



Beyond Recognition – Caregiving & Human Rights in Canada: A Policy Brief

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What are caregivers' RIGHTS?

Caregivers have the right:

- to freely choose how much and what type of care they will provide;
- to enjoy just and favourable conditions, including access to periodic respite and protection against ill health, unemployment and poverty;
- to have their work, education, leisure and health needs assessed and factored into the care plan.

Introduction

Canada prides itself on being a country that protects the rights and freedoms of individuals as enshrined in the *Canadian Charter of Rights and Freedoms* (Government of Canada, 1982). This important part of our constitution outlines how the government operates in a free and democratic society that protects the legal right to “life, liberty and security of the person” as well as the right to “the equal protection and equal benefit of the law without discrimination.”

The *Canadian Human Rights Act* (1985, Section 2) further stipulates that:

all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted or in respect of which a record suspension has been ordered.

These rights and freedoms align with the *Universal Declaration of Human Rights* (1948) as well as other UN conventions, such as the *Convention on the Rights of Persons with Disabilities* (2006), which Canada ratified in 2010.¹ Human rights is an underutilized, yet powerful approach when it comes to caregiving policies in Canada. This brief provides an overview of caregiving as a human rights issue based on a review of academic and grey literature both within Canada and internationally, as well as interviews with leading caregiving experts in Quebec, Ontario, Alberta and British Columbia.

¹ See Appendix A for a list of resources related to general and caregiver-specific human rights.



Profile of caregivers in Canada

Who are CAREGIVERS?

Every day, over 8 million Canadians (28% of the population) provide care to their spouse, parents, adult children, grandparents, other family members, friends or neighbours. Caregivers are people who care for family members and friends who have physical, cognitive and/or mental health needs. While caregivers are more likely to provide care during their peak earning years—between the ages of 45 and 64 (44%)—they can take on this responsibility at virtually any stage of their life. Indeed, 15% of caregivers are between the ages of 15 and 24, while those over 65 (12%) tend to provide more hours of care than the other age groups (Sinha, 2013). Women also provide more hours of care on average than men, although the gender gap in caregiving may be closing: in one recent Canadian survey, 54% of caregivers were women compared to 46% men (Sinha, 2013), compared to a 2012 study by the Health Council of Canada, which found that nearly 60% of caregivers were women.

What do caregivers CONTRIBUTE?

It is commonly assumed that when home care services are provided, the family will be less likely to provide care, but this does not bear out in reality (Penning, 2002; Penning & Keating, 2000). The system could not function without the countless hours of care provided by family members and friends. For example, on average, caregivers provide 70% to 75% of the care, averaging about 19 hours of care per week (between 15 and 24 hours, depending on the province or territory studied) to seniors who are receiving publicly funded home care as well. In other words, caregivers provided more than three times the 4 to 7 hours provided through formal services (Health Council of Canada, 2012).

What do caregivers DO?

While transportation is the most frequent type of support provided, caregivers also prepare meals, clean and maintain the home, schedule and coordinate appointments, advocate on behalf of care receivers, manage finances, help with medical treatment, manage behaviour, provide emotional support in cases of suicidal ideas, grief and loss, and provide personal care such as bathing, feeding and toileting (Sinha, 2013; Guberman & Maheu, 1993).

Caregivers also juggle multiple roles—60% are employed; 28% have children under the age of 18 living at home; and 27% are caring for more than one person (Sinha, 2013). A total of 47% of young caregivers attend school and another 45% are employed (Bleakney, 2014).



What are the CONSEQUENCES for caregivers?

These statistics do not in themselves tell the story of the price that many caregivers pay for assuming this responsibility. Indeed, countless caregivers experience negative consequences that impact their health, family and social life, employment and financial security.

- 51% of family caregivers reported spending less time on social activities; 46% spent less time with friends; 54% spent less time relaxing and caring for themselves (Sinha, 2013).
- 15% of employed caregivers reduced their hours at work. This figure rose to 25% for those providing 15 or more hours of care (Sinha, 2013).
- 10% of employed caregivers turned down or did not pursue a new job or promotion on account of their caregiving responsibilities, and 40% sought less-demanding work (Sinha, 2013).
- 14% reported losing some of their employment benefits (extended health benefits, dental, pension, life insurance and drug plan) (Sinha, 2013).
- 34% of parents and 10% of adult children who provide care stated that caregiving prevented them from holding down a job (Turcotte, 2013).
- 7% of young caregivers said they could not attend school because of their responsibilities (Bleakney, 2014).
- 28% of parents, 20% of spouses and 7% of adult children reported financial hardship due to caregiving responsibilities (Turcotte, 2013).
- Caregivers supporting someone living in the community with high care needs had care-related out-of-pocket expenses averaging \$7,599 per year, with as much as \$4,000 spent on transportation (Duncan et al., 2013).
- The estimated accumulated annual income loss associated with eldercare-related employment disruptions is \$336.8 million for employed caregivers (Fast et al., 2013).

Human rights of caregivers: Moving beyond recognition



If we compare the realities of caregiving with human rights documents, we quickly become aware that caregivers' rights, as defined, for example, in the following articles from the *Universal Declaration of Human Rights* (United Nations, 1948) are being denied:



- the right of non-discrimination on the basis of marital or family status related to “the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment” (Article 23. (1));
- “the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay” (Article 24);
- “the right to a standard of living adequate for the health and well-being of him [her] and of his [her] family” (Article 25. (1));
- and “the right to education” (Article 26 (1)), in the case of young caregivers.

Moreover, authors such as West [2004, 1] have affirmed that, “an individual has a right... to provide care to her or his dependents without risking impoverishment or dependency.”

In combination, these articles refer to many situations in which the human rights of caregivers may be violated. In short, caregivers are being denied basic human rights. Borrowing from Clements (2013, 423) who wrote about people with disabilities as candidates for non-discrimination legislation protection, we advance the argument for caregivers that “inherent within all human rights treaties is the obligation on states... to take action to prevent the [protected] right from being undermined.” Indeed, Clements (2013, 400) conceptualizes the protection of these rights as “positive obligations” to protect “the soft socio-economic rights rather than the hard negative civil and political rights.” These positive obligations include according caregivers the right to freely and knowingly choose to provide care and to determine for themselves, within reason, the conditions and amount of care they wish to provide, particularly if this responsibility infringes on their right to work and/or obtain an education, to rest and engage in leisure activities, to enjoy “a standard of living adequate for health and well-being,” and to participate in the cultural and social life of the community—all fundamental rights enshrined in the *Universal Declaration of Human Rights* (United Nations, 1948).

There are some promising, incremental developments in Canada regarding the recognition of caregivers as ‘rights holders.’ For example, the Canadian Caregiver Coalition (CCC-CCAN) has recommended a national caregiving strategy based on the principles of respect, choice and self-determination (CCC-CCAN, 2013). In 2011, Manitoba became the first province to enact legislation for caregivers—the *Caregiver Recognition Act* (2011)—aimed at increasing awareness and recognition of Manitoba’s family caregivers. The Human Rights Commission recently published a practical guide aimed at balancing the work and caregiving obligations of employees (Canadian Human Rights Commission, 2014; Osborne-Brown & Daye, 2013).



Internationally, the UK and Australia seem to be the most advanced in the rights-based approach to caregiving. The UK has legislation recognizing caregivers as rights holders, including the *Carers (Recognition and Services) Act* 1995; the *Carers and Disabled Children Act* 2000; and the *Carers (Equal Opportunities) Act* 2004. The Australian government enacted the Carer Recognition Act in 2010, which led to the development of a National Carer Strategy in 2011. In addition, the Australian Human Rights Commission (2013,³) published a report titled *Investing in care: Recognising and valuing those who care*, with the intent of informing policy reforms from a human rights perspective recognizing the “significant social and economic benefits” of care.²

Advantages of a rights-based approach



Regardless of whether governments and service provider organizations are legally bound to protect the human rights of caregivers, there are a number of advantages to using a rights-based approach in formulating a caregiving policy.

Canada has many of the key ingredients to embrace a human rights-based approach that would be complementary to the existing social, economic and business approach to caregiving. Such an approach would:

- encourage all Canadians to have conversations about expectations of care with other family members and friends, and prepare them for their potential role as caregivers;
- provide an impetus to enact social and economic change for caregivers;
- standardize approaches to assessing caregiving situations and developing programs and policies based on a consistent set of values and principles;
- promote gender equality, so that both men and women are supported in their caregiving responsibilities;
- value the economic and social contributions of caregivers;
- focus on the social, economic and political structures that infringe on caregivers’ rights.

² For a list of resources, see Appendix A.



Recommendations

Canada's legislation should be strengthened to recognize caregiving responsibilities and identify our societal obligation to support caregivers.

1. All provincial and territorial jurisdictions should consider enacting legislation similar to that of Manitoba to promote the recognition of caregivers and identify societal obligations to caregivers.
2. Caregiver legislation and policies should be aimed at implementing and enhancing the Canadian Human Rights Commission's recommendations on balancing work and caregiving responsibilities.
3. Extend 'family status' protection and reasonably accommodate caregivers, taking into consideration their risk of poverty and/or ill health.

Home and community care regulations should explicitly identify service obligations to caregivers.

1. Consider using the UK Carers legislation³ (1995; 2000; 2004) as a guide to establish the rights of caregivers, such as:
 - a. *The right to choose to care, or not;*
 - b. *The right to have their views taken into account in the development and implementation of care plans;*
 - c. *The right to request an assessment of their situation, especially in the case of caregivers "providing or intending to provide substantial amounts of care on a regular basis" or when "a caregiver's ability to sustain that role is compromised or threatened either in the present or foreseeable future by the absence of appropriate support;"*
 - d. *In situations where caregivers are at risk of developing "major health problems," local authorities have the duty to "safeguard" the health of caregivers "to ensure caregivers are not exposed to unreasonable risk of harm."*
2. Identify existing and/or establish new accountability mechanisms to monitor, investigate and resolve conditions that violate caregivers' rights.

Explore measures to protect the financial security of caregivers and minimize out-of-pocket expenses, such as refundable tax credits, no-cost/low-cost programs, employment benefits and compassionate benefits.

³ See Clements, 2011, *Carers and Their Rights: The Laws Related to Carers*, Carers UK. The phrases in quotation marks are taken directly from the legislation and regulations cited in this document.



Conclusion



This policy brief presents an argument for using a human rights–based approach to caregiving policy and service delivery. While caregivers are arguably recognized and respected for their contributions, they are not supported in ways that meet their needs or protect their rights. While many policies and programs address some immediate needs or problems, they do not address the structural barriers that lead to human rights violations.

With an aging population that is living longer with chronic health conditions, people with developmental disabilities living to old age, and refined technologies and pharmaceuticals, the onus is on family and friends to meet the increasing demands for care and support. By asserting that caregivers have the right to provide care without risk of poverty, isolation and ill health, we can start a discussion about how best to guarantee these rights, through a combination of legislative and regulative changes, financial measures, employment benefits, and home and community care services.



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Appendix A: Using a Human Rights–Based Approach

Canadian resources

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