



Beyond Recognition

Caregiving and Human Rights in Canada: A Policy Brief

By Lucy Barylak, M.S.W.

**Social Gerontology Consultant
West-Central Montreal Health**

*Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'île-de-Montréal*

Québec 

There are only four kinds of people in this world.....

- Those who have been caregivers,
- Those who are currently caregivers,
- Those who will be caregivers, and
- Those who need caregiving.

Former First Lady Rosalynn Carter (2003)

Human Rights Policy Brief

- Since the early nineties, we have been advocating for caregivers' rights to be recognized, and sensitized to the work that they have been doing, and how it has affected them.
- However, have their **Human Rights** been protected and addressed in the health care sectors, as well as working establishments across Canada?
- It is time to address this issue.

MSSS - Home Care Policy (2003)

- Caregiver can be a family member or a friend. It also says that caregivers have a **choice to care**.
- The caregiver is regarded as a **client for services**, a partner and a citizen who fulfills her/his obligation.
- The Home Care Policy has promoted **caregiver's status** in our health care system.

MSSS - Home Care Policy (2003)

1. No funds were allocated for caregivers in this Policy.
2. No statistics in the Home Care Department to represent caregivers. There are codes for intervention for caregivers under the care receiver's file. Therefore it is difficult to know how many caregivers are in the system.
3. No mandatory assessments to be done for caregivers.
4. Files are not automatically opened.
5. Coordination of care for caregivers is not recognized by the work that practitioners are doing.
6. Do caregivers have a choice to care? Given that there are not enough intermediate and long term beds available in the system....
7. You do not stop being a caregiver even when the care receiver is placed.

Caregivers in the workplace

- Caregivers are protected under “family status”.
- An employer must accommodate employees who are providing necessary caregiving.
- Does our Health Care System and other workplace settings accommodate their employee caregivers?

Caregivers in the workplace

- It is estimated that every year, Canada loses the equivalent of nearly 558, 000 full time employees from the workforce due to the inability to manage the conflicting demands of paid work and care. (Fast, 2015)

2008 and 2014 CSSS Cavendish (CLSC N.D.G and CLSC René-Cassin) Survey Results

(Pam Orzeck, Tina Recine, Sophie Bernardin, Isabelle Van Pevenage, Mark Tobin, Ilana Shiller)

- 1000 surveys sent out in hard copy to each site
- Posted on Survey Monkey in English and French (Electronic survey)
- 121 respondents (Paper survey: 53; English electronic survey: 44; French electronic survey: 24)

Survey Results

Change of health as a result of balancing work and caregiving responsibilities

Comment highlights – Recurrent comments

- **Most of the respondents mentioned being tired, exhausted or fatigued**
 - « Fatigue pour jongler différents rôles, manque d'attention et stress vécu au travail. Il y a moins de collègues pour du soutien ».
- **Many respondents mentioned being anxious and stressed**
 - “Levels of stress, anxiety and depression have all increased and influence each other every day. Very difficult when you have no support system of your own or people to consult with”.
- **Common mention of sadness and depression**
 - “I sometime feel I am not able to cope, depressed, discouraged”.

Survey Results

Change of health as a result of balancing work and caregiving responsibilities

Comment highlights – Other aspects mentioned

- No leisure time/self time
- Little time for basic personal care
- Unmotivated at work
- Impression of being unable to meet familial and professional expectations
- Physical pain
- Guilt if the person needs to miss work to give care
- Loss of concentration at work
- Insomnia
- Mild weight gain
- More preoccupied than normal
- One person mention that a positive aspect is that she/he sees work as a relief, as time for herself/himself, to do what she/he likes to do : « Le travail me permet d'avoir du temps pour moi, une bulle où je peux faire ce que j'aime. »

Let's examine Policies...

- Most public policies have been developed without taking into account the needs that affect caregivers. Their contribution has been mostly overlooked and largely under valued.

(MacCourt and Krawczyk, 2012)

We need a Policy Lens for Caregivers

- The Caregiver Policy Lens (CGPL) is a framework for examining policies, programs and services from the perspective of caregivers. Government, organizations, program and service delivery policies can be analyzed for their potential effects (both positive and negative) on caregivers .

(MacCourt and Krawczyk, 2012)

How the Policy Brief can be utilized to protect caregivers' basic Human Rights

1. Practitioners should give the brief to caregivers.
2. Sensitize government, management, practitioners, long term facilities, rehabilitation centers, hospitals, board members, user committees, as well as work establishments, partners, community organizations and private health care providers, about the Human Rights of caregivers.
3. Lobby at the provincial level to develop statistics that represents caregivers. The ability to assess caregivers' needs and open files for them when necessary.
4. Recognizing the coordination of work that practitioners are doing when supporting and working with caregivers.

How the Policy Brief can be utilized to protect caregivers' basic Human Rights

5. Before developing new services or policies, the Brief should be consulted when it comes to caregivers' Human Rights.
6. Before abolishing or integrating services due to budget cuts the Brief should be consulted.
7. New research should be addressed through a Human Rights lens for caregivers.
8. Human Resources Departments at all work places should develop policies that meet the basic human rights of their employee caregivers.

Especially now with the uncertainty where this reform is going.

This can be a good time to have a better understanding through the Policy Brief of what we should be doing moving forward to support Caregivers' Human Rights.