



**RENEWING CANADA'S
SOCIAL ARCHITECTURE**

POLICIES IN SUPPORT OF CAREGIVERS

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CONTENTS

PROBLEM STATEMENT	1
POLICY OBJECTIVE	1
CURRENT STATUS	1
DRIVERS OF CHANGE	3
COMPARATIVE CASE STUDIES	4
POLICY OPTIONS	6
i. Community supports	6
ii. Assistance with the cost of care	9
iii. Accommodation at work	12
RECOMMENDATIONS	16
CONCLUSION	17
REFERENCES	18

PROBLEM STATEMENT

More than one in four Canadian adults provide care that complements our health care and social service systems. But only limited and inconsistent supports are available to these caregivers. The lack of supports places a burden on the economy and negatively affects the physical, emotional and financial health of both caregivers and care receivers.

POLICY OBJECTIVE

The policy objective is to ensure a set of linked measures that recognize the vital role of informal caregivers in the health care and social service systems. These linked actions would directly address the needs of caregivers and care receivers through community supports, financial assistance and workplace provisions.

CURRENT STATUS

Invaluable and invisible. These two words, more than any others, perhaps best describe the 8.1 million caregivers in this country.

In 2012 (the latest available data), 28 percent of Canadians aged 15 and older cared for a family member or friend with a long-term health condition, disability or aging needs [Statistics Canada 2014]. Age-related needs topped the list, with 28 percent of caregivers assisting elderly parents. Cancer was next at 11 percent, followed by cardiovascular disease at 9 percent and mental illness at 7 percent.

Depending on individual circumstances, caregivers carry out one, several or all of the following roles. They assist with personal care, bathing, dressing, feeding and grooming. They do shopping, cooking and housecleaning, and provide transportation and coordination of medical appointments. They often perform routine health-related tasks, such as changing surgical bandages or cleaning breathing tubes, for which they have received basic instruction.

These caregiving tasks typically are carried out on a private basis and are generally assumed as a personal responsibility and expense. However, these tasks represent a potentially substantial cost to the public. The lack of support for caregivers means that some are unable to continue in their caregiving roles as their physical, emotional and financial health becomes adversely affected and begins to deteriorate. At that point, many families seek residential or institutional care for the care receiver - often as an undesired and undesirable last resort.

When care receivers are residents in nursing homes or patients in hospital, paid staff carry out the wide range of tasks involved in personal, household and health-related care. Informal caregivers, by contrast, deliver these essential services at no pay. Together they comprise a formidable but largely unrecognized workforce in the country.

In fact, unpaid or informal caregivers provide more than 80 percent of care required by individuals with long-term conditions. Informal workers contribute an estimated \$5 billion in unpaid labour a year to the health care system [Fast, Eales and Keating 2001]. One report pegged this figure at closer to an annual \$25 billion if all the multiple tasks performed by caregivers are included in the calculation [Hollander, Lui and Chappell 2009].

Despite their crucial contribution, the voice of informal caregivers is rarely heard. There is little formal recognition of caregiver needs in three key areas: the serious lack of community supports and services to relieve the caregiving burden, limited financial assistance to reduce caregiving costs and workplace accommodation to ease caregiver time and financial pressures. This paper explores various policy options that respond to these diverse caregiver needs.

DRIVERS OF CHANGE

The fact that caregivers are unpaid means that both their contributions and concerns have been largely ignored. But growing pressures are forcing Canadians to take notice as demographic realities create new demands on households. By 2030, about 23 percent of the Canadian population will be over age 65, double the share in 1990.

A related stress arises from the fact that many Canadians are now caring for both children and elderly parents. These caregivers are part of a large and growing “sandwich generation” squeezed between caring needs at both ends of the age spectrum.

Another major factor is the rapidly rising incidence of chronic disease, which is creating a significant burden on health care systems throughout the world. More people will be living longer with conditions that require ongoing assistance or supervision.

The Public Health Agency of Canada estimates that chronic disease rates are increasing at 14 percent each year [Elmslie nd: 5]. Three in five Canadians aged 20 and over have a chronic disease and four out of five are at risk [Public Health Agency of Canada 2013: 2]. In 2000, six major groups of chronic diseases (cardiovascular diseases, chronic respiratory diseases, cancer, mental illness, digestive diseases and musculoskeletal diseases) represented \$31 billion in direct health care costs and \$64 billion in indirect costs related to lost productivity [Public Health Agency of Canada 2013: 2].

High and rising health care costs, along with significant emotional pressures for Canadian households, mean that policy makers must start paying attention to the needs of caregivers. Improved supports for caregivers would reduce the high costs of the formal health care system as fewer people would have to go into or remain in an institutional setting in order to receive the care they require.

COMPARATIVE CASE STUDIES

Policy options related to each area of caregiver need are presented in the next section. The discussion makes clear that there is no single one-size-fits-all appropriate policy measure. Rather, a series of linked actions responding to each cluster of needs is required. There are international policy precedents for this approach.

In recognition of the importance of a set of cohesive measures, several countries have introduced caregiver strategies that act as a policy ‘umbrella’ to develop and coordinate the individual measures that comprise this policy domain. The United Kingdom, Australia and New Zealand, for example, have formalized the recognition of caregivers’ vital roles through their respective national caregiver strategies.

In the United Kingdom, the National Strategy for Carers has been in place since 1999, along with three separate Acts of Parliament: the *Carers (Recognition and Services) Act* (1995), the *Carers and Disabled Children Act* (2000) and the *Carers (Equal Opportunity) Act* (2004). [There is no consensus on terminology. The UK and several other countries use the term ‘carer’ to refer to informal caregiving while Canada and the US employ ‘caregiver.’]

The National Strategy for Carers subsequently was updated with a package of reforms introduced in June 2008 as part of a New Deal for Carers. The most recent action plan is outlined in its aptly-titled document *Recognised, Valued and Supported* [UK Government 2010]. The plan involves a coordinated approach that engages six national government departments. Services and practical assistance are provided directly to caregivers, who are also eligible for social security, sick days and vacation.

In Australia, the National Carer Strategy gives effect to the principles of the *Carer Recognition Act* (2010). It sits alongside and complements the National Disability Strategy, a ten-year plan for improving the lives of Australians with disabilities, their families and carers. It seeks to value and respect caregivers, and to ensure that they have rights, choices, opportunities and capabilities to participate in economic, social and community life.

In April 2008, New Zealand launched a national Carers' Strategy in order to improve recognition and support for informal caregivers. In partnership with the Carers Alliance, the Strategy sets a strategic direction for developing policies and services for New Zealand's caregivers over a ten-year period, starting with a five-year action plan.

In Canada, several provinces have introduced relevant strategies. The Ontario government, for example, has taken important steps through its Alzheimer Strategy and Aging at Home Strategy. In 2011, Manitoba introduced a *Caregiver Recognition Act* to raise awareness of the needs of caregivers and the diverse supports they may require. The province has also brought in an Aging in Place Long-Term Care Strategy.

POLICY OPTIONS

Because of the considerable differences among caregiver circumstances and the type of assistance they provide, caregiver needs vary substantially across households and throughout the country. These needs can be clustered into three main categories, discussed below:

- community supports
- financial assistance
- accommodation at work.

I. COMMUNITY SUPPORTS

IMPROVED RESPONSIVENESS

Despite their time and commitment, caregivers frequently feel that they are invisible and that the essential work they do is undervalued. But they need more than simple recognition of their vital contributions. They want greater appreciation of the complexity of their role and the challenges they face in their unique caregiving circumstances. As partners with formal health care and social service providers, caregivers should be involved — to the extent possible — in the planning, delivery and evaluation of the programs and services that affect their lives.

Caregivers often experience exhaustion and stress or may have a physical or mental condition that requires attention. Professional service providers need to be attuned to the health and well-being of caregivers as well as those of care receivers.

Informal groups also provide invaluable support. It is of interest that the Government of Australia committed \$10.5 million over three years to fund 262 MyTime groups across the country. The groups allow caregivers an opportunity to tell their stories and share their concerns in a safe space with others facing similar circumstances.

At some point, most caregivers need a break from their caregiving responsibilities, especially if they are raising children as well. Yet there are

relatively few available services, such as supervised respite bungalows, to give caregivers occasional relief on weekends or for a short holiday [Makhoul 2004].

In fact, a range of interventions can create respite for caregivers, including a more flexible workplace and assistance with health-related costs. Respite should be understood broadly — not just as a single service but rather as a desired outcome [Torjman 2003].

The needs of young carers, in particular, require unique interventions [Bednar 2013]. These youth typically struggle to balance caregiving responsibilities with school pressures. The Australian Carer Strategy recognizes these unique needs through the Young Carers Respite and Information Services Program. It enables school-aged carers to access flexible respite and age-appropriate services.

In addition to emotional support and occasional relief, caregivers may need guidance on administering certain treatments or handling complex conditions. Despite noteworthy efforts by many voluntary organizations, there is generally insufficient educational information and preparation — particularly for caregivers looking after someone with a mental health problem, degenerative disorder or some form of dementia.

A significant development in the caregiving field involves the use of new social technologies, which can make available support and information as required. The online Tyze personal networks program, for example, helps create relationships and opens up lines of communication among caregivers, care receivers and formal services.

But support and information are only part of the equation. Caregivers would be greatly aided by improvements in both the *quantity* and *quality* of formal services, particularly in relation to home care and homemaker services. Problems rooted in service availability and delivery are discussed in the paper for this project on Disability Supports.

The most pressing concern involves supply shortages relative to need. Some caregivers receive only one or two hours of assistance a week, which is simply not enough. One hour rarely allows enough time to do anything; all they can reasonably manage is a fast trip to buy groceries and supplies for the care receiver. The time restrictions are especially difficult for caregivers living in rural areas who may spend almost all of their limited time allocation for a medical appointment in the city.

In addition to inadequate supply, there are many access barriers. Services and supports for carers and the people for whom they care typically are fragmented across diverse delivery systems. Every program has unique eligibility criteria and requires an independent assessment of each case. Some services may be

available in theory but not in practice because of high demand and the associated eligibility restrictions linked to system capacity.

On paper, the service system may look like a rich and robust package. In reality, the services are far more limited because of their narrowly prescribed functions. For example, a support worker who comes to help with bathing may not do basic meal preparation or laundry. Caregivers usually need assistance from a home helper who can carry out a broad range of tasks. Many prefer, when they can afford it, to hire their own support worker and develop the job description according to their household needs. This personalized arrangement also ensures service consistency, cultural sensitivity and linguistic appropriateness.

SELF-DIRECTED FINANCING AND INDIVIDUALIZED FUNDING

Various initiatives are experimenting with self-directed financing options. Caregivers select the supports they need and purchase them with individualized funding, an arrangement in which a designated amount is paid to individual households on the basis of a comprehensive needs assessment.

The UK Carers Strategy emphasizes the principle of individualization and has created personalized budgets to enable this customization. A personal budget is an agreed amount of money that is used to arrange and pay for care and support, following an assessment of needs. It can be received directly as a cash payment, indirectly through a managed account or a combination of the two. Like all policy options, individualized funding has its own unique set of challenges that must be considered in the design of this approach. These challenges are discussed more fully in the paper for this project on Disability Supports.

Here at home, Veterans Affairs Canada offers individualized funding in the form of small grants to be spent on self-determined caregiver needs. Under the program, care receivers and caregivers have access to a range of goods and services including dental benefits, prosthetics and orthotics, technical aids and equipment, physiotherapy, medications, massage, health-related transportation, homemaker services and time off for respite — virtually anything that the family requires. Assessed needs are then translated into a designated amount of funds for the purchase of these goods and services.

Several provinces currently employ this flexible method of financing. Manitoba offers individualized funds for home care while Alberta and BC support various forms of disability-related assistance in this way. Ontario Special Services at Home makes available funding to the parents of dependants with severe disabilities. The program enables them to purchase services for personal development and relief support for a child or adult with a developmental disability or child with a physical disability.

COMMUNITY-BASED SERVICE APPROACHES

Innovative approaches are being tested throughout the world around the “co-design” and “co-production” of services. The former involves the formulation of service design in association with government and/or community agencies that deliver the services. Co-production entails the delivery of services in conjunction with or in replacement of formal service providers.

These concepts have been introduced in response to the fact that many publicly funded services are out of step with the needs of the population. New forms of assistance and support are emerging with citizens playing an active role in their design and delivery.

The UK-based organization Participle, for example, developed the Circle program in partnership with 250 older citizens. They identified three important needs: support with practical tasks, social connections around common interests and values (not age), and an opportunity to live life with a purpose and contribute to the community.

To date, seven circles have been initiated with more than 5,000 members. They participate in monthly events but also receive practical support around the home, which many members provide to each other through service exchange. This innovative approach represents a way of supplementing formal services while making available assistance that is responsive to individual circumstances.

The UK Carer Strategy also makes reference to the notion of time banking. Community innovations enable carers who have skills such as cooking, accounting or computing to help someone in exchange for another time bank member providing, for example, occasional respite or other practical assistance.

But these kinds of initiatives do not just happen on their own. They require financial assistance from governments to support the role of the convening organization. In 2010, the UK introduced a Reaching Out to Carers Innovation Fund to foster new community-based initiatives.

II. ASSISTANCE WITH THE COSTS OF CARE

Most of the goods and services that care receivers require usually come at a cost, unless they are made available to in-patients in hospitals or children in school settings. A 2012 BMO survey found that seven in 10 caregivers were providing some type of financial assistance to their parents or aging relatives. Half of these individuals said they had to adjust their own retirement plans as a result [Leong 2014].

The 2007 General Social Survey found that of caregivers with out-of-pocket expenses, 80 percent spent an average \$6,000 or less per year. One in six (17 percent) spent between \$6,000 and \$24,000 per year, and 3 percent spent more than \$24,000 in the year prior to that survey. Collectively, Canadian caregivers

aged 45 and older spent an average \$1,049,600 per month or almost \$12.6 million per year on care-related out-of-pocket expenditures in 2006 [Fast et al. 2013: 12].

These additional expenses can create serious financial pressures. In 2012, among family caregivers, 28% of those caring for a child, 20% of those caring for a spouse and 7% of those caring for a parent reported financial hardship because of their caregiving responsibilities. Of those caring for a child, 10% even had to borrow money from friends or family, and 12% had to take out a loan from a financial institution [Turcotte 2013: 6-7].

Not surprisingly, costs rise with level and intensity of required care. Hiring a personal care worker through an agency or privately can cost \$20 to \$30 per hour. Registered nurses cost \$40 to \$69 an hour. A full-time, live-in caregiver may charge \$1,900 to \$3,500 a month, plus room and board; around-the-clock care may require two or three full-time caregivers [Leong 2014]. Caregivers of community-dwelling adults with high needs spent on average \$7,599 per year, although there was considerable variability observed (range \$15-\$120,000 per year) [Fast et al. 2013: 12].

Low-income households are most affected by these additional expenses. They pay a disproportionately higher percentage of their incomes on caregiver costs.

Out-of-pocket costs have the greatest consequences for low-income caregivers. In 2007, nearly one-third of caregivers aged 45 and older who had care-related expenses (30%) had annual household incomes of less than \$30,000 per year, and of these, 82% spent less than \$500 per month on average, 14% spent \$500-\$2,000 per month, and 4% spent over \$2,000 per month on care-related out-of-pocket expenses. Similarly, low-income caregivers of community-dwelling care receivers with high needs spent \$7,610 annually on average on care-related expenses, while those with annual household incomes of \$60,000 or more spent \$9,326 on average. Thus it seems that caregivers with low incomes who have care-related out-of-pocket expenses spend proportionately more of their annual income (25% or more) on care-related expenses than those with higher incomes (15% or less), likely causing financial strain or hardship [Fast et al. 2013: 12].

There is relatively little financial assistance to offset these costs. The Home Adaptation for Seniors' Independence Program, cost-shared between the federal and provincial governments, makes available forgivable loans up to a maximum \$3,500 to homeowners and landlords for major repairs, accessibility modifications or the creation of secondary suites.

Budget 2015 also introduced a Home Accessibility Tax Credit that will be available to seniors and persons with disabilities to help offset the costs related to accessibility and security in their homes. The 15 percent non-refundable tax credit would apply on up to \$10,000 of eligible home renovation expenditures per year, providing up to \$1,500 in tax relief.

While assistance for home accessibility is important, the design of the new measure is problematic. Because the financial support will be delivered as a non-refundable tax credit, it will be of no value to low- and modest-income households that pay little or no income tax, even though they may have to incur these accessibility-related costs.

The federal Medical Expense Tax Credit reduces the cost of a designated list of health-related goods and services. Only expenses in excess of the lesser of \$2,208 for 2015 and 3 percent of net income can be claimed for this credit. The problem is that few Canadians are aware of the long list of relevant items. As in the case of other non-refundable tax credits, household income must be higher than the taxpaying threshold in order to benefit from this measure.

It should be noted that, in the past, caregivers who incurred medical and disability-related expenses for an aging parent, sibling or financially dependent relative were not able to claim expenses above \$10,000. This limit has been removed from the Medical Expense Tax Credit, providing greater tax recognition for extraordinary expenses incurred on behalf of a care receiver.

Two additional federal tax credits — the Caregiver Tax Credit and Infirm Dependent Tax Credit — are not linked to specific costs *per se*. Rather, they are ballpark amounts which recognize that caregivers taking care of individuals with severe impairment in function likely will incur a range of additional costs. The credits effectively acknowledge the extra costs of caregiving — though these measures provide modest financial assistance.

The Caregiver Tax Credit for the in-home care of a parent or grandparent ages 65 and older, or of an infirm adult relative, allows a federal tax reduction of up to a maximum \$691 in 2015 — calculated as 15 percent of a base amount of \$4,608.¹ The Infirm Dependant Tax Credit for the care of adults ages 18 and over allows a federal tax reduction up to a maximum \$1,005 in 2015 — calculated as 15 percent of a base amount of \$6,700.² The latter incorporates the additional Family Caregiver Amount that was introduced in Budget 2011 and took effect in 2012.³

While this financial assistance is important, it is limited in scope. Non-refundable caregiving credits are not helpful to many Canadians, notably lower- and modest-income households that derive little or no benefit from the current measures. These tax credits are not delivered to households as cash payments. Rather, they represent amounts that are deducted from tax owing.

The Caledon Institute has argued that turning these measures into refundable credits would ensure that all households receive some money in respect of their caregiving costs [Torjman 2011]. Both Manitoba and Québec provide a refundable tax credit for caregivers — so there is policy precedent for this approach.

It should be noted that the 2015 federal Budget did introduce a special measure for caregivers of veterans, in particular. Ottawa announced that family members taking care of veterans with serious disabilities will be eligible for a tax-free Family Caregiver Relief Benefit. The new measure will pay financial support of \$7,238 a year to eligible veterans so that they can purchase services to provide respite for their informal caregiver.

Alternatively, a small direct payment could be made to help offset caregiving-related expenses. Several policy options are discussed more fully below.

III. ACCOMMODATION AT WORK

In addition to immediate costs, the financial security of caregivers is affected in other ways. Most informal caregivers are employed. More than six million workers — 35 percent of the workforce in Canada — provide unpaid, informal care. The majority (74 percent) of caregivers provide nine or less hours of care per week. However, 16 percent of employed caregivers deliver 10 to 29 hours of care, while 10 percent provide a very intensive level of 30 hours or more [Employer Panel 2015: 9].

Employed caregivers face multiple competing demands. Being responsible for care can result in disruptions to normal work routines. About four in ten employed caregivers (43 percent) indicated that they arrived to work late, had to leave early or take time off during the day to care for their ill family member or friend. This figure rose to 54 percent for those providing 20 or more hours of caregiving per week [Sinha 2013: 14].

Caregivers' employment status can be jeopardized by the pressures of their caregiving responsibilities. They may have to refuse a job offer, promotion or transfer; change or resign from a position; reduce the number of hours worked; or take leave from work. Employed caregivers often lose income, benefits and pensions in trying to balance work and family responsibilities.

Employee caregivers experience more interruptions at work, lower productivity, and are frequently late or absent. They may be less able to work overtime, travel for work, or take advantage of career-advancing opportunities such as professional development. The 2012 GSS [General Social Survey] reported that 1.6 million caregivers took leave from work; nearly 600,000 reduced their work hours; 160,000 turned down paid employment; and 390,000 had quit their jobs to provide care [Employer Panel 2015: 9].

These consequences have an impact not only on the caregivers but on Canadian employers and society more broadly. The reduced work effort by caregivers was estimated at 2.2 million hours per week in 2012. In that year, the Canadian economy was deemed to have lost the equivalent of 157,000 full-time employees because of caregiving pressures — a significant loss in productive capacity. The Conference

Board of Canada pegged the annual cost of lost productivity to Canadian employers at \$1.3 billion dollars [Chenier, Hoganson and Thorpe 2012].

FLEXIBLE HOURS

Flexibility of work schedules is one of the most important employer responses. The needs of the elderly are often unpredictable, and require adaptability on the part of the caregiver. The same can be said for someone with an episodic condition, such as multiple sclerosis, where symptoms recur and remit. Many companies are beginning to recognize that certain employees may require more than personal or vacation time to deal with family-related circumstances or emergencies.

There are important policy precedents at the international level regarding flexibility at work. New Zealand allows caregivers who have worked with their employer for at least six months to request flexible arrangements, such as compressed work weeks, flex-time and work from home. These rights do not guarantee that the employer will say yes. But at least they protect the security of employees who ask for flexibility. The legislative provisions also raise employer awareness about this significant need.

A number of employment measures were introduced as part of the Carer Strategy in the UK. In 2007, for example, the *Work and Families Act* was amended to allow caregivers the right to request flexible work. The UK created an Employers for Carers Forum to consider various concerns affecting workplaces.

In June 2014, Ottawa took up the Caledon Institute's proposal to create a similar group, modelled on the earlier federal *Panel on Labour Market Opportunities for Persons with Disabilities* [Torjman 2013: 2]. The federal government launched the Employer Panel for Caregivers to explore ways to help employee caregivers participate as fully as possible in the workforce.

The Panel heard from 114 employers from diverse sectors and of varying size. These key respondents identified flexibility and working on a case-by-case basis as their preferred policy routes. They understand caregiving as a highly individualized issue that requires different interventions depending upon the circumstances of the employee and the associated care receiver.

The participant employers indicated that they typically adapt existing programs or create tailored interventions in response to identified needs. These measures include, for example, top-ups to legislated compassionate leave and extended vacation plans, flexible scheduling and condensed work hours, virtual workspace tools and emergency elder care [Employer Panel 2015: 13].

PAID LEAVE

Paid leave is another important benefit. The Employer Panel for Caregivers noted that many of the interviewed employers provide paid leave to employees

on a case-by-case basis. There are also a variety of unpaid leave arrangements in place [Employer Panel 2015: 29-31].

On a more general level, the Compassionate Care Leave provisions within Canada's Employment Insurance program allow up to six weeks' paid leave to care for a gravely ill relative who is likely to die within 26 weeks.

These eligibility criteria are too strict to provide meaningful help to most caregivers. This provision should be expanded to permit leave for other caregiving circumstances, not just terminal illness, and extended with respect to the duration of the caregiving period. For example, under the *Care Leave Act* (1989) (with revisions in 1994 and 2010), informal caregivers in Sweden are entitled to paid work leave of up to 80 percent of their income for 100 days of leave to care for a family member who requires palliative care.

The 2015 federal Budget did announce that it would extend, effective January 2016, the duration of the Compassionate Care Leave provisions from six weeks to six months. Unfortunately, it did not relax the criteria for which leave can be taken. The leave is permitted only to care for a gravely ill family member.

A new Employment Insurance (EI) measure was introduced last year in Canada. Beginning June 2013, eligible parents who take leave from work to provide care or support to their critically ill or injured child can receive EI special benefits for Parents of Critically Ill Children. Parents must be able to show that their regular weekly earnings from work decreased by more than 40 percent because they needed to provide care or support to their critically ill or injured child.

In October 2014, new employment standards came into effect in Ontario. The purpose of these new measures is to ensure that workers who need a leave of absence to act as caregivers to loved ones will not lose their jobs as a result. The *Employment Standards Amendment Act (Leaves to Help Families)* (2014) includes Family Caregiver Leave that allows up to eight weeks of unpaid, job-protected leave for employees to care for a family member with a serious medical condition. Critically Ill Child Care Leave permits up to 37 weeks of unpaid, job-protected leave to provide care to a critically child.

INCOME REPLACEMENT

Current income can be affected if caregivers must reduce their hours or leave work altogether. The provision of special allowances can help offset basic living costs and additional caregiving-related expenses.

The Swedish *Care for the Elderly* law, for instance, entitles caregivers to an allowance and social security protection comparable to the provisions for care personnel in the formal caregiving sector. Sweden makes available an Attendance Allowance, Carers' Allowance and Assistance Allowance to help offset financial

costs incurred by family caregivers. The municipality reimburses the caregiver of an elderly dependent with a salary equal to that of municipal formal home care workers. This salary is subject to income taxes [BCLI 2010: 85].

The UK Carer's Allowance pays a weekly £61.35 to assist caregivers who look after an individual with substantial needs. Caregivers need not be related to the person but must provide a weekly minimum of 35 hours of care. Payments made in regular installments throughout the year rather than in one lump sum help caregivers manage their cash flow.

Here at home, Nova Scotia offers a \$400 per month Caregiver Benefit. Throughout the country, the federal government pays a Child Disability Benefit, which delivers an annual maximum \$2,695 in 2015 to low- and modest-income parents with children with severe disabilities. This amount could be raised and the benefit extended to low-income households caring for adults over the age of 18 with severe disabilities.

As in most income security programs, there are challenges in determining eligibility for caregiver benefits. All governments in both Canada and elsewhere employ some type of screen to assess caregiver eligibility, which is typically based on the whether the care receiver qualifies for an income benefit, tax break or service that requires proof of the presence of severe and prolonged disability.

But future income can also be jeopardized if workers need to leave their jobs on a temporary or permanent basis because of caregiving responsibilities. One policy measure that helps protect future income is to make pension contributions on behalf of caregivers so that they are not penalized later in life for lost employment time during their working years.

Sweden, for example, offers pension credits for caregivers in receipt of a Carer's Allowance or Care Leave [BCLI 2010: 95]. Caregivers eligible for the Carer's Allowance in the UK also get National Insurance credits each week towards their pension if they are under pensionable age.

France contributes to caregivers' old age insurance during periods of caregiving. Family caregivers of a relative with a severe disability are eligible. The care recipient must live with carer, and have at least 80 percent permanent disability. The income of the caregiver must fall below a designated ceiling that takes into account the number of income earners and children in the household [BCLI 2010: 95].

Ottawa should consider the possibility of extending child care drop-out provisions within the Canada Pension Plan to include time that may be required for caregiving responsibilities. Alternatively, it can make Canada Pension Plan contributions on behalf of caregivers who need to leave paid employment because of caregiving responsibilities.

RECOMMENDATIONS

The following policy recommendations address the diverse needs of caregivers with respect to community supports, financial assistance and workplace accommodation. Provincial and territorial governments need to invest in the supply of services that deliver care at home. The federal government can provide vital leadership by:

- ▮ Introducing a government-wide national strategy that integrates the work of relevant departments and agencies, including Employment and Social Development, Health, Finance, Veterans' Affairs and the Public Health Agency of Canada.
- ▮ Allocating funds to selected voluntary organizations to enable them to create support groups and provide information to caregivers on various conditions and relevant services.
- ▮ Creating a Disability Supports Fund, in collaboration with provinces and territories, to improve the quantity and quality of these supports, including enhancing in-home services and allowing for more individualization and flexibility in their provision.
- ▮ Investing in a wide range of respite options, including respite bungalows.
- ▮ Supporting various forms of community innovation for caregiving.
- ▮ Turning existing non-refundable caregiver tax credits into refundable credits or converting them to allowances.
- ▮ Enhancing the Compassionate Care Leave Provisions within Employment Insurance.
- ▮ Extending the child care drop-out provisions of the Canada Pension Plan to cover caregiving responsibilities or making contributions to the Canada Pension Plan for employees who need to leave the workplace to care for a relative with a severe disability.

CONCLUSION

The individual measures proposed in this paper would help respond to the wide-ranging needs of caregivers related to community supports, financial assistance and workplace accommodation. However, the proposals are simply that: a set of disparate measures. Ideally, Ottawa will consider the introduction of a National Caregiver Strategy, which would include a set of well-designed and linked actions that work together as a comprehensive and coherent whole.

ENDNOTES

1. Eligible claimants must provide care in their own home for a dependent whose net income for the year is \$15,735 or less in 2015 and who is the caregiver's or spouse's parent or grandparent age 65 or older, or adult infirm dependent relative age 18 or over. A partial claim may be made if the relative's income is between \$15,736 and \$20,343 in that year.
2. The Infirm Dependant Tax Credit allows a tax reduction for individuals supporting an infirm dependant age 18 or older who is a relative living in Canada and whose net income for 2015 is less than \$6,720. A partial claim may be made if the relative's income is between \$6,721 and \$13,420 in that year.
3. An enhanced amount of \$2,000 (indexed for years subsequent to 2012) can be claimed for an infirm dependant under one of the existing dependency-related credits — i.e., Spouse or Common-Law Partner Credit, Eligible Dependant Credit, Child Tax Credit, Caregiver Credit or Infirm Dependant Credit.

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RENEWING CANADA'S SOCIAL ARCHITECTURE

Renewing Canada's Social Architecture is a collaborative project involving researchers from the Mowat Centre, the Caledon Institute for Social Policy, the Institute for Competitiveness and Prosperity and the Institute for Research on Public Policy. The purpose of the project is to advance public dialogue on our social architecture, and highlight areas where our core social programs and policies require modernization to meet Canadians' needs. Each report contributed to the project is the responsibility of the authors alone, and does not necessarily reflect the views of the other contributors or organizations.

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