia and two from Alberta. Between them they represented service providers and caregiver support organizations at provincial and regional levels. Consultants had diverse disciplinary backgrounds and extensive experience in providing services and supports to caregivers and persons with

disabilities. They are listed in Appendix B. In addition, three research team members participated in the meetings as facilitators. All had experience as family caregivers, and two had experience as service providers to persons with disabilities and family caregivers.

Consultation meeting to develop scenarios

The two day consultation meeting to develop the scenarios was held in Edmonton in the spring of 2006. Participants were provided with a preliminary information package outlining the purpose and process of the meetings. The meeting started with a review of the overall project and an explanation of the process that would be used to generate the scenarios. Informed consent of the consultants was collected at the beginning of the meeting. Meeting sessions were audio-recorded.

Key informants were given the skeleton profiles. In addition, they were given a longer list of characteristics for consideration when personalizing the profiles (see Table 5). The list was based on study parameters (for example, ages of caregivers and care receivers) and variables that had emerged as important from the CHAID analyses and previous research about caregiver and care receivers. Key informants were also provided with a sample profile from a previous study to give an idea of the level of detail sought in the profiles.

Table 5. Characteristics for key informants' consideration in developing scenarios

Caregiver	Care receiver
• Tasks caregiver assists with • Time spent providing care • Types of unmet needs • Gender • Age (between 25 – 64) • Marital status • Dwelling resided in (owned or rental) • Other caregiving responsibilities • Consequences incurred as a result of caregiving (employment, out-of-pocket expenses, health, social life)	• Specific medical condition associated with disability • Tasks they need assistance with • Types of unmet needs • Sources of income (employment, social assistance, disability benefit (public, insurance) • Gender • Age (between 25-64) • Marital statu • Dwelling resided in (owned or rental)

Table 6. Questions guiding scenario development

Tell us about someone you know with these general characteristics.	How old are they?
	What is their family like? Immediate family? Extended family?
	Where do they live? With whom?
	What do they do besides caring for a family member or friend?
	• Who are they caring for (including how many people)? • What is the care receiver like? • What is their relationship to the care receiver? • What type(s) of disability does the care receiver have?
Tell us about their experiences.	What do they do for the care receiver?
	How much time do they spend doing it?
	Who pays for the services the care receiver gets?
	Who else helps? With what? How do they feel about the help they are getting?
	What services are available to help with caregiving or other responsibilities?
Tell us about how caregiving has affected their lives.	Has caregiving affected their employment? In what ways?
	Has caregiving affected their social life? In what ways?
	How has caregiving affected their health? In what ways?
	How has caregiving affected their finances? In what ways?
	Has caregiving affected their independence, or control over their own lives? In what ways?
	How are they feeling? Guilty, worried, angry, sad, overwhelmed, happy, fulfilled? Why?
	How do they feel about the other help (formal help or help from family members) that they are receiving?

The consultation started with an extensive general discussion of the questions for scenario development as they related to each key informant's experience and region. After this, key informants developed the first three scenarios on the first day of the meeting, by working through the questions posed in Table 6. Flip chart notes were made on each scenario to ensure that salient details based on Table 5 and Table 6 were recorded. Key informants reviewed each scenario at the end of the first day. After the meeting, the researchers developed one-page scenarios based on the discussions that occurred.

On the second day, the one-page scenarios were reviewed to ensure that details of the skeleton profiles were still present, that scenarios were based on composites of characteristics, rather than potentially-identifiable real-life cases, and that the scenarios would be realistic and applicable in the four identified regions. Scenarios were also edited by key informants for readability and reflection of true-to-life contexts.

Extensive discussion occurred the second day about the situations represented by the first three scenarios. The first two scenarios were the same in all aspects except that the care receivers had different disability types (Skeleton Profiles 1 and 2). The third scenario described a husband and wife looking after their adult daughter at distance (Skeleton Profile 4). Key informants expressed the opinion that the breadth and complexity of employed caregiver situations that they typically experienced would not be represented by simply providing another case that mirrored the third one in all aspects but disability type. They noted the complexities of policies, particularly those of health and income support programs, in their regions. Key informants considered factors that they believed were important to represent, which included:

- At least one case that involved care to an older adult
- At least one case that involved a care receiver with a serious illness and an uncertain prognosis (a diagnosis of cancer)
- At least one case that involved a caregiver whose work was sporadic or seasonal.

Therefore, key informants were given latitude to create scenarios that did not mirror each other – that is, they did not have to use identical caregiver characteristics for profiles 1-2, and profiles 3-4. This decision was made in order to allow key informants to share a wider diversity of caregiver/care receiver situations**.** Since our objective was to analyze impact of policies on caregiver economic and non-economic costs, we anticipated that we could proceed by analyzing the impacts of policies on the costs to the caregiver in each individual scenario, rather than relying on the cross-case comparison method of the previous studies.

A decision was made to focus the fourth scenario (Skeleton Profile 3) on portraying a situation in which a caregiver was providing care to an older adult, since other scenarios had focused on younger care receivers. A fifth scenario was also created on the second day, focusing on a caregiver whose work was seasonal providing care to a care receiver with cancer who had an uncertain prognosis. This fifth scenario was based on characteristics outlined in Skeleton Profile 2. Flip chart notes were made for each scenario in the morning, and were converted by the facilitators into one-page profiles for key informants to review in the afternoon.

Scenario revisions

Scenarios were revised to clarify story lines, based on team member feedback. In 2007 and 2008, some details were added to the case studies, in order to facilitate the policy impact analysis. For example, detail was added regarding the care needs of care receivers in some scenarios, in order to clarify whether eligibility requirements for some

programs and services would be met. Further adjustment was made in the profiles in November 2008, to ensure that a more typical range of salaries and work classifications were represented by the scenarios. In order to do this, the 2006 Census was consulted to identify the most frequently-occurring employment classifications, and the median incomes for men and women in Alberta and Nova Scotia. Classifications representing low to mid incomes, while maintaining the integrity of the scenario regarding other characteristics of employment (sector, hours of work) were selected for scenarios 1, 2, and 3, to replace the higher income classifications that had previously been used in these scenarios. One scenario was further revised in December 2008 in order to clarify timelines and details regarding the care receiver's disability.

2.2.3 Scenarios

Below are the five scenarios that were developed:

Scenario 1: (built on Skeleton Profile 1, working caregiver living with care receiver who has mental health condition)

Evelyn: Caregiver to her brother with bipolar disorder

Evelyn is in her mid-50s. She is a single mother of a teenage son who lately has been getting into some trouble with the law. They live in her mother's house with her 75 year old mother, and 47 year old brother Carl, who is diagnosed with bipolar disorder. Evelyn is Carl's main caregiver, and she has a full-time job working shifts as a homemaker for a home care agency.

Evelyn's brother, Carl, has had bipolar disorder for 25 years. He is divorced and his ex-wife and children live in another province. Carl does not consistently take his medications, so experiences dramatic mood swings that affect his ability to work. He has not worked at all in the past year. Carl has been very sporadically employed in retail stores, but qualifies for provincial income assistance. He has debts from overspending during the "highs" of his illness, often buying lavish gifts for his children. His illness means he has not been able to sustain many friendships, and he relies on his family for emotional, financial and health support.

Evelyn takes care of almost all the household chores for the family and does all the financial management using her income and her mother's pension, which is limited to the federal Old Age Security and Guaranteed Income Supplement benefits, to make ends meet. Evelyn is in a state of constant worry about her brother and her son. Evelyn's mother, who is in good health, is able to do some of the household chores such as getting breakfast and lunch, and to supervise Evelyn's son and Carl in their activities at home. Evelyn monitors Carl's medication compliance and mental state, and gives him encouragement. She tries to attend his medical appointments to ensure that his health provider has an accurate

picture of how he is doing. Evelyn has used most of her sick and vacation days to provide assistance to Carl because her work hours are inflexible. She has tried to find services to help Carl, but has found little that is available without a long waiting list. One aspect of Carl's illness that frustrates Evelyn is his limited awareness of his illness. At times, this has resulted in Carl saying he does not need professional or family assistance.

The stigma surrounding mental illness is difficult for Carl and his family, and is one reason Evelyn invites few people to her home. Planned outings are often not possible because Carl's mental state fluctuates. The difficult symptoms associated with his illness sometimes cause embarrassment to Carl's family.

Evelyn is starting to feel worn out and to resent Carl's effect on her life. She feels she is need of a break, but service providers have indicated she is not eligible for respite services because they do not consider Carl to be completely dependent on her for help, and because she is employed. Evelyn and her mother cannot afford private services because they have been spending their money covering Carl's financial excesses. Lately, Carl has been determined to move out on his own and Evelyn is worried that he will not be able to manage living on his own and paying his bills.

Scenario 2: (built on Skeleton Profile 2, working caregiver who lives with care receiver who has a pain/agility condition)

Evelyn: Caregiver to her brother with multiple sclerosis

Evelyn is in her mid-50s. She is a single mother of a teenage son who lately has been getting into some trouble with the law. They live in her mother's house with her aging mother and her 47 year old brother Frank, who is single and has multiple sclerosis (MS). Evelyn is Frank's main caregiver. Evelyn has a full-time job working shifts as a homemaker for a home care agency.

Frank was diagnosed with MS eight years ago. He was self-employed most of his adult life, but had to close his business and is now unemployed. He has no savings because he had put most of his profits back into the business, but he receives a small income through the provincial income assistance program for persons with severe disabilities. His MS recently flared up and he is now unable to walk more than a few steps. He uses a wheelchair obtained from a local equipment loan program, and can transfer himself in and out of the wheelchair but occasionally falls. Their house is an older two-storey home with narrow doorways and steps up to the front door. Because the bedrooms and bathroom are upstairs, Frank stays in a makeshift bedroom on the main floor and uses a commode and urinal. Frank is occasionally incontinent at night, and has some difficulty using his hands. Frank appears to be

depressed and does not often leave the house. He gets on well with his family, but his friends from the business world have drifted away.

Evelyn takes care of almost all the household chores for the family and does all the financial management using her income and her mother's pension, which is limited to the federal Old Age Security and Guaranteed Income Supplement benefits. Evelyn is in a state of constant worry about her brother and her son. Evelyn's mother, who is in good health, is able to do some of the household chores such as getting breakfast and lunch, and to supervise Evelyn's son and Frank in their activities at home. Evelyn appreciates the help her mother gives, but it is not enough to manage. Evelyn gives Frank a daily injection of medication for his MS and ensures that her mother or son is in the house to help him while she is at work. A home care worker comes in the morning for an hour to get Frank out of bed, washed and dressed. Evelyn wants her son at home on the evenings she works because he is able to lift Frank if he falls. While Evelyn's son is fond of Frank, he resents having to be home in the evenings. He would happily take Frank on outings but the car is not always available.

Evelyn thinks the house needs to be renovated for Frank to better accommodate his limited mobility, but is not sure what needs to be done or how she would pay for it. She has no flexibility with her work schedule, and uses sick or vacation days whenever she has to accompany Frank to a medical appointment. Evelyn rarely goes on social outings. Evelyn would like to see Frank develop a life of his own, but recognizes that his condition will likely worsen.

Scenario 3: (built on Skeleton Profile 3, working caregiver who lives at distance from care receiver with mental health condition)

Arif: Caregiver to his father

Arif is in his late 20s. His father Dev is experiencing confusion and forgetfulness. Arif is a commission-based sales clerk in a retail store, and is considering moving in with his girlfriend. They live a five hour drive away from Dev. Arif has one sister, who lives in another province with her young family.

Dev is 68 and widowed, and lives in his own home. He recently retired with a very comfortable retirement income, including full CPP, private pension and investment income and benefits. Arif, and Dev's only close friend Jim, who is retired, recently noticed that Dev misplaces items, gets lost while driving familiar routes and occasionally forgets to eat or bathe. Arif has started calling Jim regularly to find out how Dev is doing. Arif is wondering if his father has Alzheimer's disease.

Arif used to visit his father monthly, but since he noticed the changes, visits every two weeks. Occasionally, he takes a day off work to be in his father's town on a weekday, so that he can do his father's banking and help with other daytime appointments. Arif is trying to arrange a meal service and an accountant to help Dev with his financial affairs. Since Dev is physically fit, he has little contact with his doctor and is unwilling to have a thorough assessment, but Arif is trying to arrange appointments for him.

Arif has thought about looking for information about his father's condition, though he is having a hard time accepting the changes his father is going through. He finds himself unable to talk about his concerns with anyone other than his sister. Both siblings are worried about Dev's lack of awareness or willingness to discuss the changes he is undergoing. Arif anticipates that his father will need increasing amounts of help managing with daily living, and eventually will not be able to live alone. While his sister is supportive, she does not have time or money to travel to Dev's more than once a year.

Arif's absences from work and time spent helping his father are not making a good impression on his manager. Arif is worried that his job and his relationship with his girlfriend will suffer if this continues. His trips home and distractions while at work are starting to add up cost-wise. He is worried about how to raise the matter with his employers if Dev's situation worsens and he needs more time away from work.

Scenario 4 (built on Skeleton Profile 4, working caregiver who lives at distance from care receiver with pain/agility condition)

Jim and Joan: Caregivers to their adult daughter

Jim is 50 and Joan is 47. They are married, and have demanding jobs – Jim as a college teacher and Joan as a financial manager for a large retail outlet, which requires extensive travel. Their daughter Melissa, 26, lives in a town that is a four hour drive away. Jim and Joan have two younger children who live with them.

Melissa had a stroke one year ago. She has paralysis on the right side of her body and has difficulty walking, using her right arm and managing household chores. With therapy, her ability to speak has improved but she communicates with difficulty. Melissa is sometimes frustrated and tearful, not knowing whether she will walk or regain her full ability to speak again.

Before her stroke, Melissa worked in office jobs and had a lively social life, volunteering and acting in a theatre group in her home community. Recently, after a long period of rehabilitation, Melissa moved back to her home community, where she is determined to live on her own.

Jim, who was on sabbatical at the time of her stroke, has taken time away from his work to be constantly available for the past year, participating in her therapy sessions and then helping her to find an apartment and move in. He will soon be returning to work.

Joan has tried to arrange a flexible work schedule so she can take a few days at a time to help Melissa get to appointments, manage her apartment and arrange in-home support. They are looking into getting some additional renovations made to the apartment entryway and bathroom to improve accessibility. The building owner has agreed to modify the apartment as long as they agree to cover the costs.

Taking time off is not easy for Joan as she has to travel frequently. Since Jim will be returning to work, Joan is contemplating requesting a leave of absence from her job for a few months to make sure that Melissa is well set up in her apartment. She is worried about how this will affect their finances, and has not heard of any of her colleagues requesting a leave. Joan wonders if a leave would be approved, and if it would decrease her chances for the promotion she was anticipating.

Melissa, Joan and Jim have been advised that Melissa can expect to continue recovering for two years, eventually regaining her ability to speak and work, but that she will continue to have mobility difficulties. Jim and Joan feel that it is important to help Melissa settle back into her community although they wish she would move in with them. They cannot imagine how she will manage on her social assistance income. Jim and Joan are worried about how they will manage to help Melissa with extra expenses until she can work again, and to meet the needs of their other children.

Scenario 5: (built on Skeleton Profile 2, working caregiver who lives with a care receiver with a pain/agility condition)

Luc: Caregiver to his wife

Luc is in his mid-30s. He is the caregiver to his wife, Noelle, who is 29 years old and has not worked outside the home. They have three children aged 8, 5 and 1. Luc is a contract worker in a seasonal job, working long hours in a neighbouring community during the summer and fall, and staying home the rest of the year.

Noelle has ovarian cancer and has received treatments over several months. When Noelle has a course of chemotherapy, she becomes very sick and requires help to perform routine tasks such as cooking, housework and taking care of the children. When Noelle is not receiving chemotherapy she is able to look after the children but is too weak to manage the house work other than cooking simple meals. Luc is able to take care of these tasks in the months he is not working.

Luc and Noelle's parents live in the same community and are very helpful. Noelle's parents both work but limit their hours in order to provide care, while Luc's parents, who are not in good health, are not able to help as much. Luc and Noelle have a strong support network through their religious community and siblings. The family has one vehicle which makes it difficult to arrange children's activities alongside the frequent trips for Noelle's treatment.

Luc is trying to keep a stiff upper lip for his wife and children, but he is on an emotional roller coaster because Noelle's care needs fluctuate, making it difficult to arrange care services and work schedules. On occasions when Noelle has needed intense amounts of care and no one else is available, Luc has not gone to work. This is creating problems with his employer, who is used to counting on Luc to work extra hours whenever needed. Luc is worried about how they will manage at his job if Noelle needs more care.

Luc is starting to feel overwhelmed and burnt out. He has been told that the prognosis for his wife is guarded and that the cancer may return. He does not know how long Noelle will live so he wants to spend as much time with her as possible. While his earnings are typically quite good, money is becoming tight because he has not worked as much as usual. The family is under additional financial stress because they have to cover some medication costs associated with Noelle's treatment.

An analysis of scenario characteristics is provided in Table 7. The scenarios generated in this study illustrate the following types of diversity, found to be important in previous research about the costs of caregiving (Lero et al., 2007), such as age, gender, relationships, family situations, and the presence of multiple caregivers. The scenarios also provide diversity in employment situations, an important characteristic in understanding the policy impacts on economic and non-economic costs to employed caregivers.

Table 7. Summary of scenario characteristics

Scenario	Proximity	Care receiver has a	Care receiver is a	Gender and age of caregiver	Gender and age of care receiver
1: Evelyn (Frank)	In home	mental health condition (bipolar disorder)	Sibling	Female, mid adult (45-64)	Male, mid adult (45-64)
2: Evelyn (Carl)	In home	Mobility/agility/ pain condition (multiple sclerosis)	Sibling	Female, mid adult (45-64)	Male, mid adult (45-64)

3: Arif	Half day away	Mental health condition (dementia)	Parent	Male, young adult (25-44)	Male, older adult (65+)
4: Jim and Joan	Half day away	Mobility/agility/ pain condition (cerebrovascular accident [stroke)]	Adult child	Male and female, mid adult (45-64)	Female, young adult (25-44)
5: Luc	In home	Mobility/agility/ pain condition (cancer)	Spouse	Male, young adult (25-44)	Female, young adult (25-44)

Table 8 provides an examination of the prevalence of the situations that the caregiving scenarios represent. The table shows the prevalence of care relationship and proximity for each scenario from the 1996 GSS dataset used for this study. It also shows the prevalence of the occupational categories represented in each scenario. PALS data indicated that of those respondents who received help from a family member or friend, 77% of respondents had a pain condition, 78% an agility condition, 83% a mobility condition, and 32% had an "other" condition (including mental health conditions).

Table 8. Population prevalence of scenario characteristics

Scenario	**Prevalence of relationship and proximity characteristics** in 1996 GSS (limited to caregivers of employment age providing care to people aged 25+)	**Rank of employment category** (2007 Canadian Census data) (1= most frequently occurring category)
1: Evelyn (Frank)	8% of caregivers lived in the same neighbourhood and cared for a sibling	Home support worker Sales and service occupation ranked 1 for women
2: Evelyn (Carl)	8% of caregivers lived in the same neighbourhood and cared for a sibling	Home support worker Sales and service occupation ranked 1 for women
3: Arif	19% of caregivers lived ½ day away and cared for a parent	Commission-based sales Sales and service occupations ranked 2 for men
4: Jim and Joan	2% of caregivers lived ½ day away and cared for a child	Jim--college teacher Occupations in social science, education ranked 8 for men Joan—financial manager Management occupations ranked 5 for women
5: Luc	28% of caregivers lived in the same neighbourhood and cared for a spouse	Seasonal contract worker Occupations in primary industry ranked 6 for men

2.2.4 Assigning scenario caregiver and care receiver incomes

Many policy instruments are programs that are income tested, but testing may be based on the income of the person with the disability, the caregiver, or family income. Because of this, we had to calculate incomes of the caregivers, care receivers, and other family members involved in each case.

To calculate caregiver incomes from employment, we used the Service Canada Labour Market Information database. This database contains 2007 hourly salaries for occupational classifications by region. This source for incomes was selected because we could obtain the most recent (2007) incomes, by occupational groups and regions. We calculated yearly gross salaries based on a 40 hour work week. To calculate Luc's income in Scenario 5, we used the average EI benefits received (weekly amount and duration) within the province for workers in the job classification of *contractors, operators and supervisors in agriculture, horticulture and aquaculture – male (I01)* (personal communication) and estimated annual employment earnings based on EI earnings. To calculate caregiver and care receiver incomes from income support programs, we used 2007 figures for these programs obtained from relevant websites and/or email and telephone communication with program representatives. Eligibility for programs was confirmed by contacting program representatives as needed. The incomes used for each scenario are presented in Appendix C.

2.2 Choosing regions for the policy impact analysis

Edmonton, Alberta and Halifax, Nova Scotia were selected as the urban regions because each is the capital city of its province. *Halifax Census Metropolitan Area* is located in south central Nova Scotia and includes the cities of Halifax, Dartmouth, and the town of Bedford. It has a population of about 373,000. The 2006 unemployment rate was 6.3 per cent. *Edmonton Census Metropolitan Area* is located in central Alberta. It has a population of just over 1,000,000 people. The 2006 unemployment rate was 4.6 per cent.

Oyen, Alberta and Parrsboro, Nova Scotia were selected as the two rural regions partly because they had been used as focal communities in previous research conducted by the RAPP unit. In addition, each of these communities is at some distance from the capital city and from smaller cities that house regional programs. *Oyen, Alberta* is a small farming community with a population of just over 1,000. It is about a three hour drive from Medicine Hat, the nearest large centre, and about four hours from Calgary. The 2006 unemployment rate in Oyen is zero per cent. *Parrsboro, Nova Scotia* is a small coastal community with a population of 1,400. It is about a one hour drive from Amherst, the nearest large centre, and about three hours from Halifax. The 2006 unemployment rate in Parrsboro was 9.5 per cent.

Appendix A contains a table summarizing additional characteristics of these four regions.

2.3 Conducting the policy scan

Gathering information about the socio-political environment is a key step in policy analysis. The policy scan done for this project provides a picture of federal, provincial and regional policies and programs in the six domains relevant to the scenarios that were in place September 2006-December 2007 and that directly or indirectly affected the caregivers. Information on policy instruments was gathered from federal, provincial, and regional government web sites relevant to the identified policy domains (see Appendix D for list of websites). Eligibility criteria, benefits and fees were clarified by phone and email with program representatives as needed.

Federal government web sites that were examined were those of the Canada Customs and Revenue Agency, Health Canada, Human Resources and Skills Development Canada (HRSDC), the National Council of Welfare, Service Canada, and the Canada Mortgage and Housing Corporation.

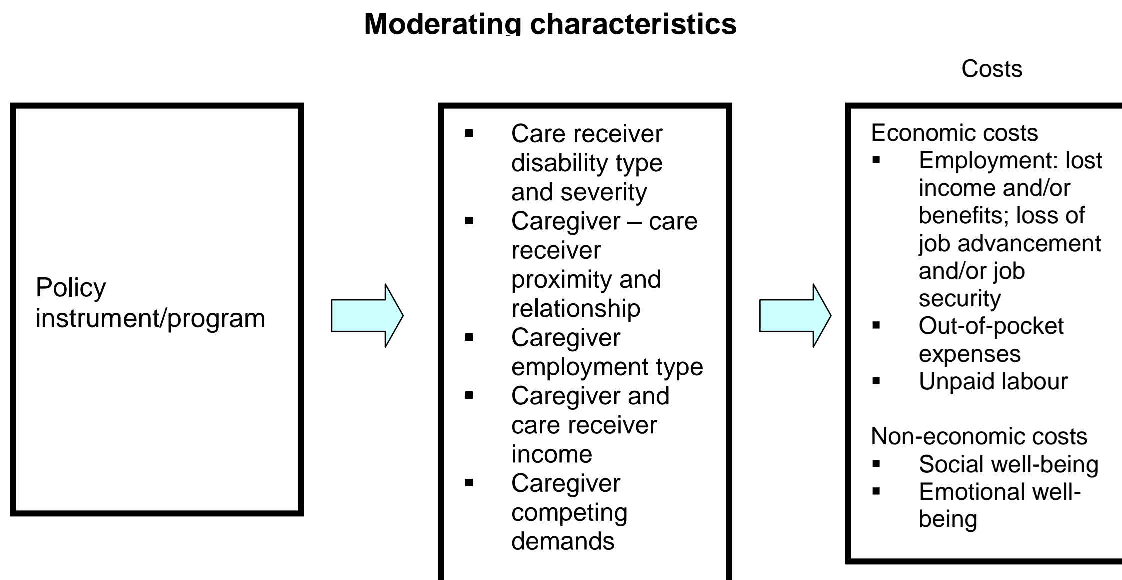
In Alberta, public policy instruments were gathered from the web sites of Alberta Employment and Immigration, Alberta Finance and Enterprise, Tax and Revenue Administration, Alberta Health and Wellness, Alberta Seniors and Community Supports, Alberta Works, Capital Health, Palliser Health Region, and Alberta Blue Cross. The booklet, Programs and Services for Seniors Guide 2001, also was consulted.

In Nova Scotia, public policy instruments were gathered from the web sites of the departments of Community Services, Health, Seniors, Labour and Workforce Development, Justice, the Disabled Persons Commission, and Service Nova Scotia and Municipal Relations.

2.4 Conducting the policy impact analysis

Using the scenarios and our policy scan, we conducted an analysis of the impact of federal, provincial and regional policy instruments in the six chosen policy domains on the economic and non-economic costs of the five caregivers represented in the scenarios. The policy impact analysis was conducted using a policy analysis framework adapted from one developed in a previous policy impact study evaluating the economic impact of policies on family caregivers of seniors (Fast et al., 2000). The framework has been adapted to include the five moderating characteristics that emerged as most important as we conducted our analysis.

Figure 4. Policy analysis framework



There are three components to the framework. The policy instrument or program and eligibility criteria in each region determine whether or not caregivers and/or care receivers qualify for it. If eligibility criteria are satisfied then certain characteristics of the caregiver or care receiver moderate the economic impact of the policy. Finally, the framework identifies the types of costs caregivers may experience. The framework illustrates the variation in the relationship between a given program and types of economic costs incurred, depending on the moderating characteristics, and the interactions between them.

We conducted our policy impact analysis using the following process:

1. Working scenario by scenario, for each policy instrument in the region:
   - we examined the impact on different categories of economic and non-economic costs incurred by caregivers. Costs for caregivers were analyzed using two questions - what costs do caregivers incur as a result of providing care and what costs are offset by the program caregivers/care receivers receive?
   - we examined whether and how the moderating characteristics influenced the nature or extent of costs incurred by caregivers.

2. We summarized the economic and non-economic impact of policies and programs on caregiver costs for each scenario, in each region;

3. We looked across profiles and regions to summarize the economic and non-economic impact of policies and programs on caregivers, and to identify which of the moderating characteristics were particularly significant in influencing the nature or extent of costs caregivers would incur.

In analyzing costs, we used the cost of care taxonomy (Lero et al., 2007) presented in Chapter 1. While an emphasis was placed on economic costs because of their potentially significant impact on people's ability to provide care and the potential of public policies to redress such costs (Eales et al., 2001, p. 10), we recognized that non-economic costs can significantly impact caregivers' quality of life and ultimately, their ability to provide ongoing care. Thus, we considered non-economic impacts that were related to the caregiver's time and energy requirements to provide care, support, supervision, or service coordination. We postulated that for employed caregivers, these requirements might be a source of stress, and might also erode opportunities for social participation. Therefore we focused on the non-economic cost categories of emotional well-being and social well-being. While physical costs are important to consider, they are complicated because the interplay of the physical strength and health of the caregiver, the needs of the care receiver and the environment in which care occurs. We considered them beyond the scope of this project.

In our policy impact analysis, we considered both the costs of providing care, and the potential of policy instruments to impact on costs. Two aspects of policy instruments are important to highlight in relation to their impact on caregivers' costs. First, the policy instruments can have direct or indirect impacts on caregiver costs. Second, instruments can simultaneously have positive and/or negative impacts on economic and/or non-economic costs to the caregiver. An example of this are programs that aim to reduce the unpaid labour burden on the caregiver, such as respite. These programs may provide the caregiver with a break, thereby reducing the costs to their social well-being, while having a fee attached to them, which entails out-of-pocket costs for caregivers.

In Chapter 3, we present the results of our policy scan in the policy domains of health, not-for-profit supports, income support, labour, housing, and transportation, followed by Chapter 4, the policy impact analysis.

Chapter 3. Policy Scan

The policy scan is organized by policy domain. Within each policy domain, policy instruments and programs are described. We selected policy instruments and programs that were most relevant to our five scenarios. For each program area, we describe what is available in each province and region.

3.1 Health care

3.1.1 Home care

Home care services are divided into health and support services. Health services are provided by visits from nurses as well as other health professionals for education, treatment, rehabilitation and consultation. Supportive services include personal care and homemaking. Hollander (2003) notes that supportive services are most important to people with on-going, long term health needs and their caregivers. Home care services are assigned based on an assessment of needs by a case manager, who also monitors and adjusts services as needs change. There is an expectation that family members, if able, will provide most care, with home care providing specialized services, monitoring, and some relief or respite.

Self-managed care is offered in several provinces in Canada as an alternative administrative model to home care delivery. In the self-managed care model, the care receiver is funded to choose, hire and manage the supports s/he needs for community living.

Alberta

In Alberta, home care professional services include case management, nursing, occupational therapy, physical therapy, respiratory therapy, and social work. Continuing care support services include personal care, homemaking and volunteer visitors.

Eligibility for home care services is based on an identified medical or care need in the home environment. Family members or friends who are providing care to someone with an identified medical or care need may qualify for some hours of respite care.

The maximum amount of service obtainable would not normally exceed $3,000 per month (including professional and support services). However, this cap was recently lifted, particularly to meet the needs of younger persons with disabilities who do not want to live in institutions. Home care services are provided at no charge to recipients.

The Alberta Home Care Program implemented a self-managed care option in 1993. This is an individualized funding program which gives the recipient funds to purchase personal help. The service-user is considered the employer and must pay all payroll deductions, train and manage their employees. Under the program the service-user may purchase administration services from an agency.

Nova Scotia

In Nova Scotia, professional services are limited to case management and nursing, with other services available for consultation in limited regions. Personal care and homemaking are available. Eligibility is based on assessed need for one or more available services. Home support may include up to ten hours per week of respite care for family members providing full time care to people with identified medical or care needs.

Nova Scotia offers home care services to a maximum of the approximate equivalent cost of subsidizing a person in a nursing home, although some individual cases may receive more support. Home support services are co-paid by the user, based on a means assessment, up to a maximum monthly amount. Presently, the co-payment is $10.68 per hour. The amount paid depends upon income and the number of persons in the home. A single person earning less than $1,565 (monthly) has no co-payment, and the maximum monthly co-payment ranges from $106 to $640.80 per month, depending upon the amount of service used, household size and income.

The Independent Living Support program provides up to 21 hours per week of support in instrumental activities of daily living to eligible persons who are semi-independent and require minimal support in their own dwelling. Wait lists for this program are significant.

Nova Scotia also offers self-managed care through their home care program. Under the Self Managed Care program individuals may be able to access funding up to a monthly maximum of $3,500. Funding can be used for support services such as personal care and homemaking services; however registered professional health services, like nursing continue to be provided directly through home care services.

The care plan is decided jointly with a case manager and the recipient is responsible for hiring and managing the workers. Just as in the home care program, recipients with sufficient income are expected to co-pay the cost of care, based on their income, the number of people in the household, and the hours of help required. The maximum monthly co-payment ranges from $160 to $640.80 per month.

3.1.2 Day programs

Day programs provide personal assistance, supervision and an organized program of health, social, educational and recreational activities in a supportive group setting. Some day programs provide basic care and supervision, while others provide comprehensive, integrated social and medical care specifically designed to delay institutionalization. They may also provide respite care, training and support to family caregivers. There are provincial and urban and rural variations in the costs, models and amounts of day care that people can access. In most cases, eligibility is limited to people of particular ages or health conditions. Typically these programs are open to older adults with physical or cognitive disabilities being cared for in their home or the home of a family member. Age limits vary from program to program.

Alberta

In Alberta, the availability of day programs is dependent on location – whereas there are no adult day support programs in Oyen, there are a variety of options available in Edmonton.

Edmonton has several adult day support programs that provide on-going services in a group setting to adults who have chronic physical or cognitive limitations affecting their ability to socialize and function in the community. The programs assist these individuals to remain as active as possible, maintaining or enhancing their level of health and independence. All day programs provide caregiver respite, support and information, and for care receivers – socialization and peer support, nutritious meals and snacks, recreation programming/activities and basic personal care.

There are three levels of day programs: medical/rehabilitation, medical/nursing, and health maintenance. A client is admitted to the level of program based on assessed need for the services the program offers. Clients may move from one level of day program to another as their needs change. The cost of these programs is $15 per day. Subsidies are available (e.g. at the client's request, with the decision resting with the day program operator), and for some programs the fee is waived entirely if the client receives a means-tested benefit. There is no cost for the Psychiatric Day Centre, although this program does not accommodate a large number of participants.

Nova Scotia

Day programs in Halifax and Parrsboro provide adults in need of care, including seniors, people with memory loss and confusion, and non-senior adults with serious and recurring mental illness, with a social environment in which they can participate in activities and meet new people. Many of these programs also offer health services such as health monitoring, counselling and assessments, referrals, nursing care, personal care, and some also offer information sessions for families/caregivers, group outings, social events, and lunches. Many day programs act as links to service provision within the community, including access to employment and housing services for those with mental illness. Some indicate that they are designed to meet the needs of employed family members and therefore target the caregiver and the care receiver; however eligibility is based on care receivers. Some programs run five days per week while others limit attendance according to availability. The cost varies by program, and in Parrsboro can be as low as $5 per visit, but is usually about $30 per day.

3.1.3 Facility-based respite

Facility-based respite enables caregivers to take a break from their caring responsibilities by providing care receivers the option of a short-term stay in a continuing care facility.

Alberta

In Alberta, facility-based respite is available in Edmonton, but not Oyen.

Continuing care facilities in Edmonton offer respite care. To be eligible, the care receiver must be an adult who is eligible for nursing home care but still living in the community. The cost is the same as the cost of long term care on a per diem basis ($44-$54, depending on the type of room), and there is no subsidy available.

Part time respite is also available, which allows a care receiver to live in a long term care facility 3-4 days per week; essentially sharing a long term care bed with another part time resident, to a maximum of two weeks, twice a year. The cost is the same per day as nursing home care.

Nova Scotia

In Nova Scotia, facility-based respite is available in Halifax, but not Parrsboro. The nearest facility-based respite to Parrsboro is in Springhill, which is approximately 40 minutes away.

Halifax has facility-based respite care for caregivers living in the community who have completed an assessment that labels them as appropriate for long term care. They must also have a family/friend that is providing care in the home and needs a break. The cost is $28.70 per day. Fees can be reduced by up to 50 per cent for applicants with an annual assessed income less than $18,786 by undergoing an income test and completing the Department of Health "Long Term Care Facility Financial Application." This service can be used up to 28 days per year. Emergency respite is also available in case of caregiver unavailability.

3.1.4 Medication

Coverage for medication required outside of hospitals, auxiliary hospitals and nursing homes are provincially run programs. Each province determines the types of medication covered and the costs a patient incurs. Within a province, there are differences in the premium and co-payment amounts, usually by age, income level or health condition.

Alberta

Three groups of Albertans either receive at no charge or can purchase supplementary health benefits through the Alberta Health Care Insurance Plan (AHCIP). For all three insurance programs, a family plan includes coverage for unmarried children aged 21 and younger who are fully dependent on the subscriber, as well as unmarried children aged 21 and older who are fully dependent on the subscriber due to a physical or mental disability. The program covers 70 per cent of the medication cost, with a maximum co-payment of $25 per prescription.

Alberta residents under 65 pay quarterly premiums of $61.50 (for individuals earning over $20,970) and $123 (for families with children earning over $39,250). Premiums are waived for individuals and families with dependent children whose family income is less than $17,450 and $32,210 respectively. Quarterly premiums for residents earning between these amounts are $43.50 for individuals and $86.10 for families with children.

Alberta seniors (65 or older), regardless of income and dependents covered on their plan receive drug coverage and pay no premium.

Recipients of Assured Income for the Severely Handicapped (AISH) benefits and those in receipt of Income Support are eligible for a broader health benefits program – the Alberta Adult Health Benefit. The program provides premium-free coverage of prescription drugs (through the AHCIP) and other services (dental, optical, diabetic supplies, emergency ambulance) for the eligible adult, their co-habiting partner and dependent children.

For eligible outpatient cancer patients, the Alberta Cancer Board provides select medications at no cost.

Alberta does not have a program to cover catastrophic drug costs.

Nova Scotia

Nova Scotia Health Insurance Programs provide residents with coverage for medically required hospital, medical, dental and optometric services with some restrictions. There are no premiums. Two groups of Nova Scotians receive prescription drug coverage through the Nova Scotia Pharmacare Program:

- Nova Scotia seniors (65 and older) who do not have drug coverage through other programs (e.g. private insurance, Veterans Affairs) can register to receive prescription drug coverage through the Seniors' Pharmacare Program. The program covers 66 per cent of the medication cost, with a maximum co-payment of $30 per prescription. Once co-payments exceed $382 annually, the full cost of prescriptions is covered by the program. Premiums vary depending on income. Current premiums are $424 annually, and half of all recipients pay this full amount. Low-income recipients pay a reduced premium.
- Income Assistance clients (which includes Extended Pharmacare and Transitional Pharmacare clients) and Services for Persons with Disabilities clients, and their dependents (children under 19, or 19 to 20 if attending an education program), are eligible for Pharmacare Benefits. The co-payment is $5 per prescription unless the client or dependent have a co-payment exemption (may be given in cases where there is a disability or large on-going medication costs).

In addition, there is drug coverage for individuals with certain health conditions (e.g. cancer, multiple sclerosis (MS), Alzheimer's), and in some cases, there is also a requirement that the individual be low-income.

Nova Scotia residents with cancer who have gross annual family income less than $15,720 and who are not eligible for coverage under other drug programs are eligible for coverage of cancer-related drugs.

Nova Scotia residents with multiple sclerosis who do not have other drug coverage and meet certain disease criteria are eligible for drug funding assistance through the Dalhousie MS Research Unit (funded by the Nova Scotia government) for coverage of select high cost medications.

Nova Scotia residents with Alzheimer's may receive coverage of Cholinesterase medication for 90 day periods.

3.1.5 Medical equipment

There is no national program for the provision of assistive devices or medical equipment (such as wheelchairs, bathroom equipment, lifts, hearing aids, and incontinent supplies) to persons with disabilities or to family members who care for them. Often people must rely on private funds or private insurance to purchase or borrow these devices. Provinces vary widely in their public funding for these supports.

Alberta

The Alberta Aids to Daily Living (AADL) Program is a province-wide initiative that, in cooperation with authorizers and vendors, assists individuals who have a chronic disability or illness, and individuals who are end-stage palliative.

AADL provides basic equipment and supplies necessary for independent functioning at home or in a home-like setting. AADL purchases equipment and supplies such as bathing and toileting aids, walking aids, wheelchairs, and hospital beds. AADL subsidizes the costs of equipment and supplies authorized for the individual, with individuals paying 25 per cent of the cost of the benefits to a maximum of $500 per year per family. Clients on Alberta's Income Support, AISH, and the premium subsidy with Alberta Health and Wellness do not co-pay. AADL has quantity limits and price maximums with clients having the option of upgrades at their own expense.

In addition to AADL, the short-term equipment loan program (STELP) provides six-month loans of medical equipment at no cost to people who are living in Edmonton and recovering from injury, illness or surgery. This program lends items similar to those listed above.

The MS Society of Edmonton also offers a short-term equipment loan program. This service is unavailable in Oyen.

Nova Scotia

There is no equivalent of the Alberta provincial assistive devices program in Nova Scotia. Some limited devices are funded through the provincial medical insurance program. The Nova Scotia government will fund assistive devices such as glasses, hearing aids, wheelchairs, and walkers for Nova Scotians with assessed needs who are receiving social assistance.

Community and disability-specific organizations provide funding for some assistive devices. The Healthcare Equipment Loan Program (HELP) is a province-wide service of the Red Cross that loans equipment such as mobility devices and wheelchairs for short-term periods (less than six months), and loans hospital beds for extended periods of time. The loans are free of charge and eligibility is based on mobility limitations. This program is intended for people with short term needs or in periods of transition. If equipment is required for the long-term, it must be purchased by the user.

The Abilities Foundation of Nova Scotia offers financial assistance for assistive devices, such as wheelchairs, and also has a small supply of equipment available for loan to the public. Any child or adult in Nova Scotia who has a permanent physical disability is eligible for this service.

3.1.6 Consultative services

Consultative services include physician, medical specialist, and therapeutic services. Physicians and medical specialists provide medical monitoring for persons with a disability. Therapeutic services may provide therapy, counselling, advice, education or equipment to enable persons with a disability to carry out day to day activities in their home environments. They may also provide counselling, advice, education or equipment to assist caregivers to carry out their caregiving tasks, or to balance work and care tasks.

Alberta

In Alberta, consultative services are available through hospitals, clinics and not-for-profit support services. Home care also provides in-home consultations with occupational therapy, physical therapy, speech therapy, social workers, and respiratory therapists. All of these services are available in Edmonton.

In Oyen, the Big Country Health Centre provides a ten bed acute care unit (including one palliative care suite) and thirty long-term care beds. Twenty-four-hour emergency room services are available. Services include on-site physical therapy, visiting occupational therapy and visiting respiratory therapy services. Other community resources include speech therapy and a mental health worker. There are two physicians in the area.

Nova Scotia

In Nova Scotia, consultative services are available through hospitals, clinics, and not-for-profit support services. Home care provides very limited in-home consultations, depending upon the health region. These are insured services under provincial health plans. All of these services are available in Halifax.

In Parrsboro, physician care is available. The South Cumberland Community Care Centre also provides access to occupational therapy, physiotherapy, social work, nutrition counselling, family counselling, outpatient and emergency services, mental

health services, a diagnostic laboratory with EKG and x-ray, ophthalmology and optometry.

3.1.7 Emergency ambulance services

Costs of emergency ambulance services vary between provinces, with basic ambulance services in Alberta costing patients more than twice that of Nova Scotia. Costs and accessibility vary within a province, with rural patients likely to experience higher costs and longer times in transit due to the distances to larger centers.

Alberta

The cost of ambulance services is covered for emergency patients being transported to a higher level of care, and for patients transferring from one hospital to another. Patients needing pre-hospital ambulance service to hospital from home, an accident scene or a workplace are responsible for the cost, with the exception of seniors and widows, who receive these services at no charge through the Alberta Health Care Insurance Program. As well, those who have private insurance have these ambulance services covered in their plan with no co-payment. Emergency ambulance costs are covered for persons on income assistance.

In Edmonton, ground ambulance services within city limits, including inter-hospital transportation for those who are not able to use any other form of accessible transportation, costs between $358-$512 for city residents, and a minimum of $497 for non-residents. If an EMS response is required but no transportation needed, residents are charged $229.

In Oyen, prices are similar to those of Edmonton but there are more travel costs involved in transporting an individual to a larger centre for emergency care.

Nova Scotia

In Halifax and Parrsboro, costs for a ground ambulance range from $128-$641 for residents, and a minimum of $641 for non-residents. No charges are incurred for hospital to hospital transfers or air ambulance services. Emergency ambulance costs are covered for persons on income assistance.

3.2 Not-for-profit support services

Community-based organizations deliver a variety of supports to care receivers and caregivers, often at no cost to the participant. Many of these supports address gaps that exist in the formal care system, such as the provision of information, training, emotional support, and counselling for caregivers. Because many of these services are developed and delivered by not-for-profit sector organizations focused on a particular health condition or age group, the nature and extent of supports available to a caregiver vary widely depending on the illness type and the caregiver/care receiver’s place(s) of residence (province, and rural/urban area). In keeping with our scenarios, we focused on services available to persons with bipolar disorder, MS, Alzheimer’s, and cancer, and persons who have had a stroke, and their caregivers.

3.2.1 Information/referral/navigation services

Alberta

In Edmonton, a variety of organizations provide information and/or referral services, either in person or via telephone/the Internet. Health-condition-specific groups like the MS Society, the Alzheimer's Society, and the Canadian Cancer Society, age specific organizations like the Seniors Association of Greater Edmonton (SAGE), and caregiver groups such as the Alberta Caregivers Association all provide these services free of charge. Information and referral services offered by these groups are accessible to both caregivers and care receivers.

In Oyen, these organizations, with the exception of SAGE, provide telephone/Internet-based information and referral services.

There are no specific information/referral/navigator services available in Edmonton or Oyen to persons with bipolar disorder, or persons who have had a stroke, though caregivers of persons with these conditions have access to services provided by the Alberta Caregivers Association.

Nova Scotia

In Halifax, various groups provide information and/or referral and/or navigator services to caregivers and care receivers free of charge. The Healthy Minds Cooperative has an in-person navigator who identifies suitable services for persons with bipolar disorder or their caregiver, and refers them to these services. Other health-condition-specific groups like the MS Society, the Alzheimer's Society, and the Canadian Cancer Society all offer in-person and/or telephone/Internet-based information and referrals. Caregivers Nova Scotia provides in-person and telephone-based information and referrals, and the Abilities Foundation of Nova Scotia assists people with physical disabilities (including those who have had a stroke or have MS) by providing information and referrals. There are no information/referral/navigator services available in Halifax to persons who have had a stroke.

All of these organizations offer the same information/referral services in Parrsboro, with the exception of the Healthy Minds Cooperative – there are no specific information/referral/navigator services available in Parrsboro to persons with bipolar disorder, or persons who have had a stroke. However, caregivers of persons with these conditions have access to services provided by Caregivers Nova Scotia.

3.2.2 Education/training services

Alberta

A number of organizations in Edmonton offer education and training services to caregivers and care receivers, free of charge. Alberta Mental Health runs a bipolar education group for consumers and their families. The MS Society offers education programs aimed at persons with MS or their caregiver that focus on such issues as financial assistance and medication management. The Alzheimer's society offers

education programs with professionals (e.g. occupational therapists, behavioural specialists, lawyers) for the person with Alzheimer's and their caregiver. There are no education or training services available to persons with cancer, or persons who have had a stroke.

Caregiver-specific groups like the Alberta Caregivers Association provide educational workshops, and the Alberta Caregiver College offers an on-line training program accessible to any adult with a computer. The program provides information and helps caregivers develop care strategies and networks with other caregivers.

Education and training services in Oyen are limited to the on-line training program offered by the Alberta Caregiver College. Comparable services to those offered in Edmonton are located in Medicine Hat, which is approximately a two hour drive from Oyen. There are no specific education or training services available in Oyen to persons with bipolar disorder, cancer, or persons who have had a stroke. However, caregivers of persons with these conditions have access to services provided by Alberta Caregivers Association and the Alberta Caregiver College.

Nova Scotia

In Nova Scotia there are relatively fewer education and training services available when compared to the services offered in Alberta. In Halifax, the MS Society offers education programs aimed at caregivers and care receivers. In Parrsboro, persons with MS and their caregivers would have to travel to Halifax to access these education programs as no comparable service is offered in this area.

In Halifax and Parrsboro, Caregivers Nova Scotia provides workshops with different modules aimed at care for the caregivers and "train the trainer" workshops (e.g. safe use of medication, facilitating support groups).

Specific education and training services for persons with bipolar disorder, Alzheimer's, or cancer, and for persons who have had a stroke are not available in Halifax or Parrsboro. However, caregivers of persons with these conditions have access to services provided by Caregivers Nova Scotia.

3.2.3 Support/self-help groups

Alberta

There are a number of support/self-help groups available in Edmonton, all free of charge. The Sisters of Charity (Grey Nuns) Alberta offer a support group for bipolar consumers and their families. The MS Society offers supportive counselling to care receivers and caregivers, and separate support groups for both. The Alzheimer's Society also provides separate support groups for the care receiver and caregiver, and annual conferences and social events for care receivers and their families. The Canadian Cancer Society offers in-person support on an individual or group basis, and one-to one peer support via telephone. While group sessions tend to focus on the care

receiver (though caregivers are welcome), caregivers have the option of accessing one-to-one support with another caregiver.

The Alberta Caregivers Association provides monthly peer support to caregivers of all ages/circumstances. Another caregiver-specific service is the Coping with Caring program, which provides one-on-one help to caregivers over the age of 50 who are learning to cope with care receivers' memory-related problems (e.g. dementia, MS, stroke). This program includes visits by an occupational therapist.

The only form of support/self-help available in Oyen is offered by the Canadian Cancer Society, and consists of telephone-based individual peer support for either the caregiver or care receiver. All other support/self-help services are located in Medicine Hat, which is approximately a two-hour drive from Oyen.

There are no specific support/self help groups available in Edmonton or Oyen for persons who have had a stroke. However, caregivers of persons with these conditions have access to services provided by the Alberta Caregivers Association.

Nova Scotia

In Halifax, various organizations offer support/self-help services at no charge. The Nova Scotia Bipolar Support Alliance runs separate weekly support groups for consumers and caregivers. The MS Society offers volunteer-run counselling and support/self-help groups for caregivers. The Alzheimer's Society runs caregiver support groups, and the Heart and Stroke Foundation offers peer self-help groups for stroke survivors and caregivers. The Canadian Cancer Society offers telephone support through their Cancer Connection program, and in-person support through their Living with Cancer support groups to caregivers and care receivers. Caregivers Nova Scotia provides twice monthly support groups for caregivers. Of these services, only those offered by the Alzheimer's Society, and the Cancer Connection telephone support service are available in Parrsboro. All other support/self-help groups would be those that are offered in Halifax, which is approximately a two hour drive from Parrsboro, and the Living with Cancer support group offered in Springhill.

3.2.4 Travel assistance

In Alberta and Nova Scotia, some not-for-profit support services groups provide funding to cover the costs of medical travel for the care receiver and/or their caregiver/attendant.

Alberta

The MS Society provides special assistance funding of up to $500 per year which can be used to cover the costs of medical travel. This assistance is not means-tested.

In Edmonton, the Canadian Cancer Society provides volunteer drivers to take care receivers to appointments, and to persons living in Oyen, offers subsidies for travel and accommodation.

Nova Scotia

In Halifax and Parrsboro, the Abilities Foundation of Nova Scotia provides a disability travel card for discounted travel rates for caregivers/attendants travelling with the care receiver.

3.2.5 Meal programs

Alberta

Meals on Wheels deliver hot or frozen meals to people who need a meal service, including the elderly and those with chronic illness. Costs and the number of meals available per day vary by community.

In Edmonton, fresh meals are $9.50/$10.50/$11.50 for one, two, or three daily meals. Frozen meals are $4 each. There is a $50 enrolment fee that can be used toward the first batch of meals. There are no restrictions on who can utilize this service. Subsidies are available, depending on income and household size (e.g. AISH and Income Support clients are likely to receive a subsidy). In Oyen, recipients receive a nutritious hot meal at noon on weekdays. Cost for the meal is $6.50 per day.

In addition to Meals on Wheels, the Seniors Association of Greater Edmonton (SAGE) provides food services for members (seniors aged 65 and older) and their caregivers. SAGE offers frozen meals at a cost of $4.95 per meal or $4.50 per meal if ten meals are ordered. There is an annual membership fee of $21, and a lifetime membership fee of $105.

Nova Scotia

Meals on Wheels offer meal services in Halifax only. Fresh meals cost $5.50 per lunch, and only one meal is available per day, with a maximum of three meals per week. Anyone with a health condition can utilize the service.

The Victoria Order of Nurses (VON) also offers meal services in Halifax. The VON provides frozen meals to anyone for $5 per meal. The meals are delivered in batches twice weekly or can be picked up anytime.

There are no meal programs available in Parrsboro.

3.3 Income security

Income security programs for caregivers and persons with disabilities include federal programs, which are available to all Canadians who meet the eligibility criteria, and provincial/territorial programs, which are available to residents of the province/territory who meet the eligibility criteria. Each jurisdiction provides different supports for seniors, persons with disabilities and caregivers. There are relatively few tax and income assistance programs specifically targeting caregivers, however, caregivers may benefit indirectly from programs that target care receivers (persons with disabilities and seniors).

There is variation within and across jurisdictions in the type and amount of benefit, and the breadth of the population that falls within the eligibility criteria. Criteria generally consist of some combination of the following factors: age bracket, net income, marital status, presence of children, level of severity or permanence of the disability, housing type, relationship of care receiver to claimant, and residency vis-à-vis care receiver. There are complex interactions of benefits within and across jurisdictions. In some cases, one has to be eligible for one benefit in order to receive another (e.g. being eligible for AISH before one can receive the disability top-up for income assistance) while in other cases, receipt of benefit from one level of government negates or reduces the amount of benefit available from another (e.g.,, receipt of CPP-Disability makes the care receiver ineligible for AISH).

3.3.1 Income support

Canada's public pension system has two levels. The first, public pension plans (Old Age Security), are available to people over the age of 65 regardless of their employment history, but are linked to income. These include programs which are supplemented in some provinces/territories by income support programs funded by provincial/territorial governments. The second, contributory pension plans (CPP), are available to individuals aged 60 and older who have contributed to the CPP while employed. The benefit level is tied to the duration and amount of contributions made.

Old Age Security (OAS) is an income-tested, taxable monthly pension for people aged 65 and older who have lived in Canada for a minimum of 10 years. The maximum OAS benefit paid to an eligible senior in October-December 2007 was $502.31, though the average benefit paid out was $472.02. The benefit amount is reduced or eliminated as income rises or length of residence in Canada decreases, such that a partial benefit is received if an individual's net income is above $63,511, and the benefit is eliminated when an individual's net income exceeds $103,191.

There are other subsidies available to low-income seniors at the federal and provincial/territorial level such as the Guaranteed Income Supplement (GIS), the Allowance, the Alberta Seniors Benefit Program, Alberta's Special Needs Assistance for Seniors, and Nova Scotia's Seniors Special Assistance. No one in our study met the eligibility criteria for these programs.

The CPP is a monthly, taxable pension for retirees who have contributed to the CPP during their working years. Contributions are made on earnings between $3,500 and $41,100 (in 2005), and are split between employer and employee, except for self-employed people, who pay both portions of the contribution. The amount of the benefit varies by the amount of earnings, years of contributions and age. Retirees who have contributed to the plan and are aged 65 and older receive a maximum monthly benefit of $863.75 in 2007, though the average monthly benefit was $473.09 in October 2006. Monthly benefits are reduced for retirees who start drawing the CPP between ages 60-64.

The CPP-Disability (CPP-D) is a monthly, taxable earnings replacement for people under age 65 who are assessed as having a severe and prolonged disability (as defined by CPP and as validated by a health practitioner) that prevents them from working on a regular basis, and who have made enough CPP contributions in four of the last six years. The monthly amount of the benefit is based on a fixed amount $405.96 in 2007, plus an amount based on the person's CPP contributions. In 2007, the maximum possible monthly benefit was $1,053.77, however the average monthly benefit paid in October 2006 was $772.88. The benefit is no longer paid once the individual turns 65 or their disability is no longer deemed to be "severe and prolonged."

Alberta

Alberta Works Income Support (IS) program provides financial assistance to cover food costs, household expenses, utilities and housing. There are three categories of recipients: those who have difficulty working because of a chronic mental or physical health problem (Not Expected to Work), those looking for work (Expected to Work) and those needing training in order to get a job (Learners). The benefit amount depends on a person's ability to work, financial resources, housing situation and marital status/number of children. Income Support is only available to those aged 18-65 (persons aged 65 and older would go onto OAS/GIS).

Drawing on the scenarios, a single individual not expected to work who lives with relatives receives $419 per month in core benefits, plus medical extraordinary transportation (cost of a monthly bus pass or $0.12 per kilometre for taxi, car) and a health benefits card, which covers some prescription medication. Supplementary benefits are also available to help with the costs related to medically required diets and child care. Adults who are assessed as severely handicapped as defined by the Assured Income for the Severely Handicapped (AISH) Act receive a supplementary Handicap Benefit of $175 per month, bringing the total monthly benefit to $594. There is a nominal earning exemption, such that single people can earn up to $115 per month and 25 per cent of additional earnings without having the amount of their benefit reduced.

AISH is a taxable living allowance and health benefit for disabled Albertans aged 18 to 64. Income and assets (individual and joint) affect the amount of the benefit, which has a maximum monthly amount of $1,050. The benefit is no longer paid when the recipient turns 65. To be eligible, applicants must obtain medical certification that they have a severe, permanent disability that substantially impairs their ability to work (even with rehabilitation and training); they do not reside in an institution; and they meet the financial criteria (e.g. assets of up to $100,000 plus house and vehicle will not affect the AISH benefit while monthly earnings are allowed up to a certain value before the amount of the AISH benefit is affected. In July 2008, for recipients who are single, the first $1,500 is exempt, while the first $2,500 is exempt for couples and single parents).

Supplementary financial assistance may be available for one time or on-going expenses (e.g. emergency situations, childcare) for those who have non-exempt assets of $3,000 or less and an identified need that cannot be met through any other program.

Nova Scotia

The Income Assistance (IA) portion of the Employment Support and Income Assistance (ESIA) program provides people in financial need with assistance with basic needs such as food, rent, utilities like heat and electricity, and clothing. The program may also help with other needs such as child care, transportation, prescription drugs, emergency dental care, and eye glasses. To be eligible, an adult must be a permanent resident of Nova Scotia; between the ages of 19 and 65; and be in financial need (i.e. his/her monthly income is less than the amount the ESIA program allows for basic expenses such as food, rent or mortgage, utilities like heat and electricity, clothing, and taxes).

The Direct Family Support (DFS) program provides supports and services to both children and adults with disabilities who live at home with their families. The intent of the program is to support and provide funding to eligible families to enable them to support their family members with a disability at home. To be eligible, an adult must be a permanent resident of Nova Scotia; between the ages of 19 and 65; reside in the home of a family member or guardian; have an intellectual disability, long term mental illness, or physical disability; have unmet needs; and meet the financial eligibility criteria.

Basic assistance for adult recipients of IA and DFS is the same and amounts to a shelter allowance ($300-$620 for renters/owners; $223-$282 for boarders), a personal use allowance ($204) and a comfort allowance ($115) as well as money for any eligible special needs (diet, transportation, etc.). In addition, a care receiver who is eligible for DFS benefits would be assessed to determine the appropriate level of respite support his/her family would receive (up to $2,200 per month).

<u>3.3.2 Tax credits and deductions</u>

The Disability Tax Credit (DTC) is a non-refundable tax credit aimed at recognizing the costs associated with disability by reducing the amount of income tax paid. Eligibility rests on certification from a qualified practitioner that the impairment is severe and prolonged and results in marked or significant restriction in activities of daily living are eligible. The federal amount of the tax credit in 2007 was 15 per cent of $6,890, which provides a tax reduction of up to $1,033. The additional provincial amount of the credit varies, but is 10 per cent of $7,131 in Alberta (to a maximum tax reduction of $713) while the Nova Scotia amount is 8.8 per cent of $4,441 (to a maximum tax reduction of $390). The Disability Tax Credit Transfer is not a separate program from the DTC, but allows any or all of the unused portion of the DTC to be claimed by a supporting spouse, parent, grandparent, child, grandchild, brother, sister, aunt, uncle, nephew or niece of the individual spouse reduce their tax liability. The person claiming the transfer must claim one of the following three caregiver credits: Caregiver Tax Credit, Infirm Dependent Credit, or Eligible Dependent Credit. Only one person per household can claim the DTC.

The Medical Expense Tax Credit (METC) is a non-refundable tax credit that a person or their spouse/partner can claim to recognize the costs of disability-related and medical expenses incurred for the individual, spouse/partner or children under the age of 18. Persons who are ineligible for the DTC can claim mileage for medical treatment for

round-trips of more than 80 kilometres ($0.48 per kilometre in Alberta and Nova Scotia, minus three per cent of the care receiver's net income off the total mileage claim). Up to $10,000 in eligible expenses can be claimed for each dependent. The federal amount of the METC in 2007 was 15 per cent of eligible expenses (those on the METC list) in excess of the lesser of either $1,926 or three per cent of the claimant's net income, with no maximum on the amount of expenses that can be claimed. The amount in Alberta in 2007 was 10 per cent of eligible expenses (those on the METC list) in excess of the lesser of either $1,994 or three per cent of the claimant's net income, with no maximum on the amount of expenses that can be claimed. The amount in Nova Scotia in 2007 was 8.8 per cent of eligible expenses (those on the METC list) in excess of the lesser of either $1,637 or three per cent of the claimant's net income, with no maximum on the amount of expenses that can be claimed.

The METC for Other Dependents is not a separate program from the METC, but allows an individual or spouse/partner to claim the portion of eligible medical expenses they paid for people who depended on them for support (adult children, parent, grandparent, sibling, uncle, aunt, niece, or nephew residing in Canada). All the other criteria of the METC apply to this benefit.

There are a variety of medical expense-related programs targeting low-income and disabled persons who are engaged in employment and education. These initiatives include the Working Income Tax Benefit, the Working Income Tax Benefit Disability Supplement, the Disability Supports Deduction, and the Refundable Medical Expense Supplement. None of the care receivers in our study met the eligibility requirements for these programs.

Caregivers can only claim one of the following three non-refundable credits per dependent: the Caregiver Credit, the Infirm Dependent Credit, or the Eligible Dependent Credit. No one in our study met the eligibility criteria for the latter two measures. In all cases, the dependant must be related to the claimant by blood, marriage, common-law partnership, or adoption, however spouses/partners cannot be considered as care receivers.

The Caregiver Credit provides tax relief to individuals providing care to a family member who is aged 18 or older and is dependent due to a mental or physical infirmity, or a parent or grandparent aged 65 and older regardless of health status. In case, the caregiver and care receiver must live in the same residence. The federal amount of the tax credit in 2007 was 15 per cent of $4,019, which provides a tax reduction of up to $603. This credit is eliminated when the care receiver's income reaches $17,745. The additional provincial amount of the credit varies, but is 10 per cent of $4,160 in Alberta (to a maximum tax reduction of $416) which is eliminated when the care receiver's income reaches $18,366. In Nova Scotia the amount is 8.8 per cent of $4,320 (to a maximum tax reduction of $380) which is eliminated when the care receiver's income reaches $16,384.

The Infirm Dependent Credit provides tax relief to individuals providing care to a family member (child, grandchild, parent, grandparent, sibling, uncle, aunt, niece or nephew) aged 18 or older who is dependent on a caregiver due to a mental or physical infirmity, and who lives in a separate residence. The federal amount of the tax credit in 2007 was 15 per cent of $4,019, which provides a tax reduction of up to $603. The federal portion of the credit is eliminated when the care receiver's income exceeds $9,721. The additional provincial amount of the credit varies, but is 10 per cent of $4,160 in Alberta (to a maximum tax reduction of $416), which is eliminated when the care receiver's income exceeds $10,062. In Nova Scotia the amount is 8.8 per cent of $2,468 (to a maximum tax reduction of $217), which is eliminated when the care receiver's income exceeds $7,481.

3.4. Labour/ Employment

The majority of Canadians are employed in sectors governed by provincial/territorial employment labour standards legislation. Most provinces/territories have a compassionate care leave provision that provides unpaid leave and job protection for employees needing a temporary absence from work to provide care or support to a family member with a serious medical condition and with a significant risk of death. For those that have worked sufficient hours in sectors that qualify for Employment Insurance (EI), the unpaid compassionate leave can be combined with short-term earnings replacement through the EI Compassionate Care Benefit.

3.4.1 Family responsibility leave

Alberta

Employees in Alberta covered by provincial labour standards are not entitled to any unpaid family leave other than maternity leave.

Nova Scotia

Employees in Nova Scotia who are covered by provincial labour standards (the majority) are entitled to three days per year of unpaid leave for family illness (i.e. the sickness of a child, parent or other unspecified family members), or for medical, dental or other similar appointments during the employee's working hours.

3.4.2 Employment Insurance (EI) Compassionate Care Benefit (CCB) and job protection

The CCB provides up to six weeks of job protection and partial earnings replacement to an employed person(s) who is temporarily absent from work to provide care or support to a family member who has been medically certified as being at risk of death in 26 weeks. To be eligible for this program, applicants must have worked at least 600 insurable hours in the previous 52 weeks, had their regular earnings decrease by at least 40 per cent when they took time away to provide care, and be a family member or close friend (as defined by the EI Program). The benefit, which is taxable, provides for 55 per cent of insurable earnings with a maximum payment of $423 per week in. No one in our study met the eligibility criteria for the benefit or job protection.

Alberta

The majority of Alberta employees (except those working in sectors regulated by the Canada Labour Code, or where it has been negotiated into a contract) do not have job protection for compassionate care leave as it is not included in Alberta's provincial labour standards. All eligible employees can access EI benefits for compassionate care regardless of job protection.

Nova Scotia

Up to eight weeks of unpaid leave is provided to those who are eligible for the CCB.

3.5 Transportation

Availability of public transportation and wheelchair-accessible transportation is cited as a key issue for older adults and persons with physical disabilities, particularly in rural areas. In this report we looked at public transportation programs for day-to-day travel, as well as programs in place to assist people to operate privately-owned motor vehicles.

Canada has wheelchair-accessible bus, train, air, and ferry transportation. While there is no legislation that requires accessibility measures, Canada does have voluntary codes of practice for disability accommodations for these transportation services. While assistance related to embarking, disembarking, luggage handling, and transportation to on-board washroom facilities is provided, persons requiring additional services must travel with an attendant, with the attendant travelling at no charge or at a reduced rate as long as medical documentation is provided. Often, arrangements for travel and requests for assistance must be made well in advance because not all carriers can accommodate persons with mobility disabilities and wheelchairs.

3.5.1 Intercity transportation

Both Edmonton and Halifax run public transit with lowered floors and wheelchair accessible ramps on selected routes. Both cities also run parallel transportation systems for people with disabilities who have difficulty accessing regular transportation systems. Access to parallel transportation systems is by special pass, which requires an application and medical documentation. Parallel transportation systems have the same cost to the user as regular public transit.

Oyen has a Handi-Bus that holds 16 people and has room for two wheelchairs. Members pay a $10 annual fee and travel locally for free. For longer trips (e.g. Medicine Hat), the cost would be $0.50 per kilometre, which can be increased to $0.75 per kilometre during periods when fuel prices are high.

Parrsboro does not currently have a service available that is comparable to the Handi-Bus program in Oyen. There is a Dial-A-Ride program in Nova Scotia that consists of a support network of non-profit, community-based transportation systems located throughout the province. However, this service will not be available to residents in Parrsboro until 2009.

3.5.2 Intercity transportation

Alberta

Greyhound bus operates wheelchair accessible buses between Oyen and major centres in the province.

Nova Scotia

Acadia bus lines serves communities within Nova Scotia and connects to neighbouring provinces. Only two of the 38 buses are wheelchair accessible. Acadia bus lines do not serve the Parrsboro area.

3.5.3 Transportation programs for privately-owned vehicles

The GST/HST Specially Equipped Motor Vehicle Rebate is available to people who have paid GST/HST on the purchase of a qualifying motor vehicle, or on a modification service performed on their motor vehicle.

Alberta

Alberta offers parking passes to persons with disabilities which allow parking in zones marked as handicap parking. The passes do not allow free parking in paid spaces.

The parking placard is available to individuals who are unable to walk more than 50 metres, and the need must be documented by a health provider. Physician fees to complete an application are set at the discretion of the physician, and are usually determined by the amount of paper work and the extent of the assessment. The Grant MacEwan College Health Centre charges $30 to complete the application. A caregiver cannot apply for a parking placard but it can be used in any vehicle in which the person with a disability rides. Registry fees are $9.45 to issue or replace a placard. The Alberta Motor Association charges $9 to members.

Nova Scotia

Nova Scotia also offers parking passes to persons with disabilities, and as in Alberta, these passes are restricted to spaces marked as handicap parking, and do not allow parking in paid spaces.

3.6. Housing

Publicly-subsidized rental accommodation is available to low income seniors and persons with disabilities in most provinces in Canada who pay a percentage of their income as rent. The federal Rent Supplement Program, the Alberta Community Housing Program, and Nova Scotia’s low-income housing initiatives constitute future options for the persons in our scenarios, but are inapplicable to their current living arrangements.

3.6.1 Housing modification programs

Only programs related to disability or age-related disability have been scanned. Low income persons and low income older adults may qualify for other home modification programs that are not disability-related.

Alberta

The Residential Access Modification Program (RAMP) provides a grant of up to $5,000 to modify the personal principal Alberta residences of low-income wheelchair users. To be eligible, homeowners or renters must have a total annual gross household income of less than $35,900 for the prior year, however additional deductions of $7,505 are allowed for spouses and each dependent child under the age of 21 who lives at home, as well as a deduction of $6,741 per disabled child under the age of 18 living at home. Applications are accepted up to one year after the modification is complete. This program also provides funding for temporary modifications for eligible applicants that have undergone an operation or are recovering from an accident which require the use of a temporary access ramp, or a porch lift, and/or a stair lift to a maximum period of up to 12 months.

Nova Scotia

The Disabled Residential Rehabilitation Assistance Program (Disabled RRAP) is a Canada-Nova Scotia jointly-funded initiative that helps Nova Scotians with disabilities access their place of residence. Forgivable loans of up to $16,000 (homeowner or rooming house) or $24,000 (self-contained rental unit) are available to homeowners and landlords to make required modifications and repairs to homes occupied by persons with disabilities. To be eligible, the home value and household income must be below established ceilings, however landlords can apply if tenants have incomes below the threshold. For Halifax, the home value ceiling is capped at $250,000 and the household income limit for a one/two/three bedroom home is $26,000/$32,000/$42,000 respectively. For Parrsboro, the home value ceiling is capped at $175,000 and the household income limit for a one/two/three bedroom home is $22,500/$27,000/$35,500 respectively. The loans are 100 per cent forgivable when the tenant's income is at or below the Household Income Limits, or in the case of rooming houses, if the landlord agrees to keep the unit affordable to persons with income below the established ceilings.

The Access-A-Home Program is intended to provide $1,000-$3,000 grants for building materials, labour, and taxes to low-income individuals that have to make their homes wheelchair accessible. To be eligible, the house must be lived in and owned by the applicant, the applicant or resident family member must use a wheelchair, and the gross family income must be less than $30,000 a year.

Chapter 4. Policy Impact Analysis

This chapter presents our analysis of the impact of benefits and services on the costs caregivers incurred, by analyzing two dimensions of costs.

The first dimension reviewed benefits and services that were applicable to the scenarios in each of the policy domains and analyzes the impact of these programs on the costs caregivers incurred. As noted in Chapter 2, the impact of these programs was assessed vis-à-vis three types of economic costs (employment, out-of-pocket expenses and unpaid labour) and two types of non-economic costs (emotional and social well-being) incurred by caregivers.

The analysis was guided by two questions – what costs did caregivers incur as a result of providing care, and what costs were offset by the programs that the caregivers/care receivers received? In assessing impact it became clear that there was a need to capture the complexity of the impact on costs, as a program can simultaneously impact economic and non-economic costs in positive and negative ways.

It is important to note that most programs do not specify the type of cost they potentially offset in their program descriptions. They have been included in the sub-categories of costs that in our view, they were most likely to affect. In addition, some programs affected more than one cost category, and in these cases, the programs were listed in each of the categories they pertained to. The large volume of programs reviewed precludes a detailed analysis for each. We have included three Appendixes to support our policy impact analysis. Appendix E summarizes program availability, eligibility, and suitability by scenario and region. Appendix F summarizes impact on caregiver costs, by scenario and region. Appendix G summarizes caregiver costs by scenario.

The second dimension of analysis woven into each cost category looked across the scenarios to identify which of the five moderating characteristics were particularly significant in influencing the nature or extent of costs caregivers incurred. These characteristics were: care receiver type of disability and severity, caregiver-care receiver proximity and relationship, caregiver employment status, caregiver and/or care receiver income, and caregiver competing demands. We also considered the influence of geography or place of residence (province/territory and rural/urban).

4.1 Economic costs

4.1.1 Employment costs

All caregivers in the scenarios were employed, which reflects the situation of the majority of caregivers aged 25-64 in Canada (Pyper, 2006, p. 5). All incurred employment related costs in order to provide care as each of them adjusted their employment in some way (e.g. taking days off work or requesting an unpaid leave of absence).

Three characteristics were particularly important in influencing the amount of costs incurred in each sub-category: caregivers' employment status and context, care

receivers' disability type and severity (which affected the amount of care needed and therefore, the type and amount of employment adjustments required) and the caregiver/care receiver's proximity.

Employment costs were incurred in the following subcategories:

- Reduced earnings and income-related benefits (e.g. CPP or EI entitlements)
- Unavailability of benefits for intended purpose (e.g. use of vacation or sick leave for caregiving)
- Reduced job security
- Foregone career advancement

Earnings and income benefits

Within the scenarios, the caregivers who were particularly vulnerable to income loss were those who worked in sectors or job types where benefits such as flexible working hours and paid or unpaid sickness or family leave were non-existent; or where the care receiver's disability meant that they had few formal care supports, required extensive amounts of care or had an episodic condition.

All the caregivers in the scenario incurred losses in this category. Luc was particularly vulnerable as a seasonal worker who would lose income and face the potential loss of some or all of his EI benefit if he was unavailable for work due to caregiving. As a home support worker, Evelyn was also in a position in which her work demanded her presence for pre-assigned shifts, which was particularly challenging in caring for Carl, whose condition (bipolar disorder) was episodic. In contrast, Arif, as a commissioned sales person, could schedule days off in order to travel to provide care for his father, however, he did not earn any income unless he made a sale and may have experienced job insecurity if he failed to meet his monthly sales quota. On the other hand, Jim and Joan had relatively well-paying white collar jobs with good benefits and flexibility to arrange their schedules. However, Joan worked for an employer where leaves of absences were not typically available, such that she may have felt vulnerable to losing a promotion or job loss if she requested a leave.

Income loss can also include future losses arising from reduced hours of work and reduced earnings due to caregiving. The potential for these losses could have been significant for caregivers like Luc, who was reliant on EI regular benefits to supplement his income in the off-season. Caregivers who work strictly on commission or who are self-employed do not contribute to these programs, thus their future incomes are seriously compromised as a result of their reduced opportunity to save against retirement or periods of unemployment. In addition, caregivers such as Evelyn and Joan who took time out of the labour market in order to provide care potentially faced reduced CPP entitlements if their absences from the labour market were of an extended duration.

Unavailability of vacation and sick leave benefits for intended purpose

This cost occurs when caregivers use up their vacation or sick leave benefits for caregiving, and experience significant work-life conflict as a result of not having "down-time" from work or caregiving. Within the scenarios, the caregivers who were particularly vulnerable to costs of this type were those who worked in sectors or job types where the basket of leave entitlements were limited or nonexistent, or where the care receiver's disability meant they had few formal care supports, required extensive amounts of care or had an episodic condition.

Of the scenarios, only Evelyn and Jim and Joan work in jobs where they received paid vacation and sick leave. As the primary caregiver, Evelyn (Carl, Frank) was more likely to exhaust her paid leave entitlements compared to Jim and Joan, because her work schedule lacked flexibility. Jim and Joan were able to share caregiving responsibilities to some degree, and Jim had flexibility in terms of arranging his schedule to work from home on certain days.

On the other hand, both Luc and Arif were the most vulnerable in this area, as they worke in jobs that did not provide paid/unpaid sick leave entitlements, and where vacation pay was paid out rather than given as paid leave days. Thus, they were the most likely to go without pay on days they could not work as a result of caregiving responsibilities, which negatively impacted their earnings. They were also the most likely to experience work-life conflict and stress as a result of not being able to have the "down-time" that can come from paid leave entitlements.

Reduced job security

Within the scenarios, employees who were particularly vulnerable to job insecurity or termination as a result of caregiving were those who had precarious employment; those who worked in positions or for employers where employment disruptions as a result of caregiving were perceived as difficult to accommodate or as impeding workflow or productivity; or where the care receiver's disability meant they had few formal care supports, required extensive amounts of care or had an episodic condition.

Each of the caregivers, with the exception of Jim (college instructor), experienced some form of job insecurity. Arif and Luc's employment was the most precarious and by potentially not meeting sales quotas or being available to work as needed during the high season, they were potentially at risk in the longer term of losing their jobs. Joan, who was considering requesting a leave of absence which is atypical for someone in her mid-level position in the company, was concerned about job insecurity as a result of being perceived to be insufficiently committed to her job or the company. As a tenured professor who worked in a sector where working from home for part of the week is the norm, Jim was least likely to experience fear of job security as a result of caregiving demands.

Foregone career advancement

This cost can entail not being selected for, or declining, opportunities for promotion by not being available to work extra hours, travel or take additional training. Within the scenarios, caregivers that were particularly vulnerable to this were those who worked in positions where there were significant advancement opportunities that required additional inputs on the employee's part, or where the care receiver's disability meant they had few formal care supports, required extensive amounts of care or had an episodic condition.

Of the scenarios, Joan was experiencing this cost as she was due for a promotion but feared her potential request for a leave of absence might be interpreted as being unavailable or uncommitted to the demands of the job.

Programs that impact employment costs

Of the various benefits and services those in the scenarios were eligible for, very few directly offset employment costs the caregivers incurred.

It is recognized that employed caregivers in non-precarious jobs may have access to some degree of benefits specific to their workplace that will assist in offsetting some of these costs. It is also recognized that health care supports such as home care, although only available to some of the care receivers in the scenarios, may help reduce the care burden and therefore reduce the level of employment disruptions those caregivers experience.

EI regular and special benefits provide temporary income support to EI eligible Canadians who are unemployed or sick, however it is not available to individuals who temporarily withdraw from the labour market in order to provide care (with the exception of the Compassionate Care Benefit available to a minority of caregivers who are providing care to someone who is gravely ill, which does not apply to any of the scenarios).

CPP has an automatic general drop out provision to reduce the impact of labour force absences or low earnings for any reason (which can include caregiving). However, this provision is capped at 15 % of the contributory period that had the lowest or no earnings, and as such, its impact is not substantial in terms of increasing monthly benefits for caregivers whose CPP contributions are significantly hampered by caregiving responsibilities.

Financial supports targeting caregivers, such as tax credits or grants for caregiving related expenses, may offset a small proportion of the economic dimension of employment related costs. The effectiveness of these in relation to the caregivers in the scenarios and the magnitude of costs they incur will be covered in the next section.

Federal and provincial/territorial labour codes covered all the caregivers in the scenarios, providing basic provisions for vacation pay, and in most cases (with the exception of the majority of Albertan employees that are covered by the Alberta labour

code), 3-5 days unpaid family leave. However, beyond what individual employers may choose to provide, there are no other guaranteed paid or unpaid leave provisions available to employed caregivers.[4].Three to five days of unpaid leave is unlikely to be used by those in precarious or low-wage jobs who cannot sustain the loss of earnings. Moreover, for those who can incur the costs but have a high caregiving burden, three to five days does not suffice. These caregivers are left having to make further employment adjustments, and incur additional employment costs, in order to provide care.

4.1.2 Out-of-pocket costs

Out-of-pocket costs are expenditures from covering costs for the care recipient and from incurring costs related to the provision of care that would not have occurred had the caregiver not been providing care to a family member/friend (Lero et al., 2007; Fast, Williamson, et al., 1999). All caregivers in the scenarios incurred significant out-of-pocket costs as a result of providing care. Several characteristics were particularly important in influencing the amount of costs incurred in each sub-category: care receiver's disability type and severity; the type and amount of income and health support available to the care receiver; geography (rural/urban) and caregiver/care receiver's proximity. In addition, the caregiver's availability to provide care (presence of competing demands such as employment, childcare; family structure) is also an important moderating factor.

Out-of-pocket costs incurred in the scenarios are in the following subcategories (Lero et al., 2007):

- Purchases or expenditures for care receiver: health services or products (e.g. home care, supervision, medical equipment), household adaptation, transportation
- Purchases for caregiver (e.g. respite, counselling, childcare, meals)
- Hotel costs for care receiver (e.g. food, shelter)
- Money transfers to lower income care receivers (e.g. food, clothing, entertainment).

Purchases or expenditures for care receiver

Higher out-of-pocket expenses were incurred by caregivers of people whose disability required housing modifications to be made (Evelyn caregiving to Frank with MS) because of the high cost of these modifications. In Frank's case, his housing situation and his family's income level meant that they were ineligible for programs that offset some of their housing modification costs. Another category of costs determined by disability type is the purchase of additional assistance (e.g. home care, supervision, medical equipment), which was likely the case for Evelyn caring for Carl or Frank, and for Luc. While these supports were available through publicly funded programs

[4] Unpaid sick leave is provided through some labour codes, including federally (12 weeks), and some provinces/territories. Alberta, does not have any unpaid sick leave provisions within its labour code, and Nova Scotia has a three day unpaid leave which is a combined family and sick leave provision.

depending on the care receivers' assessed needs, additional support of this type is often required, particularly for employed caregivers, who are not at home for significant portions of the day.

For some scenarios, the nature of the person's disability meant that they required medical equipment such as wheelchairs in the long term. These costs were covered in the case of care receivers on income support programs, however in the scenarios where the care receiver was ineligible for income support, the caregiver incurred out-of-pocket expenses for this equipment (Luc requiring wheelchair for Noelle).

All caregivers in the scenarios incurred transportation costs to transport and/or accompany the care receiver to medical appointments and as well as other activities. These costs were higher in cases where the caregiver and care receiver did not co-reside, as in Arif and Jim and Joan's cases, who had to travel to the care receiver's community to coordinate care. These costs were also higher in rural areas where public and/or accessible transportation was unavailable, and where travel to urban centres was required for medical treatment. In the latter case, expenses associated with meals and overnight accommodation might also be incurred by the caregiver.

Purchases for caregiver (e.g. respite, counselling, childcare. meals)

Caregivers incur costs associated with purchasing services related to caregiving that they would not otherwise. These included services for the caregiver (e.g. respite, counselling) in Evelyn (Carl, Frank) and Jim and Joan's case, while in Luc's case, it included services (e.g. childcare) that enabled him to provide care to the care receiver.

Services are more likely to be purchased in cases where the care receiver's disability has negatively impacted the caregiver's well-being, leading them to purchase services that enhance their emotional and social well-being. They are also more likely to be purchased in cases where the caregiver has significant time stress due to competing demands (such as employment and care for young children) and few others in the household to assist in providing care (family structure).

Hotel costs for care receiver

Hotel costs were incurred by caregivers of lower-income care receivers co-residing with the caregiver as a result of their disability. Evelyn (Carl and to a lesser degree Frank) incurred costs to supplement the income assistance the care receiver got to meet food and shelter needs. Income assistance levels tended to be modest and therefore could not be relied on as a significant source of income. When all available income supports were taken into account for these care receivers, the benefits alone would not have been sufficient to place the care receiver above the poverty line if they lived independently in any of the four communities.[5]

[5] In 2005, the low income after-tax cut-offs were $11,264 for single persons in Oyen and Parrsboro, $17,219 in Edmonton, and $14,562 in Halifax (Statistics Canada 2007).

Money transfers to lower income care receivers

Money transfers were incurred primarily by caregivers of lower-income care receivers, particularly Evelyn (Carl and to a lesser degree, Frank) and Jim and Joan, to supplement the income assistance the care receiver got, which was unlikely sufficient to cover basic needs such as transportation or clothing.

Programs that impact out-of-pocket expenses

Programs that provided a service (e.g. for respite, home care, medication, transportation, meals) often provided caregivers with a significant benefit at a nominal fee. Thus, the caregiver incurred modest out-of-pocket expenses when using these services but gained a substantial net benefit in terms of reduced economic costs and unpaid labour. However, many of these services were only available to a limited number of caregiver-care receivers and therefore yielded no benefit to those who were outside of the eligibility criteria.

There are also several programs that provide a financial benefit (e.g. tax credits, funds to purchase assistive devices and transportation to medical appointments) which can offset the out-of-pocket expenses incurred by caregivers. However, these benefits tend to be of modest financial value in relation to the amount of the costs caregivers typically incur,[6] and they are often received at the end of the tax year, months after the costs are incurred. Thus, their impact in offsetting out-of-pocket expenses is modest at best. In addition, in the case of some transferable tax credits, the benefit targets the care receiver and will benefit the caregiver only if the care receiver is low-income enough to not utilize the full value of the benefit. Finally, among the tax credit that specifically targets caregivers, a minority of caregivers are eligible due to restrictive eligibility criteria, thus they provide no benefit to the majority of caregivers in Canada.

Disability Tax Credit and transfer: This non-refundable credit targets the person with a disability, however, the eligibility requirements in terms of the severity and duration of impairment meant that only three of the five care receivers in the scenarios qualified (Frank, Melissa, Noelle).[7] Of these three, the monetary benefit only actually accrued to the caregiver in Jim and Joan's case in Alberta, Evelyn's (Frank) case in Nova Scotia, and Luc's case in both provinces through a transfer of the unused portion due to care receiver's low income. With a maximum tax value in 2007 of $1,423 for Nova Scotia

[6] A significant proportion (44 per cent) of caregivers report paying out-of-pocket costs to provide care to their family member. Four in ten report spending between $100 and $300 per month on transportation, non-prescription medications, medical supplies, prescription medications, and other equipment, with another quarter spending in excess of $300. This does not include economic losses associated with lost earnings and benefits. (Decima Research Inc. 2002, 5). To give an idea of the amounts of some typical costs incurred, a basic wheelchair would cost approximately $600-$1000; home care would cost approximately $20 per hour, childcare costs could be upwards of $30 per day per child; and travel, parking, meals and overnight accommodation for medical appointments in an urban centre would be upwards of $150 per trip.

[7] Note that this is significantly higher than the proportion of caregivers in Canada that receive the benefit (less than 10 per cent). Nearly 345,000 persons aged 15 and over reported having claimed the DTC on their income tax return for the year 2000, of which close to 80 per cent (277,000 persons) reported receiving the tax credit (Statistics Canada 2003, 11).

residents and $1,744 for Alberta residents, this benefit had the highest value, but was still unlikely to significantly offset economic costs the caregivers incurred.

METC and transfer: The METC only provides a tax savings of a small proportion (approximately 25 per cent) of eligible expenses in excess of approximately $1,637 (Nova Scotia) or $1,900 (Alberta). While anyone, including all the caregivers in the scenarios, could in theory claim the METC (either directly or through transferring the unused portion of their care receiver's claim) the caregiver-care receiver is still absorbing the vast majority of the out-of-pocket costs. In addition, certain costs (e.g. transporting care receivers for medical treatment with roundtrips less than 80 kilometres, transportation for non-medical needs such as socialization) cannot be claimed. Lower-income families such as Luc and Noelle, and Evelyn and Carl/Frank would have found it very difficult to absorb these costs.

Caregiver/Infirm Dependent credit: Along with the Eligible Dependent Credit, these are the only credits that specifically target caregivers, and caregivers are only able to apply for one of the three credits. The maximum value of the caregiver credit is $903 (Nova Scotia) and $1,019 (Alberta) while the maximum value of the infirm dependent credit is $830 (Nova Scotia) or $1,019 (Alberta). The non-refundable nature, along with the income thresholds of these credits means that a very narrow income bracket of caregivers (caregivers of people who pay taxes and therefore have incomes above the personal exemption amounts but close to or below the poverty line) will benefit from them. Among the scenarios, only two out of the five caregivers (Evelyn (Carl, Frank)) received one of these credits.

Not-for-profit organization grants for transportation to medical appointments and assistive devices: These grants, which are in the $250-$500 range, are useful, but only offset a small proportion of the costs caregivers are likely to incur in these areas.

4.1.3 Unpaid labour costs

Unpaid labour results from time spent by family/friend caregivers providing care to a family member/friend. All caregivers in the scenarios incurred significant unpaid labour costs as a result of providing care.

Three characteristics were particularly important in influencing the amount of costs incurred in each sub-category. First, the care receiver's disability type and severity determined the needs for particular forms of assistance and eligibility for certain services (primarily in the health domain) that might reduce the unpaid care required. Second, the caregiver/care receiver's proximity influenced transportation time and level of involvement in day to day activities. Third, the province of residence influenced the availability of programs and services.

Unpaid labour costs were incurred in the scenarios in the areas of:

- Direct care services (e.g. personal care)
- Supervision, coaching, mentoring and emotional support

- Coordination and case management
- Transportation

Provision of direct care services

Direct care services provided in the scenarios included personal care related to activities of daily living (self-care, eating and food preparation) that the care receiver was unable to do without help, as well as specialized care that was required due to the care receiver's disability (for example, Frank required medication by injection for his MS). While formal care supports such as home care provided for some of the personal care needs of the care receiver, the amount and scope of these services meant that caregivers in the scenarios had to supplement what is provided.

Within the scenarios, the caregivers that provided the most unpaid labour in this sphere were those caring for people whose disability type involved significant personal care needs: Evelyn to Frank with MS, Jim and Joan to Stephanie who had mobility problems, and Luc to Noelle who experienced weakness or chemo-related illness.

Provision of supervision, coaching, mentoring and emotional support

Within the scenarios, there were care receivers who were able to meet their personal care needs, but who required other forms of assistance: semi-constant supervision to ensure that their needs were met and there safety not compromised; assistance to ensure they followed through on plans, attended appointments and events; and coaching, mentoring or emotional support to help them cope with their disability and take an active role in their well-being.

All the caregivers in the scenarios incurred significant costs in this area, though the specific types of support they provided differed depending on the care receiver's disability type, severity and emotional/mental health. Those providing care to someone with a mental health condition (Evelyn (Carl) and Arif) had to provide supervision to ensure appointments and other health related matters were attended to and to ensure the safety of the care receiver. As someone caring for a person with an episodic condition, Evelyn also regularly monitored Carl for relapses and erratic behaviours. On the other hand, Jim and Joan and Luc had to provide their care receivers with significant emotional support as their care receiver adjusts to life with a significant disability.

Provision of coordination and case management

Within the scenarios, the caregivers were often required to identify, schedule and coordinate supports used by the person with a disability. While discharge planning or case management may be made available in some cases through the formal care system, families still had to play a significant role in this area.

At one end of the spectrum, those caring for people at an early stage of an illness where formal care supports had not yet been engaged (e.g. Arif) or those caring for persons with an illness for whom fewer formal care services exist (e.g. Evelyn (Carl)) incurred significant unpaid labour costs trying to map what was available and how to access it in

order to assist their care receiver. At the other end, those caring for people whose illnesses meant they were connected to numerous service providers in and outside the home had to spend significant amounts of time coordinating schedules and payments for the various services providers (e.g. Evelyn (Frank), Jim and Joan, and Luc).

Provision of transportation

All caregivers in the scenarios incurred transportation costs, though the amount depended on the extent to which the disability impeded the care receiver's ability to travel independently; whether the therapeutic services they needed were provided at home or in the community, and the caregiver-care receiver's proximity.

Within the scenarios, most caregivers spent significant amounts of time transporting and/or accompanying the care receiver to and from appointments, including specialist appointments in other communities, and therapeutic activities (e.g. peer support groups) (Evelyn (Carl, Frank), Jim and Joan, Luc). These costs were higher for those living in rural areas. In addition, some of the caregivers in the scenarios incurred significant travel time to get to the care receiver's home (e.g. Arif).

Programs that impact unpaid labour costs

Of the various benefits and services those in the scenarios are eligible for, very few will offset a substantial portion of the unpaid time caregivers spend providing care.

Home care can offset the unpaid labour time caregivers' spend on personal care tasks. However, there are significant limits in terms of the amount of assistance and types of tasks that home care assists with. Moreover, it is geared towards persons whose needs stem from physical limitations, or who are elderly and have significant needs for assistance. Thus, caregivers of persons with mental illness, such as Evelyn (Carl) and those with early dementia, such as Arif's father, will not typically receive any home care and will incur substantial unpaid labour costs in this area.

Not-for-profit sector supports such as information/referral/navigation services, education/training, and peer support/self-help groups all help offset some of the unpaid labour caregivers provide, by providing caregivers with training to perform care tasks more efficiently, and with information and case management to reduce the amount of time they spend in these areas. These services are usually available at no charge. While, caregivers will incur unpaid labour time to participate in them, there may be a net benefit in terms of offsetting the overall unpaid labour costs they incur. These services, however, are not as widely available in rural areas.

4.2 Non-economic costs[8]

4.2.1 Emotional costs

Costs to emotional well-being include being stressed for time or energy and experiencing worry or depression. All caregivers in the scenarios incurred significant costs to their emotional well-being as a result of providing care.

Within the scenarios, three characteristics were particularly important in influencing the sources and extent of poor emotional well-being: care receiver's disability type and care needs; the caregivers' circumstances, such as presence of competing demands (e.g. employment, care for young children or other dependents); and the caregivers' income and employment status (which affects the extent to which they can purchase supports to reduce the care burden and their access to workplace flexibility).

Among the caregivers in the scenarios, those caring for people whose disability or illness had an unclear prognosis or who were likely to require care over a long period of time (Arif, Jim and Joan, and Luc), were likely to be under stress. Caregivers of people who lack insight into their illness (Evelyn (Carl), Arif) and/or who had unpredictable, stressful behaviours associated with their disability that require constant monitoring (Evelyn (Carl)) were likely to experience increased anxiety.

As all the caregivers in the scenarios were employed, they all experienced the time-stress of juggling paid work and unpaid care. Caregivers that lacked job security or workplace benefits that could facilitate work-life balance (Arif, Luc) were likely to experience increased stress and anxiety, as were those who were lower income and could not afford to purchase services that might facilitate emotional well-being (e.g. Evelyn (Carl, Frank), Luc). As well, caregivers with other competing demands such as childcare (Luc) were likely to experience increased stress juggling paid work, childcare and caregiving.

Programs that impact emotional costs

Home care (to the extent that case management is available through it) and respite, for those caregivers such as Evelyn (Frank), Jim and Joan, and Luc that have access to them, contributed to reduced stress and anxiety. In the case of Luc, the cancer care patient navigator may have helped to reduce stress as a result of having professional case management services available.

Not-for-profit sector supports such as education/training and peer support/self-help groups can offset some of the emotional costs associated with caregiving by providing caregivers with information about the care receiver and a peer group from which to learn and share experiences. These services are available at no charge. While, caregivers will incur unpaid labour time to participate in them, there may be a net benefit in terms of offsetting emotional costs.

[8] As noted in the methods section, physical health and well-being costs were not considered in this study.

4.2.2 *Social* costs

Costs to social well-being include social isolation and reduced participation in social and voluntary activities as a result of caregiving. All caregivers in the scenarios incurred costs to their social well-being as a result of providing care.

Within the scenarios, three characteristics were particularly important in influencing the sources and extent of poor social well-being: care receiver's disability type and care needs; the caregivers' circumstances, such as presence of competing demands (e.g. employment, care for young children or other dependents); and income and employment status (which affected the extent to which they could purchase supports to reduce the care burden and their workplace flexibility).

Caregivers of people whose disability involved stigma or socially awkward behaviours, such as Evelyn caring for Carl, were at risk of having their social life impeded. As well, caregivers of persons whose disability type renders their caregivers ineligible for respite services, and lower-income caregivers, lacked affordable care options to free them up to engage in social activities (Evelyn (Carl), Luc). On the other hand, caregivers with heavy caregiving demands potentially lacked time and energy to participate in social activities (Evelyn (Frank), Jim/Joan, Luc). Caregivers with partners or young children were at risk of potentially disrupted social relationships, as their energy became focused on the care receiver to the exclusion of other family members or friends (Arif, Jim and Joan, Luc).

Programs that impact social costs

Respite services (home-based, day or facility-based) aim to provide caregivers with a break and time to engage in activities that enhance their social well-being. While these services typically involve a daily fee, ranging from $5 (day programs) to $50 or more (facility-based respite), the net benefits in terms of offsetting social costs can be high.

It is important to note that not all the caregivers in the scenarios were eligible for respite (Evelyn (Carl)) because respite services tend to have a medical orientation and are geared towards the needs of older adults. Thus, it is easier to qualify for respite if the care receiver needs physical support or would qualify for nursing home care, rather than those who need more general supervision for mental health conditions, putting these caregivers at particular risk of poor social well-being.

In addition, even the only caregiver who qualified for respite (Evelyn (Frank) in Edmonton), encountered limits in terms of what was available to her. For example, facility-based respite is limited to a number of weeks per year, while the hours of home-based respite are modest in most home care programs, and priority is often given to caregivers who are providing 24-hour care and not employed.

Not-for-profit sector supports such as peer support/self-help groups can help offset some of the social isolation associated with caregiving. These services are available at no-charge. While, caregivers will incur unpaid labour time to participate in them, there may be a net benefit in terms of offsetting social costs.

Chapter 5. Policy implications

Our policy analysis highlighted the complexity of assessing the impact on policies on costs caregivers incur. While programs and services often have costs, these costs need to be assessed in relation to the costs that would be incurred in the program did not exist – in other words, the net benefit of the program or policy instrument. Some programs or services have out-of-pocket costs, but offset another cost, such as time. Other programs might have a cost and a saving in the same category, such as a training program that might take the caregiver's time initially, but save time and effort related to care in the long run by giving the caregiver skills to be more efficient.

Our policy impact analysis demonstrated a number areas in which policies are likely to affect the economic and non-economic consequences experienced by caregivers. In this chapter, we focus on policy implications that are particularly specific to the population of caregivers that are employed and providing care to adults with disabilities. To summarize the policy implications of our findings, we have identified three policy-relevant question areas that have emerged from our analysis.

1. What is distinct about the economic and non-economic costs that **employed caregivers** incur? To what extent do policies and programs address the caregiving costs arising from different employment situations?
2. What is distinct about the economic and non-economic costs **caregivers of adults with disabilities** incur? To what extent do policies and programs address the caregiving costs arising from providing care to non-senior adults?
3. Is assistance to **identify and navigate supports** that might ameliorate caregivers' economic and non-economic costs provided in an effective manner?

In this chapter, we summarize the key issues in these three question areas, and highlight policy implications.

5.1 Employed caregivers

As noted in Chapter 4, employed caregivers are at risk of incurring a range of costs in the employment sphere that non-employed caregivers do not incur. In many cases, these employment consequences will negatively impact caregivers' economic security and emotional and social well-being.

Public policies to offset employment related costs and help employed caregivers of adults manage work and care are minimal, highly inadequate and in some cases, inaccessible to the majority of employed caregivers. This is in contrast to the more robust supports available to assist employees with infants or young children balance work with caregiving to this population.

5.1.1 Flexible work arrangements, leave, earnings replacement

Federal and provincial/territorial labour codes do not have provisions guaranteeing employees' right to reduce or alter work hours; or have paid leave in order to deal with caregiving responsibilities. Some jurisdictions have unpaid family leave provisions which can be used for caregiving responsibilities. However, this does not exceed five days in any jurisdiction. For lower-income caregivers, the earnings loss associated with unpaid leave may mean it is not a viable option for them. The only form of publicly provided leave and earnings replacement is the EI Compassionate Care Benefit. However, this benefit applies to an extremely narrow range of caregiver circumstances and therefore will not reach the majority of employed caregivers that temporarily withdraw from the labour market in order to provide care. In addition, the low earnings replacement level means that it may not be a viable option for many caregivers. Moreover, in Alberta, legislation has not been enacted to provide job protection while on this benefit, thereby raising accessibility issues for those in the province who may be considering utilizing it.

Enacting labour code provisions guaranteeing employees greater flexibility regarding hours or location of work and longer unpaid leave for family responsibilities will go some ways towards addressing the needs of employed caregivers. However, some caregivers with heavy caregiving demands may need to substantially reduce their work hours or withdraw from the labour market for a period of time in order to provide care. In order for this to be financially sustainable, some type of financial benefit that recognizes lost earnings and some level of job protection likely needs to be in place. In this regard, EI maternity/parental and compassionate care benefits could serve as models, particularly the former, as it is available to a far more substantial proportion of the employees with care responsibilities.

Employers play a far more significant role than governments in providing tangible supports for balancing work and caregiving, however, these are specific to collective agreements, workplaces or in some cases, particular managers. In terms of accessibility, these benefits tend to be available in large workplaces, and to those in higher-paying and/or white-collar jobs. These benefits are not typically available to those in low-wage or non-standard work arrangements (e.g. part-time or temporary employees).

Governments could play a greater role in this regard – both as a best practice employer, and by assessing the benefits of these provisions and promoting their implementation in workplaces.

5.1.2 Home care, respite and day programs

Respite services such as adult day programs are organized to provide a break from caregiving. However, hours of service that are much shorter than a workday, and limited availability (services can not be utilized every day or several months in a row) mean they are implicitly not aimed at providing a means for caregivers who are employed to cope with paid work and caregiving. Similarly except in cases where the disability is very severe, home care or attendant care is not available for the full duration of a

workday or for lengthy periods of time, and is therefore not a viable option for most employed caregivers to cope with paid work and caregiving.

Given the minimal amount of supports available to offset employment consequences and help caregivers manage the competing demands of paid work and unpaid caregiving, employed caregivers must often turn to other care supports (e.g. purchasing paid support, involving other unpaid caregivers) to cover caregiving during the time they are at work. On the positive side, those with good workplace benefits (e.g. extended health insurance; employee assistance programs) may have access to funds and services that ease some of this burden compared to those who do not have these benefits.

5.2 Caregivers of adults with disabilities

The economic costs, particularly the out-of-pocket expenses, incurred by caregivers of adults with disabilities are high in many cases. This is partly because the care receivers are more likely to have fewer financial assets to contribute towards their care than other types of care receivers, and are more likely to subsist on sporadic employment income or a public income support program. In addition, depending on the type and severity of disability, there may be few health and economic supports available to care receivers (e.g. those whose disability is not physical in nature; those whose disability is significant, but not severe) which results in additional unpaid labour and out-of-pocket costs for their caregiver.

The age of onset of the condition (e.g. in young adulthood for most of the scenarios) is a significant influence on the economic and non-economic costs of caregiving to non-senior adults with disabilities in three ways. The first is that the economic and non-economic costs incurred over a lifetime are likely to be considerably higher than many other subpopulations of caregivers (e.g. caregivers of the elderly) because the duration of care provided is likely to be longer, and the consequences accumulate over time (Fast, Keating & Yacyshyn, 2008). Second, to the extent that the disability is present during the care receiver's formative years, it can hinder their ability to acquire an education and career and form relationships. This can reduce the financial assets and human capital they have to contribute towards their care when compared to other types of care receivers, and increase the burden on the caregiver.

In terms of non-economic costs, stress, exhaustion and poorer overall emotional and social well-being is associated with situations where care demands are heavy or lifelong (Fast, Keating & Yacyshyn, 2008). Another set of costs is associated with the stigma that accompanies certain types of disability (e.g. mental illness), which can result in social isolation and other non-economic costs for the caregiver (Cook, 2007). Stigma associated with the care receiver's disability or awkward behaviours may preclude some caregivers from seeking assistance from colleagues, friends and not-for-profit sector organizations.

5.2.1 Programs and supports benefiting caregivers

Home supports

In terms of unpaid labour costs, the amount of formal in-home supports provided to those who are eligible for it may supplement the unpaid labour caregivers provide, but it does not eliminate the need for it. In fact, current research indicates that families actually provide more care to care recipients who receive home care, but that home care can provide some relief from particular caregiving tasks (Keating, Dosman, Swindle, & Fast, 2008). Publicly-funded in-home support reduces out-of-pocket costs of having to hire private help, but is probably just as important as a way of addressing emotional and social well-being costs of caregivers.

Programs for home support that offer funds to families and latitude for care receivers and caregivers to decide how they are spent on home support, can be beneficial because they have the flexibility to meet changing needs. An excellent example of such a program is the Veteran's Independence Program, which provides Veterans and their spouses with funds for needed supports and allows them to hire their own help. Another good example is Nova Scotia's Direct Family Support Program, which funds both in-home help and other needs such as transportation and equipment.

However, some of these programs do not allow the family caregivers to manage the funds on the care-receiver's behalf. In relation to the economic and non-economic costs of caregiving, an important question to ask is, who is the recipient of home supports? Most services are organized primarily for the individual needing support, with support of family caregivers as a secondary consideration. If in-home supports were restructured so that the unit of care was the family rather than the individual, perhaps these programs would go further in ameliorating the non-economic costs of caregiving.

Tax credits and transfers

Almost no public programs specifically target caregivers of persons with disabilities and recognize the unique cumulative costs they may incur over their lifetime. The DTC, for example, is an annual credit that is difficult for most care receivers to obtain, and only directly benefits the caregiver if the care receiver is so low-income as to be able to transfer the unused portion of the benefit to the caregiver.

In terms of caregivers, the maximum value of the three main tax credits caregivers can receive one of, is modest. Moreover, while employed caregivers usually earn enough to benefit from these credits, the income thresholds for the care receiver are set so low that a small proportion of caregivers can actually claim the benefit, with middle class caregivers not eligible. Conversely, the non-refundable nature of these credits means those who do not have taxable income (annual income under $9600 in 2007) do not receive any benefit from these credits. In addition, spouses are ineligible for these credits, increasing the burden for that particular caregiver.

If governments are looking to caregivers to provide care in a sustained fashion, it is important to provide them with support to enable them to continue to do so. Existing

benefit levels should be assessed against how they match the costs caregivers incur. As well, it is important to document what proportion of caregivers providing significant amounts of care receive few or no benefits from existing programs because they do not meet eligibility criteria. Finally, it is important to assist not-for-profit sector organizations providing much needed supports to caregivers, and to assess the accessibility and adequacy of existing respite services in relation to demand.

Not-for-profit sector supports

Supports such as peer support groups and education sessions play a potentially important role in offsetting the non-economic costs. While there is generally no cost to attend these programs, they do require an investment of time, and in some cases, are not available for specific health conditions or in rural communities. In addition, they tend to be available for very limited blocks of time.

Development of alternative formats for providing support, information, education and navigation can offset some of the difficulties involved in accessing these services. However, there is also a need to decentralize caregiver support services and to foster local capacity to provide these kinds of supports. Since these supports are largely in the not-for-profit sector, grants could be offered to facilitate development of services to meet needs of rural caregivers and other under-supported groups of caregivers.

Supports for rural caregivers

Urban-rural differences in services and programs were most apparent in the availability of programs for caregivers and care receivers in local areas. This had the potential to impact on out-of-pocket costs (particularly for transportation), as well as social and emotional costs associated with caregiving.

Provision of services to rural areas is an ongoing Canadian challenge. While there are some pockets of funding for transportation for appointments, these typically have very low income thresholds for eligibility, and/or are funded only for specific diseases. Better rural public transportation systems for all citizens, including accessible transit, would go a long way to ensuring that people have options for getting to needed services other than relying solely on family caregivers. Recognition of rural travel related to health care is a part of the medical expense tax credit, but other strategies that would directly benefit caregivers who are providing transportation might be explored.

5.2.2 Programs and supports benefiting care receivers

Addressing eligibility for non-senior adults with cyclical or fluctuating disability

Many health services and income supports focused on maintaining care receivers in the community have eligibility requirements aimed at persons with physical impairments or older adults, and are difficult for younger adults or those with non-physical impairments to meet. Public programs are not particularly effective in recognizing the distinct needs that arise from certain disability types and severity levels. Persons with disability types that are episodic or result in fluctuations in health or ability, such as mental illness and multiple sclerosis, are far less likely to be deemed eligible for income benefits that

require the disability to be severe and permanent or prolonged, such as AISH, CPP-Disability or the DTC. While these benefits do not directly target or benefit the caregiver (except the DTC if transferred), they do affect the assets the care receiver has to contribute to their basic needs.

In-home and day program supports are also rarely available or unsuitable for persons with mental illness or whose health conditions fluctuate. There are virtually no public programs available in an ongoing fashion to provide assistance to persons whose disability entails needing supervision, encouragement and/or case management, but not assistance with activities of daily living.

Given the relative lack of supports for persons with disabilities that are non-physical or of a significant (but not permanent) level of severity, introducing supports that target this population and would be a useful step forward in reducing the burden on caregivers. In addition, introducing provisions into income benefit programs that recognize the long-term economic impact of providing lifelong care to a person with a disability would be useful in reducing the economic costs that caregivers to these populations incur.

Addressing adequacy of benefits and regional differences

Two issues arise in relation to programs and services available to care receivers. First, many of these programs offer barely adequate or inadequate benefits. Second, there is wide variation in what is available from province to province. Income support, in-home supports, and equipment subsidy programs impact on the costs of caregiving because the caregiver is called upon to supplement hotel, equipment or care costs, or to provide unpaid care. While it is recognized that there are cost of living differences across the country, it seems that as a minimum there should be movement towards these three kinds of support:

1. A guaranteed income for persons with disability, that had the flexibility to allow part-time or sporadic employment but that was not dependent on workforce participation, and that provided a benefit level that was above the poverty line so that people would not have to live in a situation of constant potential crisis. Public programs targeting the care receiver, such as the CPP-D and AISH and the disability top up associated with social assistance, go part-way towards recognize that the disability affected the ability to participate in employment and accrue assets, however, the benefit levels are so meagre that the care receiver remains below the poverty line. Some European countries, such as Sweden and Austria, have come much further in recognizing the need, and potential benefits of providing adequate income support to people with disabilities (European Disability Forum, 2002).
2. A home-support program that offered flexible care based on both needs and preferences of individuals.
3. An equipment provision system that subsidizes the cost of necessary mobility and medical devices based on need, rather than income, such as the AADL program available in Alberta. Equipment that works properly can make caregiving easier and safer. While many provinces fund or co-fund equipment for people receiving income

supports, ideally income provision subsidies should not be tied to other programs but rather based on the need of the care receiver.

5.3 Identifying and navigating supports

Caregivers incur substantial costs in terms of unpaid labour and stress trying to identify information about, and access suitable supports for themselves and their care receiver, while in the midst of providing care to their loved one. Indeed, in conducting this study, it took several months of internet searching and telephone calls to identify available supports and details about eligibility criteria in order to conduct our policy impact analyses.

Information about supports is not coordinated by any one party nor available in one spot at the federal, provincial/territorial, or regional level. This is largely due to the involvement of numerous government and non-government providers, the use of different eligibility criteria by provider type, and the different levels of information each has chosen to make available about their programs. Once information is obtained, few caregivers / care receivers have access to case managers to help navigate the system of supports, and find suitable alternatives if particular supports are unavailable.

Because many supports are accessed at the regional level, undertaking pilot projects to create internet or telephone based clearinghouses of information on relevant supports would be a useful starting point. In addition, funding service navigators through the health or social service system and assigning navigators to families would free up caregivers time and reduce the stress associated with trying to navigate the system on their own.

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APPENDIXES

Appendix A: Summary of regional characteristics

Region	Alberta		Nova Scotia	
Name of Area	Edmonton*	Oyen	Halifax*	Parrsboro
Type of setting	urban	rural	urban	rural
Population in 2006	1,034,945	1,015	372,858	1,401
Land area (square km)	9,417.88	4.93	5,495.62	14.88
Population density	109.9	205.9	67.8	94.1
Unemployment rate in 2006	4.6%	0.0%	6.3%	9.5%
Median 2005 total income for men	$38,425	$23,797	$33,744	$26,207
Median 2005 total income for women	$22,275	$22,232	$21,891	$14,865

*Census metropolitan areas

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Appendix B: Stakeholders

Fiona Haysom
Caregiver Support Coordinator
Caregivers Nova Scotia

Lisa Mills
Palliative Care Consult Nurse
South Cumberland Community Care Centre
Parrsboro, NS

Sandra Bauld
Senior Director
Northwood Home Care Limited

Diana McIntyre
Alberta Caregivers Association

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Appendix C. Income calculations for scenarios

Table C1. Caregiver employment income

Employment Income by profession in 2007, population 15+	Edmonton	Oyen	Halifax	Parrsboro
Scenarios 1 and 2: Evelyn Home support worker - female (code)	(6741) $12.76/hr x 40hrs/wk x 52 wks Gross annual income: **$26,540**	(6741) $12.00/hr x 40hrs/wk x 52 wks Gross annual income: **$24,960**	(6741) $12.00/hr x 40hrs/wk x 52 wks Gross annual income: **$24,960**	(6741) $12.00/hr x 40hrs/wk x 52 wks Gross annual income: **$24,960**
Scenario 3: Arif Retail sales clerk – male (code)	(6421) $12.75/hr x 40hrs/wk x 52 wks Gross annual income: **$26,520**	(6421) $10.60/hr x 40hrs/wk x 52 wks Gross annual income: **$22,048**	(6421) $10.00/hr x 40hrs/wk x 52 wks Gross annual income: **$20,800**	(6421) $10.00/hr x 40hrs/wk x 52 wks Gross annual income: **$20,800**

Scenario 4: Joan Financial manager (specialist manager) - woman (A111)	(0621) $40.74/hr x 40hrs/wk x 52 wks Gross annual income: **$84,739**	(0621) $24.83/hr x 40hrs/wk x 52 wks Gross annual income: **$51,646**	(0621) $31.00/hr x 40hrs/wk x 52 wks Gross annual income: **$64,480**	(0621) $30.74/hr x 40hrs/wk x 52 wks Gross annual income: **$63,939**
Jim College professor – male (E12)	(4131) $29.01/hr x 40hrs/wk x 52 wks Gross annual income: **$60,341**	(4131) $26.79/hr x 40hrs/wk x 52 wks Gross annual income: **$55,723**	(4131) $25.00/hr x 40hrs/wk x 52 wks Gross annual income: **$52,000**	(4131) $27.51/hr x 40hrs/wk x 52 wks Gross annual income: **$57,221**
Scenario 5: Luc Contractors, operators and supervisors in agriculture, horticulture and aquaculture – male (I01)	Average EI benefit: $288 for 18 wks = $5,184/yr Assume wkly wages were $523 (55% of this = wkly EI benefit) for remainder of yr (34 wks) = $17,782/yr Gross annual income: **$22,966***	Average EI benefit: $288 for 18 wks = $5,184/yr Assume wkly wages were $523 (55% of this = wkly EI benefit) for remainder of yr (34 wks) = $17,782/yr Gross annual income: **$22,966***	Average EI benefit: $336 for 13 wks = $4,368/yr Assume wkly wages were $610 (55% of this = wkly EI benefit) for remainder of yr (39 wks) = $23,790/yr Gross annual income: **$28,158***	Average EI benefit: $336 for 13 wks = $4,368/yr Assume wkly wages were $610 (55% of this = wkly EI benefit) for remainder of yr (39 wks) = $23,790/yr Gross annual income: **$28,158***

*Assumptions: no urban/rural difference; works ~ 43 hrs/week; the type of work they do allows them to work for ¾ of the year.

Source of hourly salary information for scenarios 1-4:
http://www.labourmarketinformation.ca/standard.asp?ppid=43&lcode=E&prov=&gaid=&occ=&search_key=1&pre_sel_criteria=0

Scenario 5 information obtained by personal communication, Service Canada, December 2008.

Table C2. Caregiver and care receiver income from public income support programs and employment

	Edmonton	Oyen	Halifax	Parrsboro
Scenario 1: Carl Provincial income assistance (living at home, no top up)	$464 core benefits + $78 personal needs supplement = **$542/month** Gross annual income: **$6,504**	$464 core benefits + $78 personal needs supplement = **$542/month** Gross annual income: **$6,504**	$223 shelter allowance + $208 personal allowance + $115 comfort allowance = **$546/month** Gross annual income: **$6,552**	$223 shelter allowance + $208 personal allowance + $115 comfort allowance = **$546/month** Gross annual income: **$6,552**
Evelyn's mother: OAS + GIS + any available provincial benefit	$502.31 (max OAS) + $634.02 (max GIS) + $240 monthly (max Alberta Seniors Benefit) = **$1,376.33/month** Gross annual income: **$16,516**	$502.31 (max OAS) + $634.02 (max GIS) + $240 monthly (max Alberta Seniors Benefit) = **$1,376.33/month** Gross annual income: **$16,516**	$502.31 (max OAS) + $634.02 (max GIS) = **$1,136.33/month** Gross annual income: **$13,636**	$502.31 (max OAS) + $634.02 (max GIS) = **$1,136.33/month** Gross annual income: **$13,636**

Scenario 2: Frank Provincial income for disabled person (living at home)	(AISH) = **$1,050/month** Gross annual income: **$12,600**	(AISH) = **$1,050/month** Gross annual income: **$12,600**	$223 shelter allowance + $208 personal allowance + $115 comfort allowance = **$546/month** Gross annual income: **$6,552**	$223 shelter allowance + $208 personal allowance + $115 comfort allowance = **$546/month** Gross annual income: **$6,552**
Evelyn's mother: OAS + GIS + any available provincial benefit	$502.31 (max OAS) + $634.02 (max GIS) + $240 mnthly (max Alberta Seniors Benefit) = **$1,376.33/month** Gross annual income: **$16,516**	$502.31 (max OAS) + $634.02 (max GIS) + $240 mnthly (max Alberta Seniors Benefit) = **$1,376.33/month** Gross annual income: **$16,516**	$502.31 (max OAS) + $634.02 (max GIS) = **$1,136.33/month** Gross annual income: **$13,636**	$502.31 (max OAS) + $634.02 (max GIS) =**$1,136.33/month** Gross annual income: **$13,636**
Scenario 3: Dev CPP (+ employer pension and RRSP/ investments)	$863.75 (max CPP) & $502.31 (max OAS) = $1,366.06 (assume with employer pensions ($25,000/yr) & RRSP ($20,000) = $3,750/month) = **$5,116/month** Gross annual income: **$61,392***	$863.75 (max CPP) & $502.31 (max OAS) = $1,366.06 (assume with employer pensions ($25,000/yr) & RRSP ($20,000) = $3,750 / month) = **$5,116/month** Gross annual income: **$61,392***	$863.75 (max CPP) & $502.31 (max OAS) = $1,366.06 (assume with employer pensions ($25,000/yr) & RRSP ($20,000) = $3,750/month) = **$5,116/month** Gross annual income: **$61,392***	$863.75 (max CPP) & $502.31 (max OAS) = $1,366.06 (assume with emplyr pensions ($25,000/yr) & RRSP ($20,000) = $3,750/month) = **$5,116/month** Gross annual income: **$61,392***

Scenario 4: Melissa Provincial income assistance (living alone)	$687 core benefits + $78 personal needs supplement = **$765/month** Gross annual income: **$9,180**	$687 core benefits + $78 personal needs supplement = **$765/month** Gross annual income: **$9,180**	Up to $535 shelter allowance + $208 personal allowance + $115 comfort allowance = **$858/month** Gross annual income: **$10,296**	Up to $535 shelter allowance + $208 personal allowance + $115 comfort allowance = **$858/month** Gross annual income: **$10,296**
Scenario 5: Noelle	No income	No income	No income	No income

*In 2007, persons with incomes greater than $63,511 had 15 per cent of their OAS clawed back; Dev's annual income is $61,392, so he keeps his full OAS benefits.

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Federal government

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Appendix E. Program availability, eligibility, and suitability by scenario and region

Scenario 1. Evelyn: Caregiver to her brother with bipolar disorder

PROGRAM	Edmonton, Alberta	Oyen, Alberta	Halifax, Nova Scotia	Parrsboro, Nova Scotia
Caregiver's personal income	$26,541	$24,960	$24,960	$24,960
Caregiver's family income	$49,561	$47,980	$45,148	$45,148
Care receiver's personal income	$6,504	$6,504	$6,552	$6,552
Care receiver's family income	Because he is single, same as his individual income	Because he is single, same as his individual income	Because he is single, same as his individual income	Because he is single, same as his individual income
HEALTH CARE				
Home Care	Not eligible due to disability type	Not eligible due to disability type	Not eligible due to disability type	Not eligible due to disability type
Day programs	✓	Not available	✓	✓
Facility-based respite	Not eligible due to disability type	Not eligible due to disability type	Not eligible due to disability type	Not eligible due to disability type
Medication	✓	✓	✓	✓
Medical equipment: long-term/ purchase	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Medical equipment: short-term/loan	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Consultative services: in home	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Consultative services: in city/regions	✓	✓	✓	✓
Consultative services: specialist/tertiary	✓	✓	✓	Available in Truro
Emergency ambulance services	✓	✓	✓	✓

NOT-FOR-PROFIT SUPPORT SERVICES				
Information/ referral/ navigation services	✓	✓	✓	✓
Education/ training services	✓	✓	✓	Not available
Support/self-help groups	✓	Not available	✓	Not available
Travel assistance	Not available	Not available	Not available	Not available
Meal programs	✓	✓	✓	Not available
INCOME SECURITY				
Old Age Security (OAS)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan (CPP)	Not eligible	Not eligible	Not eligible	Not eligible
Canada Pension Plan Disability (CPP-D)	Not eligible	Not eligible	Not eligible	Not eligible
Alberta Works Income Support (IS) (AB)	✓	✓	Not applicable to case	Not applicable to case
Assured Income for the Severely Handicapped (AISH) (AB)	Not eligible	Not eligible	Not applicable to case	Not applicable to case
Employment Support and Income Assistance (ESIA) (NS)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Direct Family Support Program (DFS) (NS)	Not applicable to case	Not applicable to case	✓	✓
Disability Tax Credit (DTC) (and transfer option)	Not eligible	Not eligible	Not eligible	Not eligible

Medical Expense Tax Credit (METC) (including METC for other dependents)	✓	✓	✓	✓
Caregiver Credit	✓	✓	✓	✓
EMPLOYMENT				
Family responsibility leave	Not available	Not available	✓	✓
TRANSPORTATION				
Intracity	✓	✓	✓	Not available
Intercity	✓	✓	✓	Not available
Disability parking passes	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
HOUSING				
Housing modification programs	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case

Scenario 2. Evelyn: Caregiver to her brother with multiple sclerosis

PROGRAM	Edmonton, Alberta	Oyen, Alberta	Halifax, Nova Scotia	Parrsboro, Nova Scotia
Caregiver's personal income	$26,541	$24,960	$24,960	$24,960
Caregiver's family income	$55,657	$54,076	$45,148	$45,148
Care receiver's personal income	$12,600	$12,600	$6,552	$6,552
Care receiver's family income	Because he is single, same as his individual income	Because he is single, same as his individual income	Because he is single, same as his individual income	Because he is single, same as his individual income
HEALTH CARE				
Home Care	✓	✓	✓	✓
Day programs	✓	Not available	Not eligible	Not suitable
Facility-based respite	✓	Available in Medicine Hat	Not suitable	Available in Springhill
Medication	✓	✓	✓	✓
Medical equipment: long-term/purchase	✓	✓	✓	✓
Medical equipment: short-term/loan	✓	✓	✓	✓
Consultative services: in home	✓	✓	✓	✓
Consultative services: in city/regions	✓	Some services available in Oyen; others available in Medicine Hat	✓	Some services available in Parrsboro; others available in Amherst
Consultative services: specialist/tertiary	✓	Available in Medicine Hat or Calgary	✓	Available in Amherst or Halifax
Emergency ambulance services	✓	✓	✓	✓

NOT-FOR-PROFIT SUPPORT SERVICES				
Information/ referral/ navigation services	✓	✓	✓	✓
Education/training services	✓	✓	✓	Not available
Support/self-help groups	✓	Not available	✓	Not available
Travel assistance	✓	✓	✓	✓
Meal programs	✓	✓	✓	Not available
INCOME SECURITY				
Old Age Security (OAS)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan (CPP)	Not eligible	Not eligible	Not eligible	Not eligible
Canada Pension Plan Disability (CPP-D)	Not eligible	Not eligible	Not eligible	Not eligible
Alberta Works Income Support (IS) (AB)	Not eligible	Not eligible	Not applicable to case	Not applicable to case
Assured Income for the Severely Handicapped (AISH) (AB)	✓	✓	Not applicable to case	Not applicable to case
Employment Support & Income Assistance (ESIA) (NS)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Direct Family Support Program (DFS) (NS)	Not applicable to case	Not applicable to case	✓	✓
Disability Tax Credit (DTC) (& transfer option)	✓	✓	✓	✓
Medical Expense Tax Credit (METC) (including METC for other dependents)	✓	✓	✓	✓
Caregiver Credit	✓	✓	✓	✓
EMPLOYMENT				

Family responsibility leave	Not available	Not available	✓	✓
TRANSPORTATION				
Intracity	✓	✓	✓	Not available
Intercity	✓	✓	✓	Not available
Disability parking passes	✓	✓	✓	✓
HOUSING				
Housing modification programs	Not eligible	Not eligible	Not eligible	Not eligible

Scenario 3. Arif: Caregiver to his father

PROGRAM	Edmonton, Alberta	Oyen, Alberta	Halifax, Nova Scotia	Parrsboro, Nova Scotia
Caregiver's personal income	$26,520	$22,048	$20,800	$20,800
Caregiver's family income	$26,520	$22,048	$20,800	$20,800
Care receiver's personal income	$61,392	$61,392	$61,392	$61,392
Care receiver's family income	Because he is single, same as his individual income	Because he is single, same as his individual income	Because he is single, same as his individual income	Because he is single, same as his individual income
HEALTH CARE				
Home Care	Not suitable	Not suitable	Not suitable	Not suitable
Day programs	Not suitable	Not suitable	Not suitable	Not suitable
Facility-based respite	Not applicable	Not applicable	Not applicable	Not applicable
Medication	✓	✓	✓	✓
Medical equipment: long-term/purchase	Not applicable	Not applicable	Not applicable	Not applicable
Medical equipment: short-term/loan	Not applicable	Not applicable	Not applicable	Not applicable
Consultative services: in home	✓	✓	✓	✓
Consultative services: in city/regions	✓	✓	✓	✓
Consultative services: specialist/tertiary	Not applicable	Not applicable	Not applicable	Not applicable
Emergency ambulance services	✓	✓	✓	✓
NOT-FOR-PROFIT SUPPORT SERVICES				
Information/referral/ navigation services	✓	✓	✓	✓
Education/training services	✓	✓	✓	Not available

Support/self-help groups	✓	Not available	✓	✓
Travel assistance	Not available	Not available	Not available	Not available
Meal programs	✓	✓	✓	Not available
INCOME SECURITY				
Old Age Security (OAS)	✓	✓	✓	✓
Canada Pension Plan (CPP)	✓	✓	✓	✓
Canada Pension Plan Disability (CPP-D)	Not applicable	Not applicable	Not applicable	Not applicable
Alberta Works Income Support (IS) (AB)	Not eligible	Not eligible	Not applicable	Not applicable
Assured Income for the Severely Handicapped (AISH) (AB)	Not eligible	Not eligible	Not applicable	Not applicable
Employment Support and Income Assistance (ESIA) (NS)	Not applicable	Not applicable	Not eligible	Not eligible
Direct Family Support Program (DFS) (NS)	Not applicable	Not applicable	Not eligible	Not eligible
Disability Tax Credit (DTC) (& transfer option)	Not applicable	Not applicable	Not applicable	Not applicable
Medical Expense Tax Credit (METC) (including METC for other dependents)	Not applicable	Not applicable	Not applicable	Not applicable
Infirm Dependent Credit	Not eligible	Not eligible	Not eligible	Not eligible
EMPLOYMENT				
Family responsibility leave	Not available	Not available	✓	✓

TRANSPORTATION				
Intracity	✓	✓	✓	Not available
Intercity	✓	✓	✓	Not available
Disability parking passes	Not applicable	Not applicable	Not applicable	Not applicable
HOUSING				
Housing modification programs	Not applicable	Not applicable	Not applicable	Not applicable

Scenario 4. Jim and Joan: Caregivers to their adult daughter

PROGRAM	Edmonton, Alberta	Oyen, Alberta	Halifax, Nova Scotia	Parrsboro, Nova Scotia
Caregiver's personal income	CR1: $84,739 CR2: $60,341	CR1: $51,646 CR2: $55,723	CR1: $64,480 CR2: $52,000	CR1: $63,939 CR2: $57,221
Caregiver's family income	$145,080	$107,369	$116,480	$121,160
Care receiver's personal income	$9,180	$9,180	$10,296	$10,296
Care receiver's family income	Because she is single, same as her individual income	Because she is single, same as her individual income	Because she is single, same as her individual income	Because she is single, same as her individual income
HEALTH CARE				
Home Care	✓	✓	✓	✓
Day programs	Not suitable	Not suitable	Not suitable	Not suitable
Facility-based respite	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Medication	✓	✓	✓	✓
Medical equipment: long-term/purchase	✓	✓	✓	✓
Medical equipment: short-term/loan	✓	✓	✓	✓
Consultative services: in home	✓	✓	✓	✓
Consultative services: in city/regions	✓	✓	✓	Available in Amherst and Springhill
Consultative services: specialist/tertiary	✓	Available in Medicine Hat and Calgary	✓	Available in Halifax
Emergency ambulance services	✓	✓	✓	✓
NOT-FOR-PROFIT SUPPORT SERVICES				
Information/referral/ navigation services	✓	✓	✓	✓
Education/training services	✓	✓	✓	Not available

Support/self-help groups	✓	Not available	✓	Not available
Travel assistance	Not available	Not available	Not available	Not available
Meal programs	✓	✓	✓	Not available
INCOME SECURITY				
Old Age Security (OAS)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan (CPP)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan Disability (CPP-D)	Not eligible	Not eligible	Not eligible	Not eligible
Alberta Works Income Support (IS) (AB)	✓	✓	Not applicable to case	Not applicable to case
Assured Income for the Severely Handicapped (AISH) (AB)	Not eligible	Not eligible	Not applicable to case	Not applicable to case
Employment Support and Income Assistance (ESIA) (NS)	Not applicable to case	Not applicable to case	✓	✓
Direct Family Support Program (DFS) (NS)	Not applicable to case	Not applicable to case	Not eligible	Not eligible
Disability Tax Credit (DTC) (& transfer option)	✓	✓	✓	✓
Medical Expense Tax Credit (METC) (including METC for other dependents)	✓	✓	✓	✓
Infirm Dependent Credit	✓	✓	✓	✓
EMPLOYMENT				
Family responsibility leave	Not available	Not available	✓	✓

TRANSPORTATION				
Intracity	Not suitable	Not suitable	Not suitable	Not available
Intercity	Not suitable	Not suitable	Not suitable	Not available
Disability parking passes	✓	✓	✓	✓
HOUSING				
Housing modification programs	✓	✓	✓	✓

Scenario 5. Luc: Caregiver to his wife

PROGRAM	Edmonton, Alberta	Oyen, Alberta	Halifax, Nova Scotia	Parrsboro, Nova Scotia
Caregiver’s personal income	$28,158	$28,158	$22,966	$22,966
Caregiver’s family income	$28,158	$28,158	$22,966	$22,966
Care receiver’s personal income	No income	No income	No income	No income
Care receiver’s family income	Because she lives with her caregiver, same as caregiver's family income	Because she lives with her caregiver, same as caregiver's family income	Because she lives with her caregiver, same as caregiver's family income	Because she lives with her caregiver, same as caregiver's family income
HEALTH CARE				
Home Care	✓	✓	✓	✓
Day programs	Not suitable	Not available	Not suitable	Not suitable
Facility-based respite	Not suitable	Not available	Not suitable	Not available
Medication	✓	✓	✓	✓
Medical equipment: long-term/purchase	✓	✓	✓	✓
Medical equipment: short-term/loan	✓	✓	✓	✓
Consultative services: in home	✓	✓	✓	✓
Consultative services: in city/regions	✓	Available in Medicine Hat	✓	Available in Amherst
Consultative services: specialist/tertiary	✓	Available in Calgary	✓	Available in Halifax
Emergency ambulance services	✓	✓	✓	✓
NOT-FOR-PROFIT SUPPORT SERVICES				
Information/referral/ navigation services	✓	✓	✓	✓
Education/training services	✓	✓	✓	Not available

Support/self-help groups	✓	✓	✓	✓
Travel assistance	✓	✓	Not available	Not available
Meal programs	✓	✓	✓	Not available
INCOME SECURITY				
Old Age Security (OAS)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan (CPP)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan Disability (CPP-D)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Alberta Works Income Support (IS) (AB)	Not eligible	Not eligible	Not applicable to case	Not applicable to case
Assured Income for the Severely Handicapped (AISH) (AB)	Not eligible	Not eligible	Not applicable to case	Not applicable to case
Employment Support and Income Assistance (ESIA) (NS)	Not applicable to case	Not applicable to case	Not eligible	Not eligible
Direct Family Support Program (DFS) (NS)	Not applicable to case	Not applicable to case	Not eligible	Not eligible
Disability Tax Credit (DTC) (& transfer option)	✓	✓	✓	✓
Medical Expense Tax Credit (METC) (including METC for other dependents)	✓	✓	✓	✓
Caregiver Credit	Not eligible	Not eligible	Not eligible	Not eligible
EMPLOYMENT				
Family responsibility leave	Not available	Not available	✓	✓
TRANSPORTATION				
Intracity	✓	✓	✓	Not available

Intercity	✓	✓	✓	Not available
Disability parking passes	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
HOUSING				
Housing modification programs	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case

Appendix F. Caregiver out-of- pocket, employment, unpaid labour, emotional well-being, and social well-being costs by scenario

	Out-of-pocket	Employment	Unpaid labour	Emotional well-being	Social well-being
Evelyn 1	• Hotel costs • "Spending binge" costs • Transportation • Purchase of supervisory care	Reduced income/ pension • Lost earnings • Reduced CPP contributions Job insecurity Benefits: • Use up all sick leave/ vacation for caregiving	Time spent on: • Supervision • Transportation • Identifying and coordinating supports/ advocacy	• Time stress • On call due to unpredictable behaviour • Unclear prognosis, potentially requires lifelong care	• Lack of time/ energy to socialize • Stigma can result in social isolation • Relationship quality within family
Evelyn 2	• Housing modifications • Facility based respite/day programs • Transportation • Hotel costs (esp in NS)	As per # 1 Reduced income/ pension • Lost earnings • Reduced CPP contributions Job insecurity Benefits: • Use up all sick leave/vacation for caregiving	Similar to #1 Time spent on: • Personal care • Supervision • Transportation • Coordinating care	• Time stress	• Lack of time/ energy to socialize • Social participation • Relationship quality within family

Arif	• Transportation	Reduced income/ pension • Lost earnings (commission based) • Reduced CPP contributions Job insecurity (commission based) Benefits: • Use up all sick leave/ vacation for caregiving	Time spent on: • Transportation (distance is great) • Identifying and coordinating supports (takes additional time as is from distance)	Stress: • Coordinating from distance • Unclear diagnosis so no access to services yet • Lack of insight into problem • Uneven distribution of tasks with sister	• Relationship quality with girlfriend • Lack of time/ energy to socialize
Jim and Joan	• Transportation • Additional therapies not covered by government	Reduced income/ pension • Lost earnings • Reduced CPP contributions Job insecurity (Joan unclear what happens if she takes a leave of absence) Benefits: • Use up all sick leave/vacation for caregiving	Time spent on: • Personal care • Transportation • Coordinating services	Stress: • Unclear prognosis, may require care for long time • Uneven distribution of tasks in periods when Jim is at home (summer) or when Joan is travelling for work	• Relationship with other children may suffer • Relationship with each other • Lack of time/ energy to socialize, volunteer
Luc	• Supervision for children • Transportation • Equipment not covered by government	Reduced income/ pension (for Luc and parents) • Lost earnings • May affect EI eligibility and vacation pay Job insecurity (unsure what happens if needs more time off)	Time spent on: • Personal care • Supervision • Transportation	• Time stress juggling work, caregiving and childcare • Unclear prognosis, potentially requires lifelong care • Coordinating of children's care and Noelle's care	• Relationship with children may suffer • Relationship with each other • Lack of time/ energy to socialize

Appendix G. Impact on caregiver costs, by scenario and region

Scenario 1. Evelyn: Caregiver to her brother with bipolar disorder

Program	Province		Region	
	Alberta	Nova Scotia	Urban	Rural
HEALTH CARE				
Home Care	CR is not eligible. ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CR is not eligible. ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CR is not eligible. ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CR is not eligible. ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Day programs	Available ↓ Out-of-pocket costs ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Out-of-pocket costs ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Out-of-pocket costs ↓ Employment costs ↓ Unpaid labour costs	Available in Parrsboro ↓ Employment costs Not available in Oyen ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Facility-based respite	CR is not eligible ↑ Social and emotional costs from not having a break from caregiving	CR is not eligible ↑ Social and emotional costs from not having a break from caregiving	CR is not eligible ↑ Social and emotional costs from not having a break from caregiving	CR is not eligible ↑ Social and emotional costs from not having a break from caregiving
Medication	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs
Medical equipment: long-term/purchase	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case

Medical equipment: short-term/loan	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Consultative services: in home	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Consultative services: in city/regions	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Consultative services: specialist/tertiary	Available ↑ Employment costs	Available ↑ Employment costs	Available ↑ Employment costs	Available ↑ Employment costs. These costs will be greater for persons in Parrsboro as the nearest consultative services are in Truro
Emergency ambulance services	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs
NOT-FOR-PROFIT SUPPORT SERVICES				
Information/referral/ navigation services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs

Education/training services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available in Oyen. ↑ Unpaid labour costs ↓ Emotional costs Not available in Parrsboro ↑ Emotional costs
Support/self-help groups	Available ↓ Emotional costs	Available ↓ Emotional costs	Available ↓ Emotional costs	Not available ↑ Emotional costs
Travel assistance	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Meal programs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available in Oyen ↑ Out-of-pocket costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Unpaid labour costs
INCOME SECURITY				
Old Age Security	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible
Canada Pension Plan Disability	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible

Income support	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs
Disability Tax Credit & transfer option)	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible
Medical Expense Tax Credit (including METC for other dependents)	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs
Caregiver Credit	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs	CG is eligible. ↓ Out-of-pocket costs
EMPLOYMENT				
Family responsibility leave	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in urban Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in rural Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
TRANSPORTATION				
Intracity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs

Intercity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs
Disability parking passes	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
HOUSING				
Housing modifications	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case

Scenario 2. Evelyn: Caregiver to her brother with multiple sclerosis

Program	Province		Region	
	Alberta	Nova Scotia	Urban	Rural
HEALTH CARE				
Home Care	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs
Day programs	Available ↓ Out-of-pocket costs ↓ Employment costs ↓ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available to persons living in Edmonton ↓ Out-of-pocket costs ↓ Employment costs ↓ Unpaid labour costs	Not available/suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Facility-based respite	CR is eligible ↑ Out-of-pocket costs ↓ Social and emotional costs	Not available/suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs ↑ Social and emotional costs from not having a break from caregiving	CRs in Edmonton are eligible ↓ Out-of-pocket costs ↓ Employment costs ↓ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs ↑ Social and emotional costs from not having a break from caregiving
Medication	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs

Medical equipment: long-term/purchase	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs
Medical equipment: short-term/loan	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs
Consultative services: in home	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs
Consultative services: in city/regions	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Consultative services: specialist/tertiary	Available ↑ Employment costs ↑ Out-of-pocket costs ↑ Unpaid labour costs	Available ↑ Employment costs ↑ Out-of-pocket costs ↑ Unpaid labour costs	Available ↑ Employment costs ↑ Out-of-pocket costs ↑ Unpaid labour costs	Not available ↑ Employment costs ↑ Out-of-pocket costs ↑ Unpaid labour costs
Emergency ambulance services	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs

NOT-FOR-PROFIT SUPPORT SERVICES				
Information/referral/ navigation services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs
Education/training services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available in Oyen ↑ Unpaid labour costs ↓ Emotional costs Not available in Parrsboro ↑ Emotional costs
Support/self-help groups	Available ↓ Emotional costs	Available ↓ Emotional costs	Available ↓ Emotional costs	Not available ↑ Emotional costs
Travel assistance	Available ↓ Out-of-pocket costs ↑ Employment costs	Available ↓ Out-of-pocket costs ↑ Employment costs	Available ↓ Out-of-pocket costs ↑ Employment costs	Available ↓ Out-of-pocket costs ↑ Employment costs
Meal programs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available in Oyen ↑ Out-of-pocket costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Unpaid labour costs
INCOME SECURITY				
Old Age Security	Not applicable to case	Same	Same	Same
Canada Pension Plan	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible
Canada Pension	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible

Plan Disability				
Income support	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs
Disability Tax Credit (DTC) (and transfer option)	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs
Medical Expense Tax Credit (including METC for other dependents)	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs
Caregiver Credit	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs
EMPLOYMENT				
Family responsibility leave	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in urban Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in rural Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
TRANSPORTATION				
Intracity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs

Intercity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs
Disability parking passes	CR is eligible ↑ Out-of-pocket costs	CR is eligible ↑ Out-of-pocket costs	CR is eligible ↑ Out-of-pocket costs	CR is eligible ↑ Out-of-pocket costs
HOUSING				
Housing modifications	CR is not eligible ↑ Out-of-pocket costs ↑ Unpaid labour costs	CR is not eligible ↑ Out-of-pocket costs ↑ Unpaid labour costs	CR is not eligible ↑ Out-of-pocket costs ↑ Unpaid labour costs	CR is not eligible ↑ Out-of-pocket costs ↑ Unpaid labour costs

Scenario 3. Arif: Caregiver to his father

Program	Province		Region	
	Alberta	Nova Scotia	Urban	Rural
HEALTH CARE				
Home Care	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Day programs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Facility-based respite	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Medication	Available ↓ Out-of-pocket costs	Available ↑ Out-of-pocket costs	Available ↕ Out-of-pocket costs	Available ↕ Out-of-pocket costs
Medical equipment: long-term/purchase	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Medical equipment: short-term/loan	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Consultative services: in home	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs
Consultative services: in city/regions	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs

Consultative services: specialist/tertiary	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Emergency ambulance services	Available ↓ Out-of-pocket costs	Available ↑ Out-of-pocket costs	Available ↕ Out-of-pocket costs	Available ↕ Out-of-pocket costs
NOT-FOR-PROFIT SUPPORT SERVICES				
Information/referral/navigation services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs
Education/training services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available in Oyen ↑ Unpaid labour costs ↓ Emotional costs Not available in Parrsboro ↑ Emotional costs
Support/self-help groups	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available in Parrsboro ↑ Unpaid labour costs ↓ Emotional costs Not available in Oyen ↑ Emotional costs
Travel assistance	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs

Meal programs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available in Oyen ↑ Out-of-pocket costs ↓ Unpaid labour costs Not available in Parrsboro. ↑ Unpaid labour costs
INCOME SECURITY				
Old Age Security	CG is eligible	CG is eligible	CG is eligible	CG is eligible
Canada Pension Plan	CG is eligible	CG is eligible	CG is eligible	CG is eligible
Canada Pension Plan Disability	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Income support	CR is not eligible.	CR is not eligible	CR is not eligible.	CR is not eligible
Disability Tax Credit (DTC) (and transfer option)	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible
Medical Expense Tax Credit (including METC for other dependents)	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Infirm Dependent Credit	CG is not eligible	CG is not eligible	CG is not eligible	CG is not eligible
EMPLOYMENT				
Family responsibility leave	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in urban Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in rural Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs

TRANSPORTATION				
Intracity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs
Intercity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs
Disability parking passes	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
HOUSING				
Housing modifications	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case

Scenario 4. Jim and Joan: Caregivers to their adult daughter

Program	Province		Region	
	Alberta	Nova Scotia	Urban	Rural
HEALTH CARE				
Home Care	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs
Day programs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Facility-based respite	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Medication	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs
Medical equipment: long-term/purchase	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs
Medical equipment: short-term/loan	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs
Consultative services: in home	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs

Consultative services: in city/regions	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs These costs will be greater for persons in Parrsboro as the nearest consultative services are in Amherst and Springhill
Consultative services: specialist/tertiary	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs These costs will be greater in both regions as the nearest consultative services are in Calgary and Medicine Hat and Halifax
Emergency ambulance services	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs	Available ↓ Out-of-pocket costs
NOT-FOR-PROFIT SUPPORT SERVICES				
Information/referral/ navigation services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs

Education/training services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available in Oyen ↑ Unpaid labour costs ↓ Emotional costs Not available in Parrsboro ↑ Emotional costs
Support/self-help groups	Available ↓ Emotional costs	Available ↓ Emotional costs	Available ↓ Emotional costs	Not available ↑ Emotional costs
Travel assistance	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Meal programs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available in Oyen ↑ Out-of-pocket costs ↓ Unpaid labour costs Not available in Parrsboro. ↑ Unpaid labour costs
INCOME SECURITY				
Old Age Security	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan Disability	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible
Income support	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs	CR is eligible ↕ Out-of-pocket costs

Disability Tax Credit (DTC) (and transfer option)	CR is eligible. ↓ Out-of-pocket costs	CR is eligible. ↓ Out-of-pocket costs	CR is eligible. ↓ Out-of-pocket costs	CR is eligible. ↓ Out-of-pocket costs
Medical Expense Tax Credit (including METC for other dependents)	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs
Infirm Dependent Credit	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs	CG is eligible ↓ Out-of-pocket costs
EMPLOYMENT				
Family responsibility leave	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in urban Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in rural Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
TRANSPORTATION				
Intracity	Not suitable ↑ Employment costs ↑ Unpaid labour costs	Not available/not suitable ↑ Employment costs ↑ Unpaid labour costs	Not available/not suitable ↑ Employment costs ↑ Unpaid labour costs	Not available/not suitable ↑ Employment costs ↑ Unpaid labour costs
Intercity	Not suitable ↑ Employment costs ↑ Unpaid labour costs	Not available/not suitable ↑ Employment costs ↑ Unpaid labour costs	Not available/not suitable ↑ Employment costs ↑ Unpaid labour costs	Not available/not suitable ↑ Employment costs ↑ Unpaid labour costs
Disability parking passes	CR is eligible ↑ Out-of-pocket costs	CR is eligible ↑ Out-of-pocket costs	CR is eligible ↑ Out-of-pocket costs	CR is eligible ↑ Out-of-pocket costs

HOUSING				
Housing modifications	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs

Scenario 5. Luc: Caregiver to his wife

Program	Province		Region	
	Alberta	Nova Scotia	Urban	Rural
HEALTH CARE				
Home Care	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs	CR is eligible ↓ Out-of-pocket costs ↑ Employment costs
Day programs	Not suitable/not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Not suitable/not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs
Facility-based respite	Not available/not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs ↑ Social and emotional costs from not having a break from caregiving	Not available/not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs ↑ Social and emotional costs from not having a break from caregiving	Not available/not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs ↑ Social and emotional costs from not having a break from caregiving	Not available/not suitable ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs ↑ Social and emotional costs from not having a break from caregiving
Medication	Available ↓ Out-of-pocket costs	Available ↑ Out-of-pocket costs	Available ↕ Out-of-pocket costs	Available ↕ Out-of-pocket costs
Medical equipment: long-term/purchase	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs

Medical equipment: short-term/loan	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs	CR is eligible ↓ Out-of-pocket costs ↑ Unpaid labour costs
Consultative services: in home	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs	Available ↓ Out-of-pocket costs ↑ Unpaid labour costs
Consultative services:in city/regions	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs These costs will be greater in both regions as the nearest consultative services are in Medicine Hat and Amherst
Consultative services: specialist/tertiary	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs These costs will be greater in both regions as the nearest consultative services are in Calgary and Halifax

Emergency ambulance services	Available. ↑ Out-of-pocket costs	Available. ↑ Out-of-pocket costs	Available. ↑ Out-of-pocket costs	Available. ↑ Out-of-pocket costs
NOT-FOR-PROFIT SUPPORT SERVICES				
Information/ referral/ navigation services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs
Education/training services	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available ↑ Unpaid labour costs ↓ Emotional costs	Available in Oyen ↑ Unpaid labour costs ↓ Emotional costs Not available in Parrsboro ↑ Emotional costs
Support/self-help groups	Available ↓ Emotional costs	Available ↓ Emotional costs	Available ↓ Emotional costs	Available ↓ Emotional costs
Travel assistance	Available ↓ Out-of-pocket costs ↕ Employment costs ↕ Unpaid labour costs	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available in Edmonton ↓ Out-of-pocket costs ↓ Employment costs ↓ Unpaid labour costs Not available in Halifax. ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	Available in Oyen ↓ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs Not available in Parrsboro. ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs

Meal programs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available ↑ Out-of-pocket costs ↓ Unpaid labour costs	Available in Oyen ↑ Out-of-pocket costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Unpaid labour costs
INCOME SECURITY				
Old Age Security	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Canada Pension Plan Disability	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
Income support	CR is not eligible	CR is not eligible	CR is not eligible	CR is not eligible
Disability Tax Credit (DTC) (and transfer option)	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs
Medical Expense Tax Credit (including METC for other dependents)	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs	CR is eligible ↓ Out-of-pocket costs
Caregiver Credit	CG is not eligible	CG is not eligible	CG is not eligible	CG is not eligible.
EMPLOYMENT				
Family responsibility leave	Not available ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in urban Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs	CG is eligible in rural Nova Scotia ↑ Out-of-pocket costs ↑ Employment costs ↑ Unpaid labour costs

TRANSPORTATION				
Intracity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs
Intercity	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available ↓ Employment costs ↓ Unpaid labour costs	Available in Oyen ↓ Employment costs ↓ Unpaid labour costs Not available in Parrsboro ↑ Employment costs ↑ Unpaid labour costs
Disability parking passes	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case
HOUSING				
Housing modifications	Not applicable to case	Not applicable to case	Not applicable to case	Not applicable to case

Appendix H. Impact analysis across five profiles

	Out of pocket	Employment	Unpaid Labour	Emotional well-being	Social well-being
Evelyn and Carl	• Hotel costs • “Spending binge” costs • Transportation • Purchase of supervisory care	Reduced income / pension • Lost earnings • Reduced CPP contributions Job insecurity Benefits: • Use up all sick leave / vacation for caregiving	Time spent on: • Supervision • Transportation • Identifying and coordinating supports / advocacy	• Time stress • On call due to unpredictable behaviour • Unclear prognosis, potentially requires lifelong care	• Lack of time / energy to socialize • Stigma can result in social isolation • Relationship quality within family
Evelyn and Frank	• Housing modifications • Facility based respite / day programs • Transportation • Hotel costs (esp in NS)	As per # 1 Reduced income / pension • Lost earnings • Reduced CPP contributions Job insecurity Benefits: • Use up all sick leave / vacation for caregiving	Similar to #1 Time spent on: • Personal care • Supervision • Transportation • Coordinating care	• Time stress	• Lack of time / energy to socialize • Social participation • Relationship quality within family

Arif	• Transportation	Reduced income / pension • Lost earnings (commission based) • Reduced CPP contributions Job insecurity (commission based) Benefits: • Use up all sick leave / vacation for caregiving	Time spent on: • Transportation (distance is great) • Identifying and coordinating supports (takes additional time as is from distance)	Stress: • Coordinating from distance • Unclear diagnosis so no access to services yet • Lack of insight into problem • Uneven distribution of tasks with sister	• Relationship quality with girlfriend • Lack of time / energy to socialize
Jim & Joan	• Housing modifications • Transportation • Hotel costs	Reduced income / pension • Lost earnings • Reduced CPP contributions Job insecurity (Joan unclear what happens if she takes a leave of absence) Benefits: • Use up all sick leave / vacation for caregiving	Time spent on: • Transportation • Coordinating services	Stress: • Unclear prognosis • Concerns about care receiver's precarious financial situation • Difficulty problem-solving from afar • Uneven distribution of tasks in periods when Jim is at home (summer) or when Joan is travelling for work	• Relationship with other children may suffer • Relationship with each other • Lack of time / energy to socialize, volunteer

Luc	• Childcare • Supervision for children • Transportation • Equipment not covered by govt	Reduced income / pension (for Luc and parents) • Lost earnings • May affect EI eligibility and vacation pay Job insecurity (unsure what happens if needs more time off)	Time spent on: • Personal care • Supervision • Transportation	• Time stress juggling work, cg and childcare • Unclear prognosis, potentially requires lifelong care • Coordinating of children's care and Noel's care	• Relationship with children may suffer • Relationship with each other • Lack of time / energy to socialize