

## Canadian/Provincial Policy Concerning Statutory Rights and Recognition of Caregivers

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From the outset, it should be clear that Canada does not have national policy offering statutory rights to caregivers. This is due mostly to the fact that the federal government has control over few areas of jurisdiction that affect caregivers. Indeed, because of the historic division in jurisdictions between federal and provincial governments at the time of Confederation<sup>1</sup>, areas affecting caregivers such as health and social services, and labour are generally provincial concerns. Despite this, the previous federal Liberal government showed some openness to responding to caregiver concerns. However, the current Conservative government has defined caregivers as a manpower issue and caregiver issues have been relegated to the Ministry of Human Resources and Social Development.

The federal government has thus little legislation regarding caregivers. However, in the 1990s, a Canadian senator particularly interested in palliative care, championed legislation to support caregivers of people at the end of life. She managed to push the Liberal federal government to use its control over employment insurance benefits for unemployed workers to establish a program known as the compassionate care benefit. This program provides monetary benefits through employment insurance for up to a maximum of 6 weeks<sup>2</sup> to a person who has to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks (as determined by a medical certificate). The basic benefit rate is 55% of one's average insured earnings up to a yearly maximum insurable amount of \$42,300<sup>3</sup>. This translates into a maximum payment of \$447 per week. Other than this program, there are no direct benefits to caregivers, although federal tax law provides some provisions aimed at offsetting the loss of income associated with assuming family caregiving responsibilities. For example, there exist a number of tax credits, such as the In-home Care of a Relative credit, the Dependent Care credit, the Wholly Dependent Person tax credit, the Equivalent to Spouse credit and the Infirm Dependent credit. It is also possible to claim some of a dependent family member's medical

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1 Canada is a federation of ten provinces and three territories.

2 The leave is actually for eight weeks but only six are remunerated.

3 The Canadian dollar is worth between .87 and .97 of the US dollar depending on the moment.

expenses against the caregiver's income. These various tax credits assist the family caregiver who is employed by reducing her tax payable (Canadian Center for Elder Law, 2009).

To understand the Canadian context, one also has to understand that among the developed countries, Canada, and its provinces and territories, invest the least amount of money for homecare and long-term care. To that end, the implicit policy orientation is to assign responsibility for care to families.

### *Provincial legislation recognizing and supporting caregivers*

On the provincial level, Quebec has gone the furthest in establishing statutory rights and recognition of caregivers, mainly through home care policy. In 2003, under the Parti Québécois, a Home Care Policy was adopted that clearly stated that caregivers were to be considered as partners in care but also as clients with specific needs for services. It also stated that caregivers' commitment to care should be voluntary and the result of free and informed consent that must take into account the caregivers' capabilities, family, social and professional responsibilities (MSSS, 2003). Although the Parti Québécois went down to defeat shortly after developing this policy, the same principles were reaffirmed by the Liberal government in its 2004 document "Precisions for the application of the Home Care Policy" (MSSS, 2004). This latter document also stated that as potential clients of home care services, caregivers should have access to a needs assessment that would serve as the basis for an intervention plan. Statutory services to be offered to caregivers by all Health and Social Service Centres (HSSC)<sup>4</sup> include:

Monitoring-supervision: to substitute for caregivers who must occasionally be absent from their home for various activities.

Respite: to give caregivers a break in order to compensate for the extra stresses and fatigue caused by the specific needs of a child or adult with disabilities.

Emergency services – to help caregivers confronted with unforeseen or urgent situations. This help is temporary and generally of short duration.

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<sup>4</sup> These centers exist throughout Quebec and serve a geographical territory. One of their main programs is home care

Help with daily tasks: this service involves different measures aimed at relieving caregivers from some of their daily activities in order to care (ex. child care, supervising homework, visual and audio interpretation)

Psychosocial services: support caregivers in facing the adaptations required to care for someone with disabilities or requiring care.

Community organization services: to support the development of services for caregivers and the persons they care for

While the public HSSCs are mandated with ensuring that such services exist within their territory there is a proviso indicating that various service providers including non-profit community and voluntary organisations, social economy enterprises, or public sector institutions can offer these services. In other words, in the spirit of the mixed economy of care, public service centres offering home care do not have to offer all these services, but have to ensure that they are available from a service provider on their territory. Finally, there is no absolute right to services. These are allocated based on an assessment by professionals and are always conditional to the availability of human and financial resources<sup>5</sup>. Recently, Quebec set up a program offering a maximum of 600\$/year to caregivers of people with high levels of care to buy respite services.

On another level, the Quebec Labour Code was recently amended to include ten days of unpaid leave for family responsibilities for all Quebec workers that was intended to support caregivers, in particular. Quebec also offers a refundable tax credit for caregivers of up to \$1,033 for each eligible relative.<sup>6</sup>

To our knowledge, only one other province has specific legislation regarding caregivers, while two others are examining this possibility.

The province of Nova Scotia has been discussing the need to adopt a caregiver strategy and recently passed legislation to offer a caregiver allowance. This benefit is targeted at low-income care recipients who have a high level of disability or impairment as determined by a home care

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<sup>5</sup> This condition is written into the Health and Social Services law indicating that citizens have a right to the health and social services required by their state to the extent that resources are available.

<sup>6</sup> The eligible relative must have lived with you in a dwelling that you or your spouse owned, rented or sublet for a period of at least 365 consecutive days, including at least 183 days in the year you are making the claim.

assessment and who have a family/friend caregiver. If the caregiver and the care recipient both qualify for the program<sup>7</sup>, the caregiver will receive the Caregiver Allowance of \$400 per month. This amount is taxable income. (Government of Nova Scotia, 2009)

In Ontario, based on testimonies during a public hearing to the effect that caregivers are often at a significant disadvantage in accessing employment, housing and services, the Ontario Human Rights Commission handed down a ruling about discrimination based on family responsibility and status. Currently, the Human Rights Code prohibits discrimination because of family status, but its application is limited to situations where the individual experiencing discrimination is in a parent-child relationship. The Commission is thus presenting a new policy framework broadened to include all forms of caregiving, to help workplaces meet their responsibilities and recognize family status as a human rights issue (Ontario Human Rights Commission, 2007, 2009).

For its part, findings of the Canadian Centre for Elder Law in British Columbia conclude that there is no centralized caregiving legislation in BC. Rather, the landscape is impacted by both provincial and federal legislation including: The BC *Employment Standards Act* ; The *Employment Insurance Act* of Canada ; The *Canada Labour Code* ; The BC *Labour Relations Code* ;The BC *Human Rights Code* ;The *Canadian Human Rights Act* ;The *Income Tax Acts* of BC and Canada. This of course is the case for all provinces and territories that all have similar legislation. Based on these, caregivers may be eligible for paid or unpaid leave for family responsibility and provincial and federal non-refundable tax credits.

Despite the lack of specific policy, all provinces and territories offer some services to caregivers through their home care, palliative care and programs for disabled persons, notably respite services. These range from having home care workers come to the home for several hours a week, to receiving money to hire a worker, to sending the disabled person to a day centre to the use of short-term stays in long-term care units. In most jurisdictions caregivers must contribute on a sliding-scale based on income to offset the costs of these services (Dunbrack, 2003).

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<sup>7</sup> The care recipient has a net annual income of \$18,785 or less, if single, or a total net household income \$35,570 or less. The caregiver is in a regular, ongoing care giving relationship with the person receiving care, providing 20 or more hours of assistance per week and is Not already be receiving payment to provide assistance to the person for whom she/he is providing care

Let us turn now to an analysis of the impacts and limitations of the various measures and legislations. It should be noted that formal evaluations of the impacts of the various measures described rarely exist and our analysis is thus more impressionistic than grounded in hard empirical data.

### *Impacts of legislation, limits and lessons*

#### - Impacts on caregiver impoverishment

On the federal level, the uptake of the compassionate care benefit was so weak, that modifications were introduced to ensure wider accessibility. These included broadening the definition of “family member” to include grandparents, grand-children, uncles, aunts, nieces, nephews and their spouses or partners, current or former foster parents and even close friends or neighbours considered as family, and lengthening the period in which the eight weeks leave can be taken (within 26 weeks). Even so, very few people apply for this benefit. Notably this is because you have to be eligible to receive employment insurance payments (ex. be a salaried worker making contributions, prove that you have accumulated 600 insured hours in the last 52 weeks or since the start of your last claim). As well, the bureaucracy surrounding the process for making a claim (medical certificate indicating that the person is dying, proof that your regular weekly earnings from work have decreased by more than 40%); and the fact that you must go two weeks with no income and be able to live off the amount offered for the other six weeks (55% of your wage capped at a maximum of 447\$/week) make this an unattractive option for many people.

On the positive side, this program was one of the first to officially recognize the need to compensate for loss of earnings due to caring and gives some leverage for further demands.

For their part, fiscal benefits at both federal and provincial levels have many draw-backs, the most important being that these are regressive measures benefiting higher income earners more than lower income earners, as they are almost all non-reimbursable tax credits. Thus, people paying no taxes receive nothing. As well, to claim many of these credits, you have to make out-of-pocket payments (medical costs and other indirect costs of care that can be claimed) while the reimbursement through lowered taxes is claimed only once a year. Since out-of-pocket expenses

are generally used to supplement public support by turning to the private sector, these credits are an indirect manner of pushing caregivers to buying support within the private sector (Keefe & Fancey, 1998). Finally, the credits provide minimal amounts of money that do not adequately compensate for financial losses (Keefe & Rajnovich, 2007). This is also the case for the one reimbursable credit.

The Nova Scotia caregiver allowance has just been enacted, so it is hard to assess its impact. But clearly the amount offered is token (minimum wage in the province is 300\$/week for a 35 hour/week compared to the 400\$/month allowance) and only very low-income caregivers are eligible. Based on 2009-2010 budget provisions, a maximum of 5625 caregivers will be admitted to the program. It is thus more of a social security measure than a form of recognition of caregiving work and costs.

Clearly, Canadian measures in the area of financial compensation do not really combat the impoverishment of many caregivers.

- Impact on caregivers, practitioners and on the health and social service system

In Quebec, which is the only jurisdiction with a clearly stated caregiver policy, there are both positive impacts and serious limits for caregivers and the health and social service system. Despite defining caregivers as potential clients of the system with a certain right to assessment and specific services, the Ministry of Health and Social Services did not allocate specific monies (other than for respite) to actualize its policy. Thus, the uptake of the policy varies greatly from one HSSC to another throughout the province. In general, based on experiential information from caregiver advocacy groups in Quebec, most caregivers are dissatisfied with the limited support they receive and experience much frustration in their interactions with the system and with many health and social service practitioners.

A recent study in Quebec (Guberman et al., 2005) can help us understand some of their frustration. Beyond the fact that public support is still extremely limited (some respite, a few support groups, but extremely limited psycho-social and financial support) and inequitable around the province, the study revealed that front-line home care practitioners hold familist values defining caregiving first and foremost as a family responsibility and they often promote

the under-lying policy orientation to this effect. However, in their day-to-day practice, they are confronted with the reality that caregivers are often overwhelmed and insufficiently supported and that some might even have to be relieved of part of their work. This double understanding of caregivers' situation puts workers in a bind, on one hand expecting caregivers to have the conditions and competencies to assume more care work and fulfil their family responsibility, and on the other, seeing them as people experiencing difficulties. Faced with this paradox, many practitioners are uncomfortable and experience feelings of powerlessness, as they are caught between managers pushing them to transfer more care activities to caregivers and the caregivers themselves, who are desperate for more support. To resolve this dilemma, many orient caregivers to the private sector to supplement the limited public support they receive, but here again, they feel uncomfortable given the limited financial resources of many families (Lavoie & Guberman, 2007).

Thus, despite policy announcing the voluntary nature of caregiving and the rights' to services of caregivers, Quebec's real orientation (like that in all the other provinces and jurisdictions) is to continue cutting back on home care hours, caregiver support services and the number of publically-funded long-term beds and to implicitly solicit families to take up the slack.

However, paradoxically, given their discomfort and faced with growing demands from caregivers, many workers and managers in the HSSCs have begun making a paradigm shift that defines caregivers more and more as clients and less as resources for the system (Guberman & Maheu, 2002; Twigg, 1998). Thus the written policy has served to place some moral pressure on managers and workers to address the needs of caregivers, even within a context of scarce resources.

In comparing Canadian legislation and recognition of caregivers with its neighbour to the south, the U.S., or other Anglo-Saxon countries such as the UK, Australia or New Zealand, it is striking to note how little exists here. A brief presentation of U.S. policies makes this very clear.

Based on the scope and number of policies that exist in the U.S., one might think that caregivers are well-recognised and served. Indeed, there are several pieces of federal legislation that address the situation of caregivers. In 2000, the federal government passed the National Family Caregiver Support Program (NFCSP) "that signifies both national recognition of and commitment to

providing direct support services to caregivers” (Friss Feinberg et al., 2004, 2) and was the first piece of national legislation addressing caregivers adopted since 1970. The NFCSP “calls for the states, [...] to develop multifaceted systems of support for caregivers” including information, assistance in gaining access, counselling, training and support groups, respite and supplemental services such as emergency response systems” (ibid, 3). For the 2008 financial year, NFCSP funding reached \$153.4 million. However, researchers and activists<sup>8</sup> suggest that in practice, this program is severely under-funded and reaches very few caregivers.

In 2006, the Lifespan Respite Care Act was passed, expanding access to respite services through competitive awards attributed to State respite coalitions. While this has indeed increased respite services, the process of attribution means that not all states actually receive funding and there is thus much inequity between the various states. Besides these general programs, the Obama administration has enacted legislation to support families of war veterans and injured soldiers<sup>9</sup>, and several pieces of legislation are before Congress to expand the Family Medical Leave Act (FMLA) to cover a greater range of recipient groups and to expand the activities for which this leave can be taken. Currently the FMLA requires private employers with at least 50 employees, and public employers, regardless of size, to extend job-protected, unpaid leave to employees to care for a parent, spouse, or child with a serious health condition without fear of jeopardizing their jobs. Other workforce related proposals under study would require employers to provide paid time off to their employees for their own medical needs or to care for the medical needs of certain family members (Collelo, 2008). Caregivers in the US also have access to a certain number of tax incentives and a compassionate care bill to support caregivers of people at the end-of-life is currently under study.

Why is the Canadian context, with its timid legislation recognising caregivers, especially on the federal level, so different from the U.S. and other Anglo-Saxon countries such as the UK, Australia or New Zealand? Why does home care continually fall off the policy agenda despite several commissions and reports indicating it should be a national priority? I would suggest a

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<sup>8</sup> Thank you to Carol Levine for helping understand the real scope of the legislation.

<sup>9</sup> For example, there is legislation authorizing Veterans’ Affairs to pay a monthly stipend (in 2010 up to \$2,350) to a family member or friend who is designated as the personal caregiver of a severely injured veteran who meets certain criteria



couple of hypotheses<sup>10</sup>. First, the existence of the many tax credits appeases those with income, as they are able to buy their way out of the worse problems, given the existence of a flourishing private home care market. They then claim their expenses as tax deductions and are less vocal in their demands for public policy and services. Secondly, in Canada, home care is closely tied to health and is often seen mainly as the answer to over-crowded hospital emergency rooms and wards. Thus, much pressure is placed on case managers to move older persons with chronic conditions back to their homes where caregivers are seen as major resources for maintaining them in the community. This dovetails with the strong implicit familist ideology within the Canadian and provincial policy orientations.

With an estimated 80% of care work being assumed by family and friend caregivers, clearly Canadian and Quebec social protection and service policies to older people and those with functional limitations have not eroded family solidarities. And yet public discourse and social policies continue to evoke the danger that public services will substitute for family care, and this fear underlies the implicit and sometimes explicit familist orientation of policies and service development. In Quebec, since the 1985 Policy on Ageing, families and community resources are designated as holding the major responsibility for support to frail elderly persons (Ministère des affaires sociales, 1985). They are “encouraged”, if not forced to take on this responsibility by the low level of services available. This approach of rationing obliges families, and mainly women within families to offer the care that the State does not offer. According to Barusch (1995) and Finch (1989), this restrictive approach is the most efficient for forcing family commitment to care. It is interesting to contrast this situation with that in France where legal constraints exist obliging monetary support between family members but where the State offers a great deal of monetary and service support to older people. For example, older people receiving home care receive an average of 21 hours/month while in Quebec the average is 22.9 hours/year (Lavoie, Grand, Guberman & Andrieu, 2005). Thus, despite a discourse of voluntary participation in care, the paucity of concrete measures and services indicate the real familist ideology of Quebec and Canadian policy.

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<sup>10</sup> Thanks to Sheila Neysmith for some of these ideas

This orientation makes it difficult for caregiver rights' groups to build a genuine caregiver movement across Canada, and even within Quebec, due to a refusal on the part of governments to fund this movement. This is in contrast to the situation in the other countries where the carer movements have made major inroads in the development of caregiver recognition and legislation.

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