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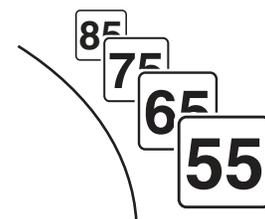
## Caregiving for Older Adults with Disabilities

### Present Costs, Future Challenges

**Janet Fast**

Canada needs a comprehensive strategy to support family caregivers, who bear a disproportionate share of the cost of assisting those with long-term disabilities.

Le Canada doit se doter d'une stratégie globale de soutien aux proches aidants, qui assument une part démesurée du coût des soins fournis aux personnes souffrant d'incapacités persistantes.



*Faces of Aging  
Les défis du vieillissement*

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## Summary

Being an unpaid caregiver for one's adult family members is increasingly common in Canada as growing numbers of disabled individuals need help with tasks such as housekeeping, meal preparation and transportation. Although the amount of care most caregivers provide to adult family members and friends is modest, the responsibilities can be demanding and can present financial risks.

The number of people requiring care is forecast to rise dramatically in coming years, while families' capacity to meet those demands will decrease as a result of demographic and socioeconomic factors. In this study, Janet Fast assesses the financial and other challenges faced by caregivers and their employers. She also examines what employers and governments are currently doing, as well as what they should do, to mitigate the negative effects of caregiving.

The vast majority of working-age caregivers are employed and work full time. Many experience conflicting demands between paid work and caregiving and have to miss days at work or reduce their paid work hours. Those who provide many hours of care, who reside with the care recipient or care for someone with a cognitive disability are more likely to quit their jobs, and they may even be fired. As such, they are at greater risk of experiencing poor social, economic, physical and mental health outcomes. Clearly, caregivers bear a disproportionate share of the costs of caring for those with long-term health problems and disabilities.

The issue also presents challenges for employers, for example, increased turnover, absenteeism, reduced productivity and more demands on employee benefit programs. Some employers offer supports such as flexible work hours, direct compensation and information for caregiver employees. However, there is a marked discrepancy between the way employers treat new parents and how they treat people with care responsibilities.

Although over the past decade governments have introduced new policies to enhance work-care reconciliation, there is no comprehensive public policy strategy to support caregivers and to mitigate the negative consequences of caregiving.

We need to correct this urgently, Fast argues. Canada should follow the example of the United Kingdom and Australia, which have recognized caregivers' contributions, introduced an allowance or wage to help cover caregivers' income security needs, and explicitly codified caregivers' rights in legislation. Policy-makers should also extend care service providers' mandates to include caregivers as clients, introduce compulsory assessment of caregivers' needs and recognize caregivers' right to have those needs met.

She calls for a comprehensive caregiver policy strategy based on four pillars: (1) recognizing caregivers and their rights; (2) adequate, accessible and affordable services for care receivers and caregivers; (3) work-care reconciliation measures; and (4) measures to protect caregivers' income security.

## Résumé

Le Canada compte de plus en plus d'aidants non rémunérés prenant soin d'un adulte qui, en raison de ses incapacités, a besoin d'aide pour se déplacer ou accomplir des tâches comme l'entretien ménager et la préparation des repas. Même si la plupart des proches aidants prodiguent des soins en quantité modeste, ils doivent parfois assumer des responsabilités et des risques financiers considérables.

Le nombre de personnes nécessitant de l'aide devrait fortement augmenter au cours des prochaines années, alors même que les familles seront moins en mesure de répondre à leurs besoins en raison de facteurs démographiques et socioéconomiques. Janet Fast examine dans cette étude les difficultés des proches aidants et de leurs employeurs, notamment sur le plan financier. Elle analyse aussi les mesures gouvernementales et privées qui visent à atténuer les effets négatifs subis par ces aidants, et elle propose un cadre d'action publique pour soutenir adéquatement ces derniers.

La vaste majorité des proches aidants d'âge actif occupent un emploi à temps plein. Entre cet emploi et leurs tâches d'aidants, beaucoup font face à des exigences conflictuelles qui les obligent à s'absenter du travail ou à réduire le temps de travail rémunéré. Ceux qui consacrent de longues heures aux soins, vivent sous le même toit que la personne aidée ou s'occupent d'une personne souffrant de déficience cognitive sont plus susceptibles de quitter leur emploi, voire d'être licenciés. Ils risquent davantage de connaître des difficultés économiques et sociales ou des problèmes de santé physique et mentale. En clair, les proches aidants assument une part démesurée du coût des soins fournis aux personnes souffrant de problèmes de santé et d'incapacités persistantes.

Cette situation représente aussi un défi pour les employeurs, qui doivent souvent gérer un roulement de personnel et un absentéisme accru, une productivité réduite et un recours plus fréquent au régime d'avantages sociaux. Certaines entreprises soutiennent par divers moyens leurs employés qui prennent soin d'un proche (horaire flexible, indemnisation, information). Mais les mesures offertes aux employés ayant des responsabilités de proche aidant sont nettement plus limitées que le traitement réservé aux nouveaux parents.

Si les gouvernements ont adopté depuis une décennie certaines mesures de conciliation entre travail et prestation de soins, il n'existe toujours aucune politique globale de soutien aux proches aidants et d'atténuation des effets négatifs qu'ils subissent.

Il est urgent de remédier à la situation, soutient l'auteure. Le Canada devrait suivre l'exemple du Royaume-Uni et de l'Australie, qui ont reconnu la contribution des proches aidants, instauré des indemnités pour sécuriser leurs revenus et reconnu légalement leurs droits. Nos décideurs devraient aussi élargir les mandats des fournisseurs de services sociaux et de santé pour y intégrer les proches aidants, imposer l'évaluation de leurs besoins et reconnaître leurs droits à recevoir du soutien.

Le cadre d'action préconisé par Janet Fast repose sur quatre piliers : reconnaissance du travail et des droits des proches aidants ; prestation de services adéquats, accessibles et abordables pour les proches aidants et les bénéficiaires ; mesures de conciliation entre travail et prestation de soins ; mesures de sécurité du revenu pour les proches aidants.

# Caregiving for Older Adults with Disabilities: Present Costs, Future Challenges

Janet Fast

Demographic, socio-economic and political trends throughout the developed world are making caregiving an increasingly important public policy issue. Population aging and rising disability rates at all ages mean that escalating numbers of Canadians need help from family members and friends with daily living tasks such as housekeeping, meal preparation, yard work and home maintenance, transportation, personal and medical care, money management, monitoring, care management, and social support. At the same time, smaller and more geographically mobile families with more complex and ambiguous structures, together with concerns about escalating costs in the health and continuing care service sectors, are constraining the supply of care. Efforts to encourage more labour market participation and to extend the working lives of Canadians, as well as the loss of retirement savings on the part of many Canadians, further suggest that many individuals and families will need to continue to manage both paid work and care work well into the future.

Although caring for family members and friends is a normal midlife experience, there is increasing recognition both of caregiving's potential to affect the life course of caregivers profoundly and of the limits to the care that family and friends can provide. Research has shown that the financial, health and social consequences of caregiving can substantially increase the risk of poor caregiver outcomes and caregiver burnout. Moreover, these effects can accumulate and intensify over the lives of adult caregivers and spill over to other stakeholders, such as employers and public service providers, thus jeopardizing the sustainability of the public care sector and affecting both the labour force and employer's profits.

As Keefe (2011, 15) notes, "the current system of supports for family and friend caregivers is limited and inconsistent." Despite repeated appeals, there is still no comprehensive public policy strategy for supporting caregivers.<sup>1</sup> Indeed, government involvement has been slow to evolve. Home and continuing care services that are subsidized in whole or in part for some care *recipients* might support caregivers indirectly, but pressure on health care budgets means that these services are tightly rationed. Similarly, tight eligibility criteria for monetary benefits exclude the majority of caregivers. And although employers are becoming more aware of the implications of having employees with care responsibilities in their workplaces, few consider it a high-priority human resource management issue. In fact, most employers are convinced that flexible working options available to all employees are sufficient to meet the needs of caregiving employees (Lero et al. 2012).

In this study, I address the following questions:

- What financial risks do caregivers face?
- What are the financial risks for employers and the labour force more generally?
- What are Canadian governments and employers doing to address these risks?
- What other options are available to governments and employers?

In answering these questions, I have relied largely on findings from several of my own research projects, including a comprehensive review of the literature on care-related costs to caregivers and employers (Keating, Fast, Lero et al. 2014; Keating, Lero, Fast et al. 2014), empirical studies of these costs and their predictors (Fast and Dosman 2014; Fast, Dosman, Lero et al. 2013; Fast, Lero, DeMarco et al. 2014) and a study of workplace supports for employed caregivers (Lero et al. 2012).<sup>2</sup> Where Canadian data are absent or limited, and in discussing ways forward for Canadian public policy and workplace strategies, I call on findings from the international literature as well.

I begin by profiling Canadian caregivers and by exploring the benefits and negative consequences of their caregiving. I identify the factors that are the most predictive of caregivers' risk of experiencing negative financial effects, together with the ripple effects of caregiving on employers and on the labour force. I then describe the public and private policies currently in place to mitigate and redistribute the costs of caregiving, and I assess their strengths and the remaining gaps. In the final section, I advance recommendations for building a comprehensive, inclusive and sustainable framework for caregiver support.

## A Profile of Caregiving

**I**n 2012, 28 percent of Canadians ages 15 and over (8.1 million) were caregivers. Caregiving can be demanding: most (74 percent) spent under 10 hours per week on care, but for one in ten it occupied 30 or more hours, equivalent to a full-time job. Many (43 percent) cared for more than one family member or friend at the same time, and about half had been caring for their primary care recipient for more than four years (Sinha 2013).

The population of caregivers is growing rapidly. Between 2007 and 2012, the number of Canadians ages 45 and older who were caregivers grew by 20 percent (Sinha 2013). As the number of Canadians needing assistance is forecast to double over the next 30 years (Carrière et al. 2008), more of us can expect to take on care responsibilities in the future. One can become a caregiver at any time and multiple times during one's life, so caregiving is even more common when examined over the course of the lifetime. In 2012, 46 percent of Canadians (13 million) had been involved in at least one caregiving episode (lasting a minimum of six months) at some time since they were age 15 (Sinha 2013). In 2007, Canadians ages 45 and older reported an average of 2.7, and as many as 30, episodes of care across their lifetime. Women spent more of their lifetime providing care than did men (5.8 years and 3.4 years on average, respectively) (Fast, Dosman, Lero et al. 2013). Women continue to be overrepresented among caregivers relative to the general population, though by a smaller margin than is often assumed (54 percent in 2012; Sinha 2013). Other gender differences, however, are more pronounced. Women spend more time on care tasks and perform "traditionally female" tasks (housekeeping, meal preparation, personal and medical care) that tend to be more time consuming and to allow for less flexible scheduling. Women also are more likely to experience financial, health and social consequences as a result of their care work.

Although most caregivers (84 percent) cared for relatives, 16 percent cared for friends and neighbours. More than one-quarter (28 percent) were "sandwiched" caregivers — caring simultaneously for a child under age 18 and another family member or friend with a long-term health

problem or disability. The majority lived near their primary care recipient;<sup>3</sup> in fact, more than 20 percent resided with their primary care recipient, which is more demanding than caring for someone who is living elsewhere (Sinha 2013). Most caregivers (82 percent) ages 19 to 70 are employed. Most of these (69 percent of women, 72 percent of men) work full time (Fast, Lero, DeMarco et al. 2014). Caregivers now account for 30 percent of the paid labour force.

In sum, caregiving is an increasingly common experience for Canadians. Yet it can be demanding, sometimes equivalent to a full-time job. It is most often combined with a paid job, and for a substantial minority it is also combined with child care. As a result, caregivers are vulnerable to a wide range of consequences.

## The Benefits of Caregiving

Studies of the benefits of caregiving consistently show positive aspects for caregivers. Caregiving can enhance the quality of the relationship between caregiver and care recipient — for example, in the form of companionship, love, reciprocity, continuity and a feeling of being appreciated. It often gives the caregiver a feeling of accomplishment, and it can represent a meaningful role in the caregiver’s daily life by, for example, conveying a sense of self-worth, of usefulness and of fulfilling an obligation. These positive features have been shown to promote better physical and mental health for caregivers, to reduce the burden of and negative reactions to the problems of the care recipient, and to improve coping with and adaptation to the caregiving situation and ultimate bereavement (Carbonneau, Caron and Desrosiers 2010). These features, in turn, might buffer the negative effects of caregiving, help caregivers maintain their involvement and enhance the effectiveness of caregiver interventions (Hilgeman et al. 2007).

Care provided by family members and friends also contributes significantly to Canadian society. The Organisation for Economic Co-operation and Development estimates the Canadian family care sector to be more than 10 times the size of the formal care workforce (Columbo et al. 2011), while the Conference Board of Canada similarly reports that the 15.5 billion hours of care Canadians ages 45 and older provided in 2007 exceeded by 10 times the hours of paid care provided that year (Hermus et al. 2012). This care carries considerable monetary value. The most recent estimate places the market replacement value<sup>4</sup> of unpaid care work by Canadian caregivers ages 45 and older caring for adults ages 65 and older at between \$25 billion and \$26 billion in 2009, representing as much as 2 percent of gross domestic product (GDP) that year (Hollander, Liu and Chappell 2009). Since about half of all caregivers are under age 45 and 60 percent of all recipients of care are under age 60, the market replacement value of unpaid care is actually much higher. In 2012, the mostly modest amounts of care provided by individual caregivers represented the equivalent of the work of 1.2 million full-time employees (Fast, Lero, De Marco et al. 2014) at a time when the entire Canadian labour force numbered fewer than 18 million (Galarneau 2013). Yet there still is a lingering assumption that care is “freely” provided by caregivers whose rewards lie in their fulfillment of family obligations and reciprocity to spouses or parents.

Unpaid care provided by family members and friends can substitute for publicly provided or subsidized care (Bonsang 2009). In a recent study, unpaid family care was shown to reduce reliance on

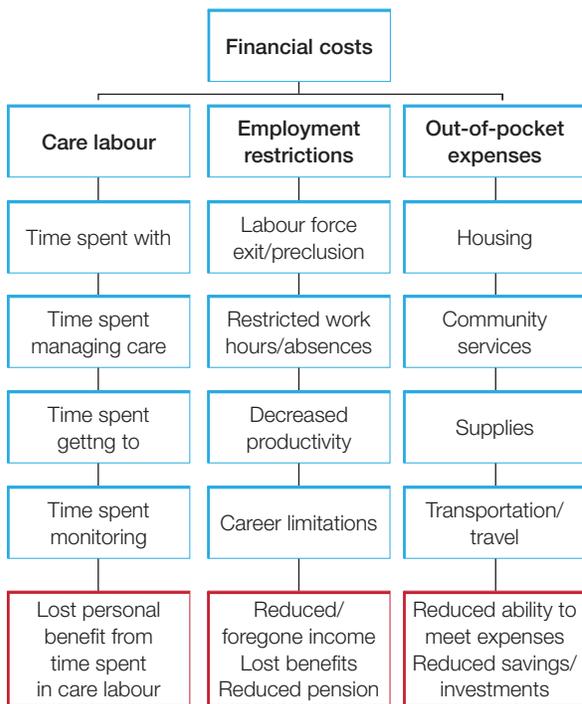
publicly supported paid care, saving Canadian governments an estimated \$2,951 per male caregiver age 45 or older and \$2,075 per female caregiver age 45 or older. The aggregate net benefits from the caregivers of these ages who provide fewer than five hours of care per week amounted to \$4.4 billion. This vastly outweighs the cost to government associated mainly with lost income tax revenues and higher social assistance expenditures among those who provided more than 15 hours of care per week and who exhibited much lower labour force participation (Jacobs et al. 2013). The high rate of employment among caregivers further suggests that their continued participation in paid work is important to the sustainability of the labour market and to government revenues in the form of income tax paid on employment earnings.

So, the care Canadians provide, without pay, to family members and friends benefits not only caregivers and care recipients, but also Canada’s economy and society as a whole (Canadian Institute for Health Information 2010; Hermus et al. 2012). Yet, because the work is unpaid, its economic value and its contribution to society often are invisible, and policy-makers should be concerned about mitigating the negative consequences of caregiving if this important service to family and friends is to be sustained.

### Financial Risks for Caregivers

In a recent systematic scoping review of the literature on the economic costs of care for caregivers (Keating, Fast, Lero et al. 2014), my colleagues and I identified three primary domains of cost, depicted in figure 1: care labour; employment restrictions; and out-of-pocket expenses. Immediate and longer-term financial outcomes for caregivers include reduced or foregone income, lost employment benefits, reduced pension benefits, reduced savings and investments, and reduced overall financial security.

Figure 1. A taxonomy of financial costs to caregivers

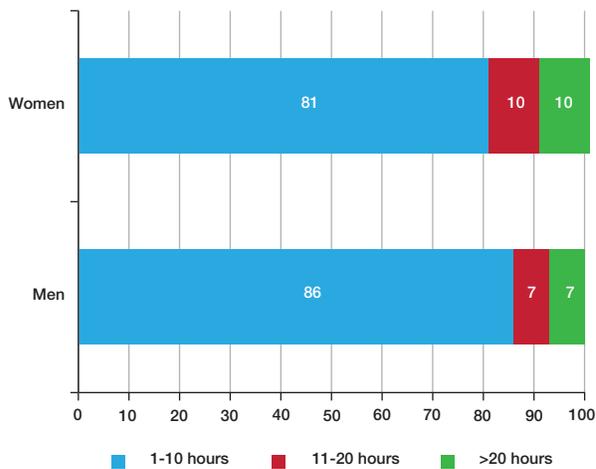


Source: Keating, Fast, Lero et al. (2014).

#### Care labour

In our review, we identify four main categories of care labour: time spent with the recipient; time spent on behalf of the recipient (care management); time spent getting to the recipient (commuting); and time spent monitoring the recipient (Keating, Fast, Lero et al. 2014). The vast majority of caregivers (more than 90 percent) report checking up on or monitoring the condition of the family members and friends for whom they care. The next most common care tasks are providing transportation (73 percent), housekeeping (52 percent) and outdoor maintenance (45 percent) (Sinha 2013). About one-quarter of caregivers provide personal care and help with medical treatments.

**Figure 2. Distribution of caregivers and hours of care provided per week by gender, Canada, 2012 (percent)**



Source: Fast, Lero, DeMarco et al. (2014).

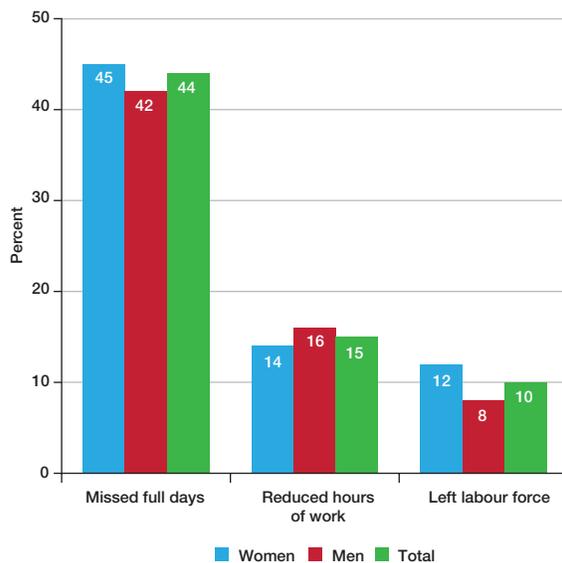
Estimates of the amount of care provided vary considerably across studies, caregivers, tasks and jurisdictions. In 2012, most Canadian caregivers (81 percent of women, 86 percent of men) provided care for 10 or fewer hours per week, but women were more likely than men (10 percent and 7 percent, respectively) to provide more than 20 hours of care per week (see figure 2). It should be noted, however, that, in most Canadian surveys, data are not collected on time spent on some of the most common care tasks — such as commuting to provide care, care management, monitoring and social support — so these estimates represent lower bounds.

### Employment restrictions

In the past decade, research on the effect of caregiving on the employment of caregivers has grown rapidly. Of the 126 articles we reviewed, 108 examined the effect of caregiving on caregivers' labour force participation or on how they accommodated their paid work to caregiving demands (Keating et al. 2014). Even though most caregivers are employed full time, evidence that caregiving is associated with disruptions in paid work is strong and consistent over a number of years, across studies using a range of rigorous methodological approaches and throughout much of the developed world. Financial and labour force imperatives make it likely that the proportion of caregivers who are employed will continue to grow, as will the likelihood of conflict between the demands of work and caregiving.

Our scoping review identifies four main categories of employment restrictions: labour force exit/preclusion; restricted work hours/absences; decreased productivity while on the job; and career limitations (Keating, Fast, Lero et al. 2014). As figure 3 illustrates, in 2012 care-related absenteeism was the most common consequence or coping strategy. Some 44 percent of employed caregivers had missed an average of between 8 and 9 days of work in the past 12 months because of their care responsibilities. About one in seven employed caregivers reduced their paid work hours to provide care. Women cut back their hours by 10 hours per week and men by 9 hours per week, on average. A small but significant proportion of Canadian caregivers (10 percent) had quit, been fired or had retired from a job because of their care responsibilities within the past year (Fast, Lero, DeMarco et al. 2014). Stone and Short (1990) found not only that caregivers reported quitting their jobs, but also that the prospect of having to accommodate work to the demands of caregiving kept some people from entering the work force entirely (labour force preclusion).

Figure 3. Proportion of employed caregivers ages 19-70 reporting care-related employment consequences, Canada, 2012



Source: Fast, Lero, DeMarco et al. (2014).

Some care providers also take temporary unpaid leave from their jobs when care demands become unmanageable (Dautzenberg et al. 2000; Gillen and Chung 2005; Lai and Leonenko 2007), although accurate data on the number of employees who take a leave of absence for caregiving reasons are scarce. A recent US study suggests that “one in five caregivers took a leave of absence at some point while they were caregiving,” with the average length of the absence being 10 days (NAC, AARP and MetLife Foundation 2009, 9).

In Canada, a small proportion (10 percent in 2012) of caregivers report having turned down a job offer or promotion because of caregiving responsibilities (Sinha 2013). Elsewhere, caregivers also report having turned down training opportunities or declining relocation, which could limit career advancement (Bernard and Phillips 2007; Keck, Saraceno and Hessel 2009; Koerin, Harrigan and Secret 2008).

The literature shows that caregivers also change their work schedules (Dautzenberg et al. 2000; Ellenbogen et al. 2006; Fast, Keating and Yacyshyn 2008; Habtu and Popovic 2006; Henz 2004), use holidays or sick days to meet care responsibilities (often used as a way to avoid loss of pay) (Dautzenberg et al. 2000; Gillen and Chung 2005) or change jobs (Eales et al. 2015; Gray, Edwards and Zmijewski 2008; Lai and Leonenko 2007; Rossi et al. 2007; Sinha 2013) in order to accommodate their care responsibilities. Caregivers at higher risk of experiencing employment consequences include those caring for close kin or someone with a cognitive disability, those residing with the care recipient, and those providing more hours of care (Fast, Dosman, Lero et al. 2013; Lilly, Laporte and Coyte 2007; Uriarte-Landa and Hébert 2011).

Employment restrictions can have significant financial implications for caregivers, including foregone income, reduced pension benefits, lost employment benefits, and reduced savings and investments (Keating, Fast, Lero et al. 2014). Evidence as to the magnitude of foregone income is scarce, especially in Canada. Our own (conservative) estimates, based on Statistics Canada Labour Force Survey panel data collected between 1997 and 2008, suggest that short-term wage losses arising from employment disruptions were modest (\$100-\$1,000 per year) for some individual providers of care to elders, but much more substantial (exceeding \$16,000 per year) for others (Fast and Dosman 2014). Qualitative evidence from our study of caregivers of nonsenior adults with high levels of disability suggest that the range is even greater, with some respondents reporting having to give up jobs with annual salaries of up to \$120,000 (Fast, Keating and Yacyshyn 2008). Women are more likely than men to experience wage losses, and collectively to experience higher losses than men; individually, however, men experience

higher losses, likely because of their higher earning power (Fast and Dosman 2014). Similarly, self-employed caregivers are the most likely to lose work time, but public sector employees lose the most time. Education appears to be a protective factor: those with higher levels of education are the least likely to be out of the work force, and they lose less time when they miss days of work or take a partial leave of absence.

Early retirement precipitated by caregiving responsibilities, such as that reported in Canada by Uriarte-Landa and Hébert (2011), working reduced hours and unpaid absenteeism all are likely to create longer-term income losses as well, reducing retirement benefits from contributory pension plans, including most employer-provided pensions and the Canada and Quebec Pension Plans (CPP/QPP). With a few notable exceptions, however, the monetary effect is not well documented. According to one comprehensive and rigorous Australian study, the “opportunity cost of time devoted to informal care, measured as reduction in paid employment due to caring, provides a ‘lower bound’ estimate of AU\$6.5 billion (equivalent to 0.5 percent of GDP and 9.5 percent of the value of formal health care)” (Access Economics 2010, i). A recent US study reports that the total impact on income of caring for a parent was \$324,044 for women, \$142,693 of which comes from lost wages, \$50,000 from lost pension benefits and \$131,351 from reduced social security benefits. Men were estimated to lose a total of \$283,716, of which \$89,107 is in the form of lost wages, \$50,000 in pension benefits and \$144,609 in social security benefits (MMMI, NAC and CLTCRP 2011; all dollar amounts are US dollars).

The loss of other job-related benefits could have serious implications as well. In 2012, 14 percent of Canadian caregivers who left their jobs or reduced their usual hours of work reported losing some or all of their employment benefits, such as extended health and dental benefits and employer-provided pension, life insurance and prescription drug plans (Sinha 2013). The loss of such benefits might lead, in turn, to extra expenses for such things as health services and medications for themselves and other family members that would otherwise have been covered by employer benefit programs (Fast, Eales and Keating 2001).

### **Out-of-pocket expenditures**

Evidence of the incidence and magnitude of care-related out-of-pocket costs is less robust than that of employment costs, but clearly many caregivers incur expenses that otherwise would have been absent. These expenses might be goods and services for the care recipient or for things (such as housekeeping, child care or yard maintenance) that allow them to carry out their care tasks or to accommodate recipients in their own homes. Some of these expenses might be covered or reimbursed by recipients or by public benefits, but caregivers still end up out of pocket for a number of reasons. The high cost of services coupled with inadequate income and/or assets means that some care receivers are unable to cover the cost of all of their care needs (Groucutt and Holzhausen 2007). Caregivers also attribute their care-related expenses to the lack of locally available services (which forces them to travel farther or to purchase more expensive local substitutes); the lack of insurance coverage and the existence of long waiting lists; or the inability to qualify for publicly provided services, benefits and subsidies (Fast, Keating and Yacyshyn 2008). This might explain why, in 2012, only a minority of caregivers received financial help from family or friends (between 9 and 24 percent) or government (between 3 and

30 percent) and why some had to borrow from friends or family (between 1 and 10 percent) or from a financial institution (between 3 and 12 percent) (Turcotte 2013).

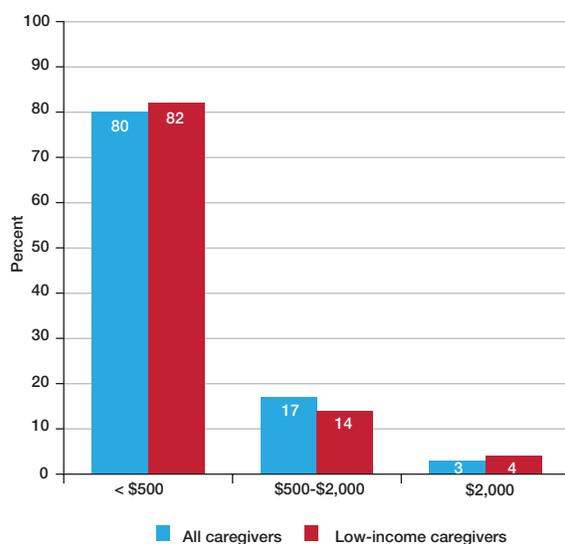
Out-of-pocket expenditures fall into four main categories: residential care; community services; supplies; and transportation and travel (Keating, Fast, Lero et al. 2014). Canadian data on care-related out-of-pocket expenditures are limited, and estimates of the proportion of caregivers incurring expenses in one or more of these expenditure categories vary widely, from 40 percent among a general population of Canadian caregivers in 1996 (Keating et al. 1999) to 80 percent among those caring for family members with high levels of care needs in

2008 (Fast, Keating and Yacyshyn 2008).

One study finds that in 2007 35 percent of caregivers ages 45 and older (more than 1.2 million Canadians) reported incurring care-related out-of-pocket expenses (Duncan et al. 2013).

Estimates of amounts spent out of pocket also vary widely, depending on the data collection method used and the care recipient's needs. Canadian studies of care provided to veterans in Toronto, Halifax, Ottawa and Victoria using expenditure diaries have generated estimates of annual out-of-pocket expenses averaging \$2,144 for those caring for someone in community care and \$14,340 for those caring for someone in a care facility (the latter includes facility copayments) (Miller et al. 2008; Miller, Hollander and MacAdam 2008). Self-reports

Figure 4. Caregivers ages 45 and older reporting care-related out-of-pocket expenses (per month), Canada, 2007



Source: Duncan et al. (2013).

collected in our own telephone survey of Canadians caring for family members with high levels of care needs generated an estimated average annual expenditure of \$7,599, with some reporting expenditures in excess of \$120,000 (Fast, Keating and Yacyshun et al. 2008). Most (80 percent) of the caregivers ages 45 and older who reported out-of-pocket expenditures spent \$6,000 or less per year, but about 17 percent spent between \$6,000 and \$24,000 per year and 3 percent spent more than \$24,000 annually. Collectively, such expenditures are significant, amounting to almost \$12.6 million annually (Duncan et al. 2013). As figure 4 illustrates, the distribution of expenditures among higher- and lower-income earners (those with incomes below \$30,000 per year) was very similar, suggesting that out-of-pocket expenses hit hardest those who can least afford it.

Out-of-pocket expenses can affect caregivers' discretionary income. For example, in one Saskatchewan study, after incurring out-of-pocket expenditures on home renovations, transportation, medication and funerals, the caregivers of family members with a range of chronic conditions reported that, although they were able to make ends meet every month, they no longer had any discretionary income and worried about whether their future incomes and savings would be adequate for their needs (Sawatzky and Fowler-Kerry 2003).

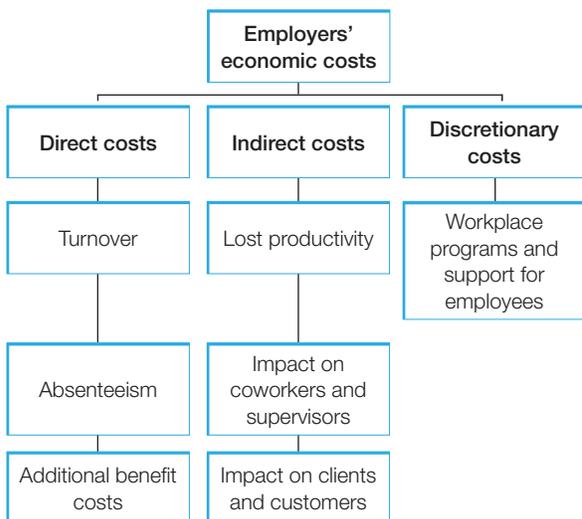
### Financial security outcomes

The overall cumulative outcome of employment and out-of-pocket costs is a financial burden and insecurity for some caregivers. In 2012, 3 percent of Canadians caring for a friend or neighbour and 28 percent of those caring for a child with a disability experienced financial hardship as a direct result of their caregiving responsibilities (Turcotte 2013). Similarly, in an Ontario study, out-of-pocket costs associated with cancer treatments were reported to result in a significant or unmanageable level of financial burden by over 20 percent of caregivers (Longo et al. 2006). Caregivers with the highest out-of-pocket costs — and so with the least discretionary income — are the most likely to cut back on spending on their own necessities such as clothing, transportation, utilities, and dental and health care, to spend down their own savings to cover extra costs and to acquire new debt (Groucutt and Holzhausen 2007; Lai and Leonenko 2007). The financial burden is also related to caregivers’ income level, with those whose costs represented a higher proportion of income reporting a higher burden (Lauzier, Maunsell, De Koninck et al. 2005; Lauzier, Maunsell, Drolet et al. 2010; Longo et al. 2006). As with our own study (Duncan et al. 2013), in the US Evercare study (Evercare and NAC 2007), caregivers with the lowest income reported average care-related expenditures of more than 20 percent of their annual income.

### Financial Risks for Employers and the Labour Market

Job loss, absenteeism, reductions in hours and earnings, foregone career opportunities, health impacts and stress create obvious financial and other costs for caregivers, but caregiving results in costs for employers as well. Employers are increasingly challenged to ensure workplace efficiency in the face of employee turnover, absenteeism, reduced productivity and demands on employee benefit programs among people with caregiving responsibilities. These challenges, and their far-reaching implications for the labour market and the economy, make it imperative to obtain a better understanding of the broader financial costs of caregiving. Our scoping review turned up evidence of three distinct domains of costs that employers experience as a result of having employees with care responsibilities: direct costs, indirect costs and discretionary costs (see figure 5) (Keating, Lero, Fast et al. 2013).

Figure 5. A taxonomy of the financial costs of caregiving for employers



Source: Keating, Lero, Fast et al. (2013).

Our scoping review turned up evidence of three distinct domains of costs that employers experience as a result of having employees with care responsibilities: direct costs, indirect costs and discretionary costs (see figure 5) (Keating, Lero, Fast et al. 2013).

#### Direct costs

Direct costs arise from turnover (wage, benefit, search and managerial costs when employees who retire, quit or leave a job must be replaced), absenteeism (wage and benefit costs for absent workers and their replacements) and additional benefit costs (such as health care claims and disability leave for care-related health consequences). Several studies suggest that the direct cost of replacing employees runs

between 50 and 300 percent of the employee's annual salary; the cost of recruiting and replacing senior executives is at the higher end of this range (see, for example, Bachmann 2000). A study by the Conference Board of Canada estimates that care-related turnover among caregiver employees ages 45 and older costs Canadian employers \$355 million annually (Hermus et al. 2012).

In 2012, the 2.4 million employed caregivers in Canada who missed an average of 8 to 9 days of work in the previous 12 months because of their care responsibilities accounted for 9.7 million days of absenteeism, while an additional 828,739 employed caregivers collectively worked 256 million fewer hours (Fast, Lero, DeMarco et al. 2014). To put this in perspective, the Conference Board of Canada (2013) reports that the average rate of absenteeism *for all reasons* in Canadian workplaces was 9.3 days per full-time employee in 2011. Another Conference Board of Canada study estimates that care-related absenteeism cost Canadian employers nearly \$700 million, while partial absences (missing a few hours of work) cost \$234 million (Hermus et al. 2012).

Additional costs that can arise from health care claims and disability leave for employees with caregiving responsibilities have received little attention to date, but they are an emerging concern. Employees with long-term and/or intense caregiving responsibilities are generally in poorer health than their noncaregiver counterparts (Duxbury, Higgins and Smart 2011; Edwards et al. 2008). In 2012, between 5 percent and 38 percent of caregivers ages 15 and older reported care-related health effects (Turcotte 2013). There are no estimates of what the additional costs might be for Canadian employers, but one US study suggests they might account for an additional 8 percent in direct costs for physician fees, prescription drugs and increased health premiums (MMMI and NAC 2010). Although there are marked differences between the United States and Canada with respect to health care insurance coverage, even in Canada only basic physician and hospital services are covered by provincial insurance programs, making extended benefit plans important recruitment and retention tools for Canadian employers. Care-related illness and disability that increase caregiving employees' reliance on these benefit plans thus have the potential to affect Canadian employers' bottom lines as well.

### **Indirect costs**

Indirect costs relate most often to lost productivity — meaning reduced return on investment in employees, poorer on-the-job performance, and effects on coworkers, supervisors, customers and clients. Because of their relatively hidden nature, indirect costs are difficult to quantify, but they are believed to be more detrimental and more costly financially to employers than the direct costs associated with employees' care-related absenteeism, leave or turnover.

By far the most dominant theme running through the existing literature on employer costs related to caregiving is productivity losses that result from absenteeism, reduced physical and mental health, and decreased energy, engagement and performance when at work ("presenteeism") (Burton et al. 2004; Duxbury, Higgins and Schroeder 2009; Fast, Eales and Keating 2001; Lilly 2010; Sherman and Reed 2008). Research confirms that caregivers are more likely than noncaregivers to report physical health and emotional problems; difficulty with time management; being distracted at work; requiring help from others to get work done; high levels of stress, anxiety and depression; and less time for sleep and physical exercise. This pattern has been noted even among

those with low levels of caregiving responsibility, but it increases with caregiving time (Burton et al. 2004). In the absence of Canadian data, I again turn to the United States, where the Metlife Caregiving Cost Study estimates that the one hour per week of workday interruptions reported by 34 percent of male and 52 percent of female full-time employed caregivers resulted in an estimated productivity loss of US\$6.2 billion to employers, while additional care-related supervision requirements cost close to US\$1.8 billion (MMMI and NAC 2006). Mazanec et al. (2011) similarly report a mean productivity loss of 22.9 percent arising from absenteeism, presenteeism and work and activity impairment among caregivers to persons with cancer.

There is even less empirical evidence about indirect costs associated with poorer service to clients and customers that may result in lost sales revenue, foregone contracts or other business income, but it stands to reason that such costs would result when individuals who provide direct services to the public or to specialized clients are absent or fail to provide the quality or timeliness of service expected. Such circumstances are most likely to affect specialized service organizations in such fields as research, financial, legal and consulting services, for which loss of billable hours and dissatisfaction or loss of key clients could have significant financial effects.

### **Discretionary costs**

Discretionary costs are those associated with the provision of additional flexibility, support and information to employees with caregiving responsibilities — strategies that are often considered to represent “best practices” in human resource management for offsetting turnover, absenteeism and productivity losses (Lilly 2010; MMMI and NAC 2006; Yeandle et al. 2006). Indeed, the desire to retain experienced, skilled employees and to reduce the costs associated with staff turnover are often cited as reasons employers introduce work-life initiatives, especially given concerns about looming labour and skill shortages (AARP 2008; Lilly 2010; Yeandle et al. 2006), although such initiatives are also accompanied by service costs (for employee assistance program services, for example) that are borne either by all employees or by employers. To the extent that they reduce other costs of having caregiving employees in the workplace, however, the cost of implementing such strategies represents an investment.

Care-related employment consequences and/or out-of-pocket expenditures have implications for the labour market and economy more generally, although studies in which these implications are monetized are rare. As reported above, caregivers reduce their hours of paid work or leave their jobs to provide care which resulted in nearly 9.7 million days of absenteeism and the turnover of more than half a million caregiver employees in Canada in 2012 (Fast, Lero, DeMarco et al. 2014). When we aggregated the wages that individual caregivers lost due to absenteeism, reducing their hours of work or leaving employment entirely, we arrived at population-level estimates of lost wages of \$220.5 million annually for women and \$116.3 million for men during the period 2003 to 2008. Moreover, these losses were substantially higher than during the previous six-year period, almost doubling (from \$127.8 to \$220.5 million per year) for women and increasing by 40 percent (from \$91.5 to \$116.3 million per year) for men (Fast and Dosman 2014). In effect, Canada is losing the equivalent of 557,698 full-time employees from the workforce annually as a result of the inability to juggle the conflicting demands of paid work and care (Fast, Lero, DeMarco et al. 2014). For governments, the most time-consuming care situations result in lost income tax revenues and additional social

assistance payments when caregivers can no longer maintain their employment alongside care work. Jacobs et al. (2013) estimate that Canadian caregivers who provide the most hours of care created an aggregate net cost to government of \$641 million in lost income tax revenues and higher social assistance benefit payments.<sup>5</sup> Similarly, when caregivers' health is affected negatively by their care responsibilities such that they require more health care services, government health care expenditures also rise.

## Employers' Strategies to Reduce the Negative Consequences of Caregiving

Since most caregivers are employed, and care-related employment consequences are common and costly to both caregivers and employers, employers are critical players in supporting caregivers. It also is in employers' own best interest to avoid turnover, absenteeism and presenteeism among employees in whom they have invested significant time and money. Forty-four percent of caregivers are ages 45 to 64 (Sinha 2013), peak earning years for employees and peak productivity years for employers.

There are few nationally representative data on the extent to which Canadian employers provide flexible work arrangements, access to leave and information and support services that would be particularly beneficial for employed caregivers, and none on the costs of providing such support. What little evidence there is suggests that, since the late 1990s, Canadian employers have provided limited access to support and services for their caregiver employees, particularly related to elder care (Ferrer and Gagné 2006), but they are now beginning to offer a wider range of such support and services (Galinsky, Sakai and Wigton 2010; Society for Human Resource Management 2010, 2011). A study of employer practices and supports involving a nonrandom but broadly representative sample of nearly 300 Canadian workplaces confirms that Canadian employers are beginning to recognize and respond to the needs of employees with adult and elder care responsibilities (Lero et al. 2012). Seventy percent reported being aware that they had employees with significant care responsibilities in their workplaces, and most (89 percent) reported that they provide some form of assistance to at least some employees to balance their jobs with other aspects of life. It is evident, however, that adult and elder care remains an emerging issue, reported as a low priority or not on the radar screen of important workplace issues by 57 percent of senior managers and human resource department representatives in the sample. It also is not yet appreciated as an organizational challenge, but rather is approached as an individual, personal matter for employees.

Supports for caregiver employees include measures that increase the flexibility of work arrangements, direct compensation and information and referral. The flexibility of work arrangements can be enhanced by allowing employees some choice as to when and where they do their jobs. This might include their choosing starting and quitting times, taking time off during the day to attend to other responsibilities, being able to work at least some time at home or offsite, working part-time or part-year schedules and taking a leave from the job. Eighty-nine percent of employers who participated in the Lero et al. (2012) study reported that they offered at least one of these types of flexibility to at least some employees, but only 16 percent said they offered flexible working options specifically for employees with care responsibilities.

**Table 1. Proportion of employers providing child care and adult care leave benefit, by type of benefit (percent)**

Maternity, parental, paternity leave		Compassionate care leave	
More than 18 weeks of unpaid maternity leave	60	More than 8 weeks of unpaid compassionate leave	29
Additional unpaid parental leave beyond legislated mandate	45		
Top-up of EI/QPIP maternity leave benefit <sup>1</sup>	41		
Top-up of EI/QPIP parental leave benefit	30	Top-up of EI compassionate leave benefit	10
Top-up of QPIP paternity leave	24	1-8 weeks of fully paid compassionate leave	4

Source: Lero et al. (2012).  
<sup>1</sup> Employment insurance/Quebec parental insurance program.

A few employers extend what is provided by the federal compassionate care leave, either by offering more weeks of leave or topping up the benefits, but there is a marked discrepancy between the way they treat employees who are new parents and those with adult or elder care responsibilities. It is the latter who experience more work-life balance problems, yet they benefit less from supports than do employed parents of young children. Considerably fewer employers (29 percent) provided extended (more than eight weeks) unpaid compassionate care leave than extended maternity (60 percent) or parental leave (45 percent) beyond that mandated by legislation (see table 1). This suggests that most employers still see employees with child care responsibilities as having a more “legitimate” claim on employer support than those with dependent adult care responsibilities. Moreover, although many caregiver employees report having the option to work part time, to work flexible hours or to work at home, nearly half feel unable to access these options without jeopardizing their careers (Fast, Lero, DeMarco et al. 2014). Direct compensation in the form of interest-free loans, subsidies or direct financial assistance might be helpful to employees, particularly those with substantial out-of-pocket costs related to caregiving. Approximately 41 percent of employers who participated in the Lero et al. (2012) study provided some type of financial assistance to employees, but less than 3 percent indicated that any of their financial support was designed for employees with adult or elder care responsibilities. Financial assistance for in-home or external care for seniors or adult family members with disabilities was rare, as was assistance for respite care and travel subsidies for employees with caregiving responsibilities (available in less than 3 percent of workplaces). A few employers (4 percent) did report that they top up employment insurance compassionate care benefits, but many more top up maternity, parental or paternity leave benefits (see table 1).

Seventy-one percent of employers in the Lero et al. (2012) study provided some form of information, counselling or other assistance to help caregiver employees cope better with their care responsibilities, most often organized through a contracted employee assistance program or similar service. On-site seminars and lunch-and-learn sessions were available to parents in 19 percent of the surveyed workplaces and to caregivers with adult or elder care responsibilities in 13 percent. On-site child care services were available in 12 percent of the firms surveyed, while on-site or nearby day programs for dependent adults were rare (available in less than 3 percent).

Managers and supervisors handled most requests from employees with significant caregiving challenges on a case-by-case basis and with individualized responses. In general, managers used a mix of informal responses and leave policies, often involving employees using sick leave first as

a means to cover immediate needs. The most common factors influencing managers' responses were organizational factors and workplace culture, the nature of the employee's work (including whether the employee is a manager or supervisor), perceptions of the employee and manager attitudes. For example, workplaces in the public sector and broader public sector (such as hospitals and universities) provided a larger number of flexible options to more of their employees than did their counterparts in the private sector, as did workplaces with a higher proportion of women and a higher proportion of permanent employees. Interestingly, workplace size was not a significant predictor of flexibility, adding to prior evidence that smaller organizations can be at least as flexible as larger ones (Lero et al. 2012).

Evidence is mounting that providing support for caregiver employees makes good business sense. In a recent case study by the European Foundation for the Improvement of Living and Working Conditions, initiatives by British Telecom to address the needs of working caregivers were described as part of the company's commitment to flexible working in general (Byrne 2011). Seven out of ten British Telecom employees use some form of flexible working arrangement, such as limited or annualized hours or compressed weeks. An internal evaluation concluded that these flexible working options increased the productivity of these employees by as much as 21 percent (the equivalent of \$8.5 to \$9.9 million per year) and reduced stress-related absence by 26 percent. Heywood and Miller (2014) also find a strong negative association between flexible schedules and absenteeism. Evidence also suggests that the relationship between flextime options and firm profitability depends on the employer's motivation for providing such options. Lee and DeVoe (2012) find that firm profitability increases when workplace flexibility is implemented as part of a strategy focused on employee quality enhancement but decreases when flexibility is part of a cost-cutting strategy.

Caregivers consistently flag workplace flexibility as a key need for integrating care and paid work responsibilities (Duxbury, Higgins and Smart 2011; Eales et al. 2015). Yet, although most employers provide flexible working options to at least some employees, few recognize the distinct needs of those caring for dependent adults or understand that one-size-fits-all strategies cannot provide solutions to all employees who experience work-care conflict. In fact, this blindness to circumstantial differences likely reinforces some of the inequitable outcomes. Women, lower-income earners and those in precarious employment are likely to be most seriously disadvantaged. One survey of caregiver employees showed lower participation in flextime arrangements among women than among men, even in managerial and professional occupations, where one would expect more inherent flexibility and more gender equity (Comfort, Johnson and Wallace 2003).

## Government Strategies to Reduce the Negative Consequences of Caregiving

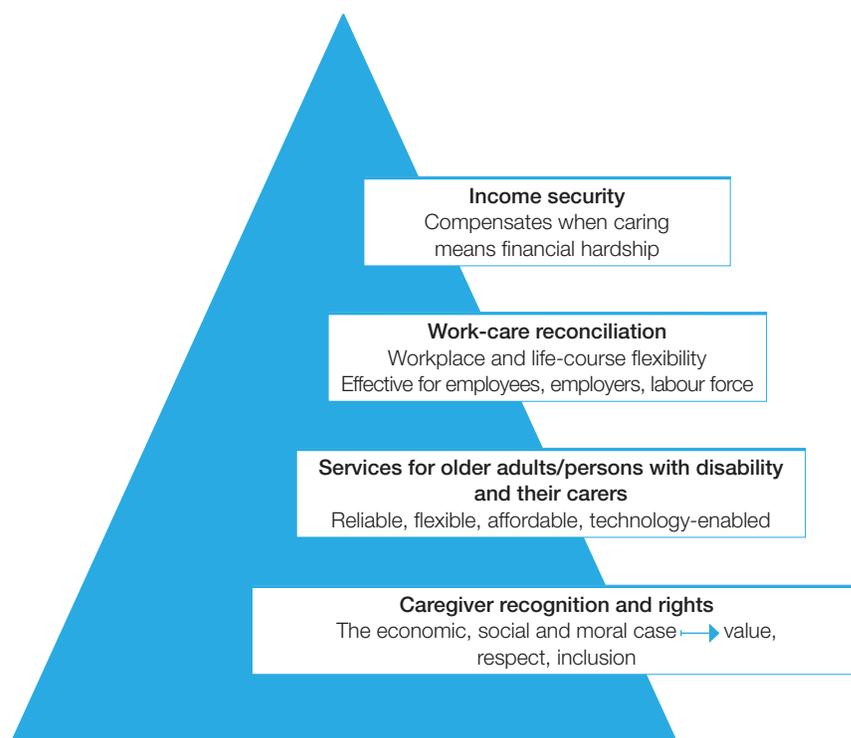
**P**ublic policy essentially determines how the costs of caregiving will be distributed among caregivers, employers and governments, thus influencing outcomes for these stakeholders. In the absence of adequate support, caregiving can put caregivers at risk of poor social, economic, physical and mental health outcomes. This, in turn, can threaten the sustainability of the formal health care system, the labour market and the economy more generally.

Canada's federal political structure is an important overarching characteristic of the policy context for any policy issue because it divides jurisdiction over policy domains among the federal, provincial and territorial governments. Responsibility for labour, education, child care, and health and human services falls to provinces and territories for the most part. That said, the federal government does transfer funds to the provinces and territories that are used to deliver services within these policy domains, and it also delivers health and human services directly to select populations (First Nations, Inuit, veterans and serving military). Municipal governments also enter the picture when they opt to provide or subsidize services and benefits to residents. Canadian governments have taken on some responsibility for addressing the consequences of family and friend care, implementing a range of approaches to help reduce or redistribute caregiver costs.

As in most policy domains, caregiver support policies are characterized by split jurisdiction among different levels of government. This, in turn, means that there is a complex, variable and uneven network of public caregiver support policies and programs. Originally developed for a seminar for members of the UK Parliament, the framework presented in figure 6 has proved useful in guiding a comparative analysis of caregiver support policies in three Commonwealth countries (Cass, Fast and Yeandle 2014). Here it is used to frame a systematic review of what governments are doing to support Canadian caregivers and is proposed as a tool to build a comprehensive policy framework to better support them.

The first layer of a comprehensive system of caregiver support policies consists of acknowledging and appreciating care work and conveying basic rights. Recognizing the important role

Figure 6. Requirements for delivering sustainable and inclusive support for caregivers



Source: Cass, Fast and Yeandle (2014).

that caregivers play, acknowledging their contributions to families, friends, communities and Canadian society more generally, and understanding the potential for care responsibilities to disadvantage caregivers and other stakeholders represents a foundational first step to legitimizing public action. Caregivers themselves see this as critical, as exemplified in the Canadian Caregiver Coalition's declaration that "Caregiver recognition must be the foundation on which to build" (2003, 2).

The second layer is a health and continuing care infrastructure that provides reliable, flexible, affordable and technology-enabled services to both caregivers and care recipients. Health and continuing care services and supports can reduce the risk of negative health and social consequences for caregivers and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care. Although far more of the care that adults in need receive comes from family and friends than from the formal health care system (Chappell, MacDonald and Stones 2008), formal care services might provide either direct or indirect support to caregivers that sustains or even extends their caring capacity and helps them to avoid incurring some costs *a priori* (Chappell 2011). Such services can provide a temporary break to recuperate from the demands of caregiving, increase caregivers' autonomy or help meet escalating demands as care recipients' needs increase without resorting to institutionalization.

The third layer consists of policies to facilitate the reconciliation of care work and paid work so as to moderate or avoid employment consequences. The fourth layer consists of income security policy to compensate when care makes it difficult for caregivers to provide for themselves. Instruments for moderating the financial risks of caregiving include direct compensation through caregiver allowances, indirect compensation through social assistance benefits or tax measures and self-managed care schemes. I now turn to an exploration of Canada's policy — and its limitations — based on this framework.

### **Caregiver recognition and rights**

In 2011, Manitoba became the first — and to my knowledge the only — jurisdiction in Canada to codify acknowledgement of the role of caregivers into its *Caregiver Recognition Act*. The Act recognizes the value of caregivers' work, promises that the government will work with caregivers to provide a system of supports and creates a set of general principles for how caregivers should be treated. Manitoba also established a caregiver advisory committee to provide the minister with information, advice and recommendations and required the committee to produce biannual progress reports that evaluate caregiver needs and supports. Several provinces, including Manitoba, Alberta, Newfoundland and Labrador, and Quebec, have proclaimed annual caregiver recognition days or weeks in order to raise public awareness of and appreciation for caregivers' contributions.

In addition, since about the mid-2000s, human rights legislation has been invoked to protect employed caregivers from discrimination in the workplace. The *Canadian Human Rights Act* has prohibited discrimination on the basis of family status since 1984 (later in provincial and territorial counterparts). The Canadian Human Rights Tribunal has interpreted this to mean that employers and unions must accommodate individual employees' needs related to their family

caregiving responsibilities, so long as the employee has made a reasonable attempt to reduce family-work conflict and unless the accommodation will cause the employer undue hardship. According to the tribunal, undue hardship includes excessive cost or risks to health or safety created by making an accommodation; although there is no explicit standard or metric for undue hardship, employers are required to provide evidence as to the nature and extent of the hardship. Recent tribunal decisions have been upheld by federal and provincial courts, reaffirmed as recently as May 2014 in Federal Court of Appeal decisions.<sup>6</sup>

These initiatives are evidence of the growing awareness and acknowledgement of the caregiver role and assert the legitimacy of public support for it in Canada. That said, although Manitoba's legislation demonstrates that particular government's moral support for caregiving, no new substantive measures to improve the financial situation of caregivers have yet been implemented there, and the Act is not indicative of any practical headway in achieving redress. In contrast, federal human rights legislation has practical implications. It gives the issue of accommodating family caregivers' needs quasi-constitutional status, which, in turn, could help normalize the caregiver role. The recent application of human rights legislation to employees' right to request workplace accommodation for family responsibilities could create conditions similar to UK and Australian legislation on the right to request flexible working arrangements. The British Columbia Law Institute and the Canadian Centre for Elder Law consider that the family responsibilities approach appears "to have achieved some success in shaping a more progressive understanding of the impact of caregiving responsibilities on labour force participation" (2010, 56).

Some harmonization of human rights legislation needs to take place. Because each federal and provincial jurisdiction has its own unique legislation, differences in terminology have emerged, including the meaning of "family status." For example, in Ontario, family status refers to parent-child relationships, while Alberta and Nunavut define family status more broadly as including relationships of blood, marriage or adoption (British Columbia Law Institute and Canadian Centre for Elder Law 2010).

### **Services for older adults with disability and their caregivers**

The only service that targets caregivers directly across Canada is respite care, and even then eligibility typically is based on the care recipient's needs, rather than the caregiver's (Canadian Health Care Association 2012). Federal transfer payments for health and social services help to support provincial long-term and continuing care programs, but, because such services are not covered by basic public health insurance schemes, the availability of services, at what cost and under what conditions, varies substantially across jurisdictions. Despite robust evidence of the cost-effectiveness of home care (Hollander 2001; Hollander and Chappell 2007), there has been a hollowing-out of health and continuing care systems since the 1970s: health services increasingly are provided outside the medicare or hospital systems; there is a distinct trend toward the privatization and commodification of health and continuing care; and home care services are being diverted from chronic to postacute care (Chappell 2011). The upshot is an increase in private expenditures on health and continuing care services (Le Goff 2002).

Every province, as well as Veterans Affairs Canada, has a self-managed care program in which benefits are paid directly to older adults or persons with a disability with which they can hire their own care services. Many now allow recipients of self-managed care benefits to “hire” relatives and friends as their designated care providers. Examples include Manitoba’s Family Managed Care Program, Newfoundland and Labrador’s Paid Family Caregiving Option and British Columbia’s Choice in Supports for Independent Living program. Eligibility criteria and program administration vary across jurisdictions, although eligibility for provincial health insurance, age and ability to self-manage are common criteria (Spalding, Watkins and Williams 2006).

Canada’s universal health insurance system is such that few Canadian caregivers incur out-of-pocket expenses for hospital or physician visits. In addition, although care and support services provided outside acute care settings (such as home care and residential long-term care) are not insured services, they are available in all jurisdictions and subsidized for low-income and high-needs individuals. However, resources in the home and residential long-term care system are lacking, so that hours of services received might not meet care needs. Caregivers therefore might have to turn to private-pay services to fill gaps in care needs at home, and many jurisdictions require copayment even when publicly subsidized services are available. Further, expenses covered in acute care settings — for medications, dressings or equipment such as hospital beds — are not covered outside hospital settings. Available evidence shows that, despite publicly insured physician and hospital care and publicly subsidized community care, Canadian caregivers incur costs for health care goods and services purchased outside the public domain (Decima Research 2002; Dumont et al. 2009; Fast, Keating and Yacyshyn 2008; Lauzier, Maunsell, De Koninck et al. 2005).

In addition, eligibility criteria, program administration and goods and services covered under home care programs vary substantially across jurisdictions, resulting in significant inequities among caregivers and recipients. Self-managed care programs provide a certain amount of flexibility and control to recipients, and there is some evidence that they result in cost efficiencies and better outcomes (Spalding, Watkins and Williams 2006). But here, too, there is substantial geographic variability in eligibility and program administration. In addition, these programs require the care recipient to become an employer, with all the attendant responsibilities, and they assume a ready supply of care providers in the local community willing to work for the amount provided. Yet labour shortages, rapid turnover and lack of training among paid care workers make it difficult for self-managed care benefit recipients to find qualified paid care workers (Columbo et al. 2011).

Even where services are available, caregivers often are unaware of them, report them to be too expensive, or have difficulty identifying and accessing them. During Manitoba’s consultations leading up to the introduction of its *Caregiver Recognition Act*, navigating the system and accessing information, programs and services were identified as the challenges caregivers encountered most frequently (Manitoba 2013). Some programs explicitly require a family member, friend or support group to assist in managing care. Even when this is not an explicit requirement, if care recipients lack the capacity to manage benefits and care arrangements themselves, family caregivers likely need to step in, and this adds to their responsibilities.

### **Work-care reconciliation**

Federal and provincial labour laws include a range of provisions that allow caregivers to take a break from their paid work to deal with periods of caregiving without fear of losing their jobs. In all Canadian jurisdictions, family responsibility leave entitles workers to short-term (two to ten days a year), job-protected leave that can be used to fulfill a wide range of family responsibilities, including caregiving. Although this provides caregivers some flexibility and job protection, all the care episodes captured by nationally representative Canadian data have been a minimum of six months' duration, and half have lasted for more than four years. Similarly, the average number of days of absenteeism reported by caregivers exceeds most provinces' family responsibility leave limits. Moreover, such leave is unpaid (British Columbia Law Institute and Canadian Centre for Elder Law 2010). Consequently, family responsibility leave does not address most caregivers' long-term needs for flexibility and fails to protect their income, often forcing caregivers to use their own paid vacation and sick time instead and leaving them with reduced means to protect their own health and well-being.

Federal compassionate care leave, and its provincial equivalents, is another policy instrument aimed at protecting caregivers whose employment is disrupted by caregiving. At the time of writing, the federal program guarantees 8 weeks of job-protected leave over a period of 26 weeks to provide care or support to gravely ill family members at risk of dying within six months. The leave may be taken in one-week increments and split among multiple caregivers. For the 10 percent of workers employed in federally regulated industries, the leave is provided under the Canada Labour Code; for those employed in provincially regulated industries, the relevant provincial labour codes apply. As of February 2014, when Alberta became the last province to implement compassionate care leave, all eligible employees have had access. With few exceptions, federal and provincial regulations require minimum periods of employment prior to the leave, but these vary somewhat across jurisdictions. There also is some variability in eligibility criteria and the length of leave to which employees are entitled, but most provinces provide 8 weeks of leave, in line with the federal program, with a maximum of 16 weeks (British Columbia Law Institute and Canadian Centre for Elder Law 2010).

Ontario and Quebec have elected to build on compassionate care leave with additional leave for the most extreme circumstances. Quebec provides up to 104 weeks of leave for those caring for an ill minor child. In April 2014, to its existing 8-week family caregiver leave, Ontario added critically ill child care leave of up to 37 weeks and crime-related child death or disappearance leave of up to 52 weeks for parents of a missing child or up to 104 weeks for parents of a child who has died as a result of a crime.

In sum, work-care reconciliation measures have attracted a good deal of attention from Canadian policy-makers, with a number of new policy instruments being introduced over the past decade or so.

### **Income security**

Of Canadian jurisdictions, only Nova Scotia provides direct financial compensation for caregiving labour. Its caregiver benefit is a monthly cash benefit (\$400 in 2015) for caregivers

providing 20 or more hours of care per week to low-income adults with a high level of disability or impairment, as determined by a home care assessment. This income-tested, taxable benefit is available to caregivers of low-income family members or friends (single care receivers with annual earnings of \$22,125 or less and married and common law care receivers with annual earnings of \$37,209 or less ).

Caregivers are not always eligible for social assistance benefits, even when their care responsibilities prevent them from seeking employment. In Saskatchewan caregivers are eligible for social assistance benefits when they “need to care for a family unit member” (Saskatchewan 2015, 4). In British Columbia, eligibility is restricted to “persons who reside with and care for a spouse who has a physical or mental condition that, in the minister’s opinion, precludes the person from leaving home for the purposes of employment” (British Columbia 2015).

The federal and some provincial governments provide some income tax relief that takes into account caregivers’ reduced capacity to pay, thereby compensating, indirectly, for some of the financial costs they incur. The federal caregiver amount tax credit (\$4,530 in 2014) is available to those who reside with a relative over age 18 who is dependent on the taxpayer because of a mental or physical infirmity. In 2012 the federal government also implemented a family caregiver amount tax credit (\$2,058 in 2014) as an enhancement for taxpayers already eligible for the spouse or common-law partner credit, the eligible dependent credit, the caregiver tax credit or the child tax credit. Both the caregiver amount tax credit and the family caregiver amount tax credit are means-tested (on the dependent’s income), are nonrefundable and require a physician’s statement as to the infirmity. All provincial and territorial governments also provide caregiver tax credits, most of which are subject to the same eligibility criteria as the federal tax credits and are similarly income-tested and nonrefundable. Exceptions include Manitoba’s primary caregiver tax credit, which is fully refundable and not means-tested, and Quebec’s caregiver and respite care tax credits, which are means-tested but refundable. Caregivers also may be able to claim any portions of the federal disability, attendant care and medical expense tax credits that are not needed to reduce the tax payable of the person for whom they are caring to zero (Canada 2011).

Although the tax system is being used to redistribute income and to encourage caregiving and the combining of care work and employment, it is neither an efficient nor equitable mechanism for supporting caregivers. Most tax credits are nonrefundable, so only taxpayers with sufficient taxable income benefit. Lower-income caregivers, who most need financial assistance, receive little, if any, of the tax credit. Only a small minority of caregivers reside with the person for whom they care (Fast, Lero, DeMarco et al. 2014), rendering most caregivers ineligible for the caregiver tax credit and its enhancements. Indeed, only a minority of caregivers responding to Statistics Canada’s 2012 General Social Survey said they had received a federal tax credit specifically meant for caregivers (only 3 percent of those caring for their parents, and 28 percent of those who cared for a child with a disability) (Turcotte 2013). Shillington observes that such nonrefundable credits produce the “anomalous result that only 1 percent of tax filers can use the credit, and 75 percent of these are male” (2004, xii).

Compassionate care benefits, delivered under the federal employment insurance (EI) program, are an important component of Canada's repertoire of policy instruments intended to achieve greater work-family integration and income security, especially for women. Caregivers eligible for compassionate care leave also are eligible for compassionate care benefits (Service Canada 2011), which provide partial income replacement for up to six weeks (beginning after a two-week waiting period) at a rate of 55 percent of earnings at the time of the leave up to a maximum of \$524 per week in 2015. If the leave is split among more than one caregiver, each may receive benefits for his or her portion of the leave (although only the first claimant is subject to the waiting period). According to the most recent available report on EI benefit claims (for the period April 2009 to March 2010), 5,978 claims were established for compassionate care benefits, a modest 2.4 percent increase over the previous 12-month period (Canada Employment Insurance Commission 2011). Since June 2013, parents who take leave from work to provide care or support for a critically ill or injured child also have been eligible for a special EI benefit for parents of critically ill children. Benefits replace 55 percent of preleave income to the same maximum as other EI benefits, for up to 35 weeks.

The main limitations of compassionate care benefits are the two-week waiting period and low level of income replacement. Although they do enhance income security for some, low-income earners continue to be especially disadvantaged, receiving less financial assistance than higher-income earners. The low rate of income replacement makes it rational for the lower-income earner in the family to take the leave (if anyone does), diminishing the ability of the leave and benefit to redress gender and longer-term socio-economic disadvantage. In addition, the strict eligibility criteria mean that only a small portion of all leaves taken to meet caregiving needs are eligible for the benefit, with the remainder being unpaid and uncompensated, unless individual employers volunteer to pay and compensate for them. Further, caregivers with nonstandard jobs and career paths have little or no access to compassionate care benefits, yet self-employed caregivers are more likely to report care-related absences and their absences tend to be longer than those who work for an employer (Dosman, Fast and Rowe 2010).

The requirement for a physician's certificate affirming that the care receiver is at significant risk of death within 26 weeks also presents a significant barrier to access for caregivers. What little evidence is available about the willingness and ability of physicians to provide official prognoses of imminent death suggests that they feel poorly prepared, find it stressful and worry about patients' judgments if their prognosis is wrong; moreover, their prognoses have low levels of accuracy (Christakis 1999; Christakis and Lamont 2000).

In sum, compassionate care leave and compassionate care benefits have significant limitations, including their short duration (especially if shared), their exemption of self-employed, part-time and casual workers, and their restriction to end-of-life care. These eligibility criteria mean that such leave and benefits are available to only a small number of caregivers, likely accounting for their low take-up rate (Williams et al. 2006). However, the trend seems to be toward a more liberal caregiving leave program. In April 2014, Ontario and New Brunswick eliminated the requirement that the care recipient be terminally ill in order for the caregiver to qualify for family caregiver leave (although compassionate care benefits are still available only to those

providing end-of-life care). In addition, Nunavut has implemented paid leave for government employees who must care for a seriously ill family member. In its 2015 budget, the federal Conservative government proposed to extend compassionate care leave to six months, but only for employees working in federally regulated industries and meeting minimum insured prior work requirements. The new Liberal government has stated that this measure will come into effect on January 3, 2016.<sup>7</sup> This will address one of the most common criticisms of the program.

## Improving Supports for Caregivers

A clear case for improving supports for caregivers is emerging. Caregivers are at higher risk of poor health, social and financial outcomes than noncaregivers or those caring for their own (healthy) children. As well, they have less access to support, services and benefits than do care recipients. There also are inequities among caregivers themselves, with some caregivers having less access to, or benefiting less from, caregiver support measures than others. For example, because benefits are calculated as a proportion of earnings, higher-income earners will benefit more than lower-income earners; as well, nonrefundable tax credits benefit higher-income earners more than lower-income earners. Employed caregivers in higher-quality jobs and more senior positions are more likely to benefit from flexible working arrangements than those in poor-quality jobs, those in jobs that require on-site presence at specific times and the precariously employed. Similarly, self-employed, part-time employed and precariously employed caregivers are not generally eligible for compassionate care leave or compassionate care benefits.

Measures to redress such risks and inequities are necessary, together with initiatives to reduce additional costs to governments associated with caregiver unemployment, underemployment, poverty and ill health. Human rights legislation and emerging case law are establishing that the boundaries around the prohibition against discrimination on the basis of family status encompass persons caring for dependent adult family members — although with some variations in the definition of family across provinces. This is setting a broad legal foundation for more equitable treatment of caregivers to dependent adults.

The sheer magnitude of the contributions made by caregivers to maintaining the health, well-being and independence of ill, disabled and frail Canadians points to the critical role they play in the sustainability of Canada's health and continuing care systems, which could not begin to replace the millions of hours of care work family members and friends perform. It is important to recognize that the social and economic contributions of such care subsidize the labour market and public health care sectors (Cass, Hill and Thomson 2012). Yet, by virtue of these contributions, many caregivers struggle to meet their own needs and live their own lives. Many are unaware that their good work comes at a cost to themselves, and in any case would be undeterred even if so informed, either because of their sense of obligation or because there are no other viable choices. But promoting greater awareness of the risks and of the likelihood that we all might someday become caregivers should motivate some of us to engage in advance planning and preparation, and might prompt service providers to develop and deliver programs and services that facilitate caregiving.

Simplifying, streamlining and coordinating programs, services and delivery systems across gov-

ernment departments would improve caregivers' access to relevant resources. Governments could follow the example of Manitoba, where consultations and fact-finding have been ongoing and efforts have been made to inform and empower caregivers — for example, through the creation and distribution of an inventory of programs and services and the establishment of information-sharing mechanisms for public employees (Manitoba 2013).

That said, the recognition of caregivers and their rights should extend beyond the rhetoric extolling their virtues and contributions, and also beyond a more progressive understanding of caregivers' responsibilities and the effects of caregiving on labour force participation. Needed are more services for older adults and their caregivers and concrete measures such as the introduction of formal, publicly funded or subsidized caregiver support programs and services and the incorporation of caregiver support principles into public continuing care systems. These measures would place caregiving definitively in public policy territory, rather than continuing to treat it as a mainly private matter.

Care coordination and management are now commonly practised in health care delivery systems, and this could improve access to services that support caregivers' work and reduce care-related costs. Studies provide strong and consistent evidence of the potential for programs and services directed at caregivers to reduce many of the negative outcomes for them and for society at large (Dionne-Odom et al. 2015; Sörensen, Pinquart and Duberstein 2002). Early intervention, before caregivers experience severe burden, carries greater benefit than intervention later in the caregiving episode, when caregivers already might have reached burnout. In an examination of community care policy reform in the United Kingdom that gave caregivers the legal right to have their own needs assessed, Pickard (2004) found that day programs, home care, respite care and counselling services not only improved outcomes for caregivers, but they also delayed care recipients' transition to residential care. More recently, the right of caregivers to have their needs *met*, and not just assessed, was recognized in the United Kingdom with the *Care Act 2014*.

Improving on the current situation in Canada — where services are tightly rationed and highly variable across jurisdictions, where private costs can be high, and where identifying and accessing even those services that are available is difficult — is imperative. Canadian governments should consider extending the mandate of service providers to include caregivers as clients with unique needs. They should introduce mandatory assessment of caregivers' needs and recognize the right of caregivers to have their needs met. Possible ways to achieve this include developing a national home care program and introducing national principles for the delivery of home and continuing care services. Whichever strategy is chosen, it should be adequately funded and staffed, be transparent and consistent across jurisdictions, yet be sufficiently flexible to meet the highly variable needs of caregivers and recipients. In this regard, the United Kingdom's experience with addressing caregivers' needs is clearly worth considering.

Effective caregiver support policy requires flexibility and capacity for customization to a wide variety of caregiver needs. Policy-makers, however, typically seek a single characteristic (or a small number of them) to distinguish those who are deserving of public support from those who are not. Having convenient, easily measurable eligibility criteria for determining access to a standardized

set of services or benefits makes the job of those charged with assessing eligibility and delivering services simpler, and it conveys an appearance of equity. The diversity of caregivers, recipients and the caregiving situation means, however, that caregivers' needs are equally diverse and variable. One can only agree with Hicks, who argues that it is time to "move beyond addressing the broadly defined needs of broadly defined groups of beneficiaries in a broadly uniform manner to an approach that is truly individualized and based on a life course perspective" (2015, 2). Given the limited capacity of current home care services (Canadian Home Care Association 2013), the case for more technology to support independent living and aging in place, increasing funding for both preventive services and home care, and improving the quality and sustainability of the professional health care work force, especially in the continuing care sector, would improve the lot of caregivers. One strategy that is attracting attention is to fill the growing gap between the demand for and supply of care through initiatives to incentivize and accelerate the growth of the private care market. This would have the added advantage of benefiting the wider economy by increasing business and employment opportunities (Carers UK 2013).

Accommodating caregivers in the workplace also would make good business sense. Evidence suggests that greater workplace flexibility could help at least some employers avoid costs arising from work-care conflict by reducing absenteeism, improving caregivers' health and reducing "presenteeism." Yet, the only public policy provisions concerning workplace flexibility for caregivers in Canada are compassionate care leave, (brief) family responsibility leave and those sections of human rights legislation that prohibit discrimination on the grounds of family status. The language of legislation in the United Kingdom, New Zealand and Australia, however, makes it much clearer that discrimination against those with family responsibilities is prohibited. A more direct approach also has emerged in those three countries, all of which have implemented "right to flexible working" legislation, rather than relying solely on general antidiscrimination legislation (Hegewisch and Gornick 2008).

Work-care reconciliation measures are still uncommon in Canada, but they are crucial to caregivers' short- and long-term financial independence. To that end, Canadian governments should incentivize employers to become part of the solution. They should encourage employers by making available evidence of a convincing business case for caregiver supports in the workplace, and set an example by accommodating the needs of caregivers in their own workforces and by providing tax incentives for caregiver-friendly workplace initiatives. Additionally, as the British Columbia Law Institute and the Canadian Centre for Elder Law (2010) suggest, protections offered under current Canadian human rights legislation could be enhanced by entrenching caregivers' right to request flexible working arrangements in labour legislation, as several of Canada's Commonwealth partners have done, which would represent a more universal approach than existing arrangements. Family responsibility leave and compassionate care leave are also a foundation on which to build greater workplace flexibility. Extending compassionate care leave and compassionate care benefits to cover serious caregiving circumstances other than end-of-life care would provide needed flexibility to most of those in high-demand caregiving situations. Provincial and territorial programs should also be enhanced and harmonized based on current best practices, which include a minimum of 10 days' family responsibility leave, six months' compassionate care leave and necessary amendments to their respective labour codes. In November 2015 Nova Scotia

extended its compassionate care leave from 8 to 28 weeks, thus becoming the first province to amend its labour code to align with recent federal changes (Nova Scotia 2015).

When such measures fail to protect adequately caregivers' income security, short-term financial hardship could be addressed by ensuring that caregivers are more explicitly eligible to receive social assistance benefits in all provinces whenever their care duties prevent their participating in the workplace or in training programs, or by implementing direct compensation for caregivers in the form of a caregiver benefit. Although Nova Scotia is the only jurisdiction in Canada to provide financial compensation to low-income caregivers, Australia, the United Kingdom, France, Germany, Sweden and Finland are among the countries that offer some form of caregiver allowance or wage (British Columbia Law Institute and Canadian Centre for Elder Law 2010; Kröger and Yeandle 2013). The programs in these countries vary in terms of the amount of the payment, eligibility criteria and whether they are delivered through social assistance/income security systems or the health and home care system. In addition, following Manitoba's example of making tax credits refundable would provide more direct financial relief to low-income caregivers and help to reduce inequities inherent in current tax measures.

Longer-term financial implications of caregiving, such as reduced benefits from contributory pension plans, should also be addressed. Pension credit schemes such as those employed in various European countries allow caregivers to continue to accumulate pension eligibility during periods of unemployment arising from care responsibilities. For instance, the United Kingdom, France and Germany allow the accumulation of "care credits" toward caregivers' public pension contributions in recognition of their caring work, and Norway offers a carer's pension (British Columbia Law Institute and Canadian Centre for Elder Law 2010; Kröger and Yeandle 2013). A made-in-Canada solution that is often suggested involves introducing a caregiver dropout to the CPP/QPP similar to the childrearing dropout to which parents of preschool children already are entitled. This approach would drop out of the calculation of pension benefits periods of low or no earnings resulting from care-related unemployment, thus effectively raising the pension benefits to which eligible caregivers would otherwise be entitled when they retire. Although Finance Canada has already increased the general dropout from 15 percent to 17 percent of years with lowest earnings — in part to raise the pension benefits of those who experience more employment interruptions — the anticipated effect of such a reform on caregivers' pension benefits is minimal (British Columbia Law Institute and Canadian Centre for Elder Law 2010). An explicit caregiver dropout provision would be more likely to compensate adequately for care-related pension losses.

To sum up, caregiver recognition and rights should be enhanced by following the example of other Commonwealth countries that have not only recognized caregivers' contributions, but also adopted comprehensive strategies to cover caregivers' care and income security needs and codified caregivers' rights explicitly in legislation.

## Conclusion

**R**ecent developments suggest that support for caregivers is slowly being taken more seriously in Canada and that progress toward developing support strategies is being made, but there

is more to be done. The number of adults requiring care is forecast to rise dramatically, while families' capacity to meet care demands is expected to fall as the result of various demographic and socio-economic factors (fewer children, more divorce and remarriage, more geographic mobility, more adult children employed and so on). There is an increasingly urgent need to correct deficiencies in approaches to redressing the financial consequences of caregiving in order to safeguard not just the sustainability of caring for family and friends, but also the sustainability of workplaces and the labour force.

Despite some redistribution of the burden in recent years, family caregivers continue to carry a disproportionate share of the costs of caring for those with long-term health problems and disabilities. Ultimately, decisions about whether and how to redistribute the financial implications of caregiving are the responsibility of policy-makers, which means that they are also, ultimately, ideological decisions and the outcome of weighing competing policy goals such as full employment, financial self-sufficiency based largely on employment income and cost containment in the public health care sector. Caregiving also needs to be recognized as a complex, cross-cutting policy issue. Its complexity, together with the equally complex structure of Canada's policy context, requires collaboration and cooperation across levels of government and across policy departments within each level of government. The model used to frame Canada's existing caregiver support policies I have outlined in figure 6 offers guidance for building an inclusive and sustainable policy framework for caregiving. Together, the measures I have proposed in this study would address — equitably, flexibly and comprehensively — the chief challenges caregivers face.

## Notes

- 1 Several provinces (including Nova Scotia and Alberta) and the federal government have recently developed (but not yet implemented) comprehensive strategies regarding dementia that include attention to the needs of the families of dementia patients, but these are limited to dementia caregivers and likely lack coordination and consistency across jurisdictions.
- 2 These empirical studies involved extensive analysis of Statistics Canada's 2007 and 2012 General Social Surveys (GSS), which collected wide-ranging data on the provision and receipt of care by Canadians. The 2007 GSS sample comprised respondents ages 45 and older, while the 2012 survey comprised respondents ages 15 and older. We also collected primary survey and interview data from a nonrandom, but relatively representative, sample of Canadian employers (a wide range of firm sizes in the public, private and nonprofit/voluntary sectors. We assessed the extent to which workplaces provide a variety of flexible work arrangements, leave policies and information and support to enable employees successfully to combine employment and care work and what factors are associated with their provision.
- 3 The person to whom they provided the most care during the past 12 months.
- 4 What it would cost if paid workers were hired from the labour market to do the same work.
- 5 New analysis from Age UK, building on work from the London School of Economics, reveals that lost earnings due to caregivers' labour force exit cost the UK Exchequer almost £1 billion in forgone taxes, while the estimated carer allowance paid to caregivers who left the labour force amounted to an additional expenditure of £300,000 in 2012 (Pickard et al. 2015).
- 6 Canada (Attorney General) v. Johnstone, 2014; Canadian National Railway Company v. Seeley, 2014.
- 7 Private e-mail correspondence with Employment and Social Development Canada, November 26, 2014.

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## About This Study

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