

*Sunita is a unionized employee working in health care as a nurse. She works a shift schedule set out in her collective agreement: a rotation that includes twelve hour shifts and frequent overnights. Recently her father-in-law suffered a stroke resulting in partial paralysis, and requiring administration of medication at home as well as ongoing accompaniment to medical and rehabilitation appointments. Although the man has many children, the family decided he should live with Sunita, who has health care skills, can administer his medication, and can deal best with his other health care providers. Sunita requested a one month paid leave to allow her to get father-in-law settled into her home, onto a new routine, and stabilized on medication. Her employer denied her request for a paid compassionate leave and is considering granting her an unpaid leave. In terms of longer term adjustments, Sunita's employer has denied Sunita's request for a set schedule of shorter shifts that excludes evenings. Sunita thinks this modification in her hours of work is necessary because her father-in-law is at greatest risk of respiration problems when he is sleeping or lying down. Shift work that includes evenings has become problematic but there are very few positions in her bargaining unit that are not associated with rotations that include nights.*

## **CHAPTER 2 – Family Caregiving in BC**

### **I. The Growth of Community Care in Canada**

A number of recent changes to the delivery of health care in Canada have had significant consequences on the growth of family caregiving. Most of the activities associated with family caregiving – bathing, toiletry, grooming, cooking, housework, emotional support, shopping, managing appointments – are not covered by the *Canada Health Act*, the federal legislation governing health care in Canada.<sup>30</sup> Health care is regulated at the provincial level and there exists tremendous diversity in access to services across the country. Key caregiving activities may or may not be covered by the various provincial medicare programs; however, their performance remains pivotal to the wellbeing of many people with disabilities, chronic illnesses and various health issues associated with aging.

In BC there has been a growing emphasis on community care and family caregiving as a function of de-institutionalization of certain forms of caregiving, changes in the administration of health care such as revisions to long-term care facility legislation reducing access to residential care, and a decrease in access to home support caused by stricter eligibility requirements.<sup>31</sup> Increasingly, you need to be in poorer and poorer health to have access to either institutional care or publicly-funded community care services.

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<sup>30</sup> *Canada Health Act*, R.S.C. 1985, c. C-6.

<sup>31</sup> Marcy Cohen, Jeremy Tate & Jennifer Baumbusch, *An Uncertain Future for Seniors: BC's Restructuring of Home and Community Health Care 2001-2008* (Vancouver: Canadian Centre for Policy Alternatives, 2009).

The *Romanow Report* on Canadian health care identified home care as “one of the fastest growing components of the health care system” in Canada.<sup>32</sup> Changes in technology have resulted in more outpatient care and a shift toward community delivery of some forms of care previously provided institutionally, resulting in an expansion in both the prevalence and complexity of family caregiving. A positive outcome of this is a potential for increased independence and autonomy for some people with disabilities and a heightened capacity on the part of the elderly to “age in place” – assuming there is someone in the community available to assist with tasks no longer covered by provincial health care programs. However this shift has also enhanced the burden of care on families. As Pat Armstrong, writes, while women have often been engaging in caregiving in the home, “[o]ur grandmothers never cleaned catheters or checked intravenous tubes; they did not examine incisions or do much wound care.”<sup>33</sup>

Recognizing the scope of family caregiving and its indispensable place in the current Canadian health care system, the *Romanow Report* called for improved support for “informal caregivers”, defined as family and friends who provide unpaid support. “Quite simply,” states the Report, “home care could not exist in Canada without the support of social networks and informal caregivers.”<sup>34</sup>

## II. Demographics Fueling the Caregiving Crisis

Canada is aging. Seniors constitute that fastest growing subgroup of the population of Canada. Whereas in 1921 they accounted for only five percent of the overall population, by 2001 they formed nearly thirteen percent of Canadians.<sup>35</sup> Seniors are anticipated to account for nearly half of the overall population growth in Canada between now and 2041– the fastest growth occurring amongst older seniors age 85 and older – and seniors are expected to make up close to fifteen percent of the population by 2011,<sup>36</sup> and twenty percent of the population by 2056.<sup>37</sup>

This rapid growth is in part a function of the aging of the country’s baby boomers (people born in the years subsequent to WWII, between 1945-1965), the first of whom will reach age 65 in 2011. Birth rates are also falling. Children form an increasingly smaller aspect of the population and fertility continues to be below replacement rate.<sup>38</sup> Another factor impacting on the aging of our population is the increasing average life expectancy in Canada: average

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<sup>32</sup> Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada*, by Roy J. Romanow (Ottawa, 2002) at 171, online: <<http://publications.gc.ca/pub?id=237274&sl=0>> [Romanow Report].

<sup>33</sup> Armstrong & Kits, *supra* note 20 at 26.

<sup>34</sup> Romanow Report, *supra* note 32 at 183.

<sup>35</sup> Health Canada, *Canada’s Aging Population* (Ottawa: Division of Aging and Seniors, 2002) at 3 [*Canada’s Aging Population*].

<sup>36</sup> *Ibid.*

<sup>37</sup> Kelly Cranswick & Donna Dosman, “Eldercare: What we know today”, *Canadian Social Trends*, Statistics Canada – Catalogue no. 11-008 48 at 48 [Cranswick & Dosman].

<sup>38</sup> Government of Canada, *Addressing the Challenges and Opportunities of Ageing in Canada*, prepared for the United Nations Commission for Social Development for the 5<sup>th</sup> Anniversary of the 2002 United Nations Second World Assembly on Ageing (2007) at 6.

life expectancy reached 80 years for the first time in 2004 (77.8 for men and 82.6 for women).<sup>39</sup>

British Columbia remains one of the “oldest” provinces in Canada: in 2006, 14.6 percent of its population was 65 years or older, compared with 13.7 percent for Canada as a whole, and BC maintains both the lowest national fertility rate and the highest life expectancy.<sup>40</sup>

These statistics will result in an increasing need for elder care. For while these numbers also mean an increasing pool of elderly retired caregivers, as many older adults maintain significant well-being long into their retirement years, increased life expectancy made possible by scientific development means a potential for adults to live long lives of dependency and disability, potentially increasing the period of time during which they will be recipients of family caregiving.

While some seniors continue to work, the vast majority are retiring.<sup>41</sup> Sources are inconsistent with respect to whether the average retirement age is going up or down. In 2002 Health Canada suggested adults were retiring earlier and earlier in life.<sup>42</sup> Statistics Canada data confirms that the majority of Canadians plan to retire at age 65 or earlier, although it does indicate that labour force participation into the late 60's has gone up again in recent years.<sup>43</sup> As only a small portion of seniors claimed to be retiring as a result of mandatory retirement policies in 2002 (14 percent)<sup>44</sup> the recent eradication of mandatory retirement in BC and other Canadian jurisdictions is not likely to have a huge labour force impact. Still, age 65 continues to be a benchmark year for older Canadians considering retirement.

The size of the Canadian workforce may continue to grow very slowly until 2013, as a function of anticipated increased female participation and longer earning potential resulting from higher levels of education, at which point a gradual decline in labour supply is anticipated.<sup>45</sup> The result is more seniors requiring care, fewer younger adults to provide care, a smaller labour force contributing to national wealth, and an increasing portion of employed people participating in family caregiving. Caregiving labour will become concentrated on fewer caregivers and fewer income earners.

However, while Canada's aging population has significant implications for family caregiving, both in scope and character, elder care forms but a subset of family caregiving. Family caregivers care for a diverse group of people including adults with developmental and physical disabilities, addictions, chronic health problems and mental illnesses.

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<sup>39</sup> *Ibid.* at 5.

<sup>40</sup> Statistics Canada, *Portrait of the Canadian Population in 2006, by Age and Sex*, catalogue no. 97-551-XIE at 26 [Statistics Canada].

<sup>41</sup> *Canada's Aging Population*, *supra* note 35 at 15.

<sup>42</sup> *Ibid.*

<sup>43</sup> Statistics Canada, *supra* note 40 at 19-20.

<sup>44</sup> *Canada's Aging Population*, *supra* note 35 at 16.

<sup>45</sup> Hunsley, *supra* note 10 at 8.

### III. The Prevalence of Family Caregiving

One of the most often cited statistics on family caregiving is that in 2002, over two million family and friend caregivers aged 45 years and older provided care to seniors.<sup>46</sup> According to Statistics Canada, this figure rose to 2.7 million in 2007,<sup>47</sup> representing roughly eight percent of the population. 57% of these caregivers were employed.<sup>48</sup> One of the few studies that focus on working family caregivers indicates that one in four employed Canadians is involved in elder care alone.<sup>49</sup> Other studies indicate that up to 90% of eldercare is delivered through family caregiving.<sup>50</sup>

High as these numbers are, these figures only partially capture the scope of family caregiving in Canada and BC, including, as they do, only the care of older adults. Health Canada figures indicate that about 500,000 people, roughly two percent of the population is caring for an adult with a mental illness.<sup>51</sup> Again, the majority of caregivers surveyed were women,<sup>52</sup> and about 70% of caregivers were employed.<sup>53</sup> Similarly, a 2002 Health Canada survey found that four percent of the population was providing care to a family member who was chronically ill or frail or suffered from a physical or mental disability,<sup>54</sup> 77% of whom were female caregivers.<sup>55</sup> Comparable studies have not occurred in BC. However, given that the population of BC is older than the national average, family caregiving is likely even more prevalent in this province.

The scope of caregiving is also likely greater than suggested by statistics. For instance, statistics likely under-report spousal caregiving of women to male partners: Statistics Canada data indicate that only 1 in 10 caregivers cares for a spouse, and postulates that some aspects of caring of aging seniors may not be characterized as caregiving by a female partner who took responsibility for domestic and other tasks long before her spouse became physically or cognitively incapable of performing them.<sup>56</sup> The same explanation may point to under-reporting of caregiving by parents of children with lifetime support needs. A number of studies predict that caregivers generally under-report caregiving because they do not characterize what they are doing as providing care.<sup>57</sup>

Another interesting feature of family caregiving is that a great number of caregivers are not caring for members of their biological family. Family caregiving includes the care of friends

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<sup>46</sup> Cranswick & Dosman, *supra* note 37 at 49. This study relies on Kelly Cranswick, *General Social Survey Cycle 16: Caring for an Aging Society*, (2002), Statistics Canada – Catalogue no. 89-582-XIE, online: <<http://www.statca.ca/bsolc/english/bsolc/?catno=89-582-X>>.

<sup>47</sup> *Ibid.*

<sup>48</sup> *Ibid.*

<sup>49</sup> Duxbury, Higgins & Shroeder, *supra* note 19 at 8.

<sup>50</sup> *Ibid.* at 29.

<sup>51</sup> Decima Research, *Informal/ Family Caregivers in Canada Caring for Someone with a Mental Illness*, (Ottawa: Health Canada, 2004) at 14.

<sup>52</sup> *Ibid.*

<sup>53</sup> *Ibid.* at 16.

<sup>54</sup> Decima Research, *National Profile of Family Caregivers in Canada* (Ottawa: Health Canada, 2002) at 3.

<sup>55</sup> *Ibid.*

<sup>56</sup> Cranswick & Dosman, *supra* note 37 at 49.

<sup>57</sup> Duxbury, Higgins & Shroeder, *supra* note 19 at 29

and neighbours in high numbers. Recent Statistics Canada data places friend care as the second largest group of care recipients, after people caring for their mothers, at fourteen percent, slightly above spousal caregiving.<sup>58</sup>

#### IV. Family Caregiving and Women

Caregiving is overwhelmingly the work of women. Although Statistics Canada data indicates that men are involved in caregiving, studies suggest that women are more intensely involved in care, dedicating more hours to care, providing more hands on care, and making more compromises in terms of their paid employment choices to continue to provide care.<sup>59</sup> Caregiving also appears to have more significant long-term financial consequences for women carers.<sup>60</sup> Employed women, and to a lesser extent men, juggle caregiving responsibilities and employment rather than choosing to “relinquish to care.”<sup>61</sup> As Philipps points out with respect to domestic labour more broadly, Statistics Canada data indicates that “women’s share of unpaid work has remained fairly consistent since the 1960s (at about two-thirds) despite the dramatic increase in their paid labour market participation.”<sup>62</sup> The results of the BCLI’s survey of BC family caregivers indicate that over 75% of caregivers are women. The impact of balancing caregiving and paid employment also has been shown to be particularly stressful for employed women.<sup>63</sup>

Research tells us that female caregivers are more likely than their male counterparts to find themselves members of the sandwich generation, a growing subgroup providing care simultaneously to under-age children and older adult family members, often while maintaining paid employment.<sup>64</sup> There were over 2 million sandwich generation caregivers in Canada in 2001.<sup>65</sup> This group is likely growing as a function of later marriage and parenting later in the life-course.

Why do women perform the majority of caregiving labour? According to Marika Morris women are socialized as caregivers: they are both “viewed by society as “natural” caregivers and feel pressure to do this work.”<sup>66</sup> As the primary caregivers of children, women often assume caregiving generally within the family. Moreover, as a function of greater longevity and age disparities between partners, heterosexual women are often the caregivers of their aging spouses and friends.<sup>67</sup>

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<sup>58</sup> Cranswick & Dosman, *supra* note 37 at 29.

<sup>59</sup> Pyper, *supra* note 2, and Marika Morris, *Gender-Sensitive Home and Community Care and Caregiving Research: A Synthesis Paper*, Final Report, Women’s Health Bureau, 2001 [Morris].

<sup>60</sup> Morris, *ibid.* at 22.

<sup>61</sup> Phillips, “Working”, *supra* note 24 at 49.

<sup>62</sup> Philipps, “One Worker”, *supra* note 8 at 8.

<sup>63</sup> Lee, *supra* note 21; Martha MacDonald, Shelley Phipps and Lynn Lethbridge, “Taking its Toll: Implications of Women’s Paid and Unpaid Work Responsibilities for Women’s Well-being” (2005) 11(1) *Feminist Economics* 63.

<sup>64</sup> Duxbury, Higgins & Shroeder, *supra* note 19 at 29.

<sup>65</sup> *Ibid.*

<sup>66</sup> Morris, *supra* note 59 at 22.

<sup>67</sup> Armstrong & Kits, *supra* note 20 at 12.

## V. What is Family Caregiving?

We define a family caregiver as a person who is providing care, without pay or wage, to a friend or family member, including an adult child, for at least 2 hours a week. This care is provided outside of a hospital or care facility and may include any of the following activities: assistance with attending and scheduling appointments; transportation; feeding, meal planning or diet management; personal care (bathing, dressing, toiletry); household chores, including cooking, laundry and shopping; medications management and administration; mobility assistance. “Parenting” and “family caregiving” may be overlapping concepts in the experience of parents of adult children with disabilities.

Caregiving is often delineated according to categories of care. Armstrong and Kits divide care into the following overlapping groupings:

- Care management: identifying and arranging formal care services, mediating between and dealing with care providers, advocating for the rights of the care receiver, completing forms
- Assistance with instrumental activities of daily living: cooking, shopping, household tasks
- Assistance with activities of daily living: dressing, bathing, eating, personal care, administration of medication and other health equipment
- Emotional and social support<sup>68</sup>

Although often characterized by the presence of types of activities, ultimately caregiving is not an action, but rather a “complex social relationship”.<sup>69</sup> The caregiving relationship emerges out of a previous familial or friendship connection. Social relationships are by definition associations of interdependency, and caregiving heightens the demands placed on the time and energies of one of the partners.

While there is great diversity in the amount of time caregivers spend in caregiving, caregivers face substantial demands on their time. Duxbury, Higgins and Shroeder’s recent study of employed caregivers who maintained full-time positions, found that “the majority of caregivers in the interview study “work” the equivalent of two full time jobs: they spend an average of 36.5 hours per week in paid employment and 34.4 hours per week in caregiving”.<sup>70</sup>

Family caregiving encompasses very diverse relationships. Some caregiving relationships are life-long, as is the case with the parenting of some children with disabilities. Other care recipients have fluctuating needs, increasing during periods of poorer mental or physical health and becoming minimal when an illness is effectively in remission. This may be the case with a family member with a mental illness or with some conditions like Multiple Sclerosis.<sup>71</sup> People recovering from various types of surgery may require significant post-

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<sup>68</sup> *Ibid.* at 3-4.

<sup>69</sup> *Ibid.* at 1.

<sup>70</sup> Duxbury, Higgins & Shroeder, *supra* note 19 at 9.

<sup>71</sup> Armstrong & Kits, *supra* note 20 at 10.

surgical monitoring as well as ongoing emotional support and assistance with basic tasks of daily living; however, their needs may diminish over time to the point that caregiving is no longer required at all.<sup>72</sup> In contrast, some degenerative conditions are characterized by increasing care needs and lengthy life expectancy, meaning that a caregiver can be providing care on a full-time basis for many years. Still other family members may require support through a lengthy period of convalescence. A sudden car accident may precipitate a temporary or lifelong period of caregiving. Care needs may increase or decrease over time, but, in any event, are extremely varied.

Caregiving itself is also not static or linear. For example, even within the context of providing care to a single person, caregiving is often not stable, but consists of ups, downs and plateau phases. For example, a caregiver caring for someone with a chronic condition may find needs shift when that person develops an acute illness. In this case extra time and resources may be needed. Similarly, an individual may have a period of remission where, for a prescribed period of time, they require less assistance. To make matters more complicated, these changes in caregiving do not always have a clear onset and resolution phase as suggested by some research (Yeager & Roberts, 2003), but are highly variable and context-specific. From an employment perspective, this means that while it is important to consider the nature of the relationship and the duration of the caregiving commitment, it is equally important to understand that caregiving needs may be variable and unpredictable. It is difficult to quantify how much “time” it takes to care. The burden of care is unique for each individual circumstance. What is certain is that caregivers need flexibility and support to manage their unique caregiving situations. There must be short-term, long-term and crisis-type solutions for employed caregivers.

## VI. A Note on the Term “Family Caregiver”

The term “family caregiving” has been the subject of some criticism. Many studies employ the alternate term “informal caregiving” to denote the same behaviours and in a sense this is a more accurate term. “Family care” includes the care of friends, neighbours and other non-family members in receipt of voluntary unpaid care. Australia and the U.K. use the term “carer” to capture care delivered in a family setting.<sup>73</sup>

We use the term “family caregiver” because, as compared with the alternatives, it captures the reality that caregiving behaviour generally exists in the context of pre-existing relationships. The language of “informal” fails to capture the social reality of caregiving and sterilizes an emotionally complex subject. The term “informal” emphasizes organization and the absence of infrastructure, and obscures the lack of payment. The language of “family” also emphasizes the public-private distinction implicated in the relegation of caregiving to family members. This is useful to our study, which looks at the relationship between paid employment (public) and unpaid caregiving (private) manifest in legislation. The word “carer” is arguably too broad: we may care for many people for whom we are not

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<sup>72</sup> *Ibid.* at 9.

<sup>73</sup> See, for example, Australia, Commonwealth, House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the Inquiry into better support for carers* (Canberra: Parliament of the Commonwealth of Australia, 2009) at 18 [*Who Cares...?*].

performing any caregiving activities. Caregiving, denoting an action, again brings the emphasis back to labour and work. Moreover, ultimately “family caregiving” remains the term most commonly invoked in Canada to capture unpaid care and would like to situate *Care/Work* firmly within this larger body of literature.