APPENDIX E

Summary of the Results of the BC Family Caregivers Survey

I. Overview

In 2009, the British Columbia Law Institute conducted a survey of unpaid family caregivers in order to assist research on the project that ultimately became *Care/Work*. At the time a number of caregiver surveys and consultations had occurred in recent years in Canada; however, our research did not locate a quantitative study into the needs of family caregivers specific to BC. The BCLI survey appeared necessary given variation in access to services across the country and the BC focus of this research project. The goal of the survey was not to produce statistically significant results, but rather to insure the research into alternatives to supporting caregivers and valuing the labour of caregivers was informed by a sense of how existing family caregivers characterized their own needs.

Approximately 340 people completed the BC Family Caregivers Survey. Most respondents completed the survey electronically. A small number of caregivers handed in their responses in print. Caregivers were accessed via attendance at a number of caregiver information fairs (Vancouver and Burnaby) and by forwarding a link to our electronic survey to a number of caregiver organizations. The survey was made available in multiple languages but the majority of respondents completed the survey in English. However, about 5% of the respondents who completed the English survey indicated that English was their second language. The survey period was from April to November.

II. Results

A. Caregiving Relationships

Just over 85% of the caregivers we surveyed were providing care for either their mother (28%), spouse or partner (28%), or adult child (30%), with a small number indicating that they were caring for two family members simultaneously and 10% stating they were caring for their father. Care of friends represented slightly under 4% of the caregivers we surveyed.

Over 80% of the caregivers who completed our survey were female. This is consistent with the gendered picture of caregiving emerging out of most reports on family caregiving, but the number is slightly greater than the statistics found in other Canadian studies. This may be partly due to the fact that our study included the care of adult children, and our respondents were almost equally likely to be involved in spousal, parental or adult child care, whereas many studies concentrate on elder care.

B. Intensity of Caregiving

With respect to the intensity of caregiving, close to 50% of the caregivers indicated they were providing more than 25 hours per week of care. Less intimate forms of care were most frequently cited as part of the caregiving relationship: over 85% of caregivers stated they assisted their friend or family member with scheduling and attending appointments, provided general transportation, and shopping; and slightly over 80% of caregivers were engaged in basic household chores, including cooking and laundry. However, other more intimate activities also figured prominently: over 70% of caregivers were involved in feeding, meal planning and diet management; close to 45% performed elements of personal care, a category that included bathing, dressing and toiletry; over 40% of caregivers provided mobility assistance; and almost 70% of caregivers managed or administered medication. Overall this paints a portrait of very comprehensive caregiving occurring within family caregiving relationships in BC.

C. Employment Consequences of Caregiving

For the purposes of our study, the most useful information was what caregivers had to say about their needs in relation to their employment circumstances. The data reveals significant adjustments in order to manage care. Over 55% of caregivers indicated they were employed. Close to 30% of caregivers stated they lost or left a job because they needed to provide care for someone in their lives and almost 50% indicated they had to make changes to their work schedule in order to accommodate caregiving responsibilities. Almost 40% of respondents reduced their hours of work, over 35% used up their vacation time, and over 25% used up sick time to provide care.

Although many respondents indicate that work flexibility is key to managing caregiving responsibilities, BC caregivers appear to have some support from their employers: almost 85% of caregivers answered no to the question as to whether they had been denied time of work to provide care. Also, 40% indicated their employers had permitted them to change their hours of employment, over 25% were able to change the number of hours they were working; and close to 20% were permitted to change the location of work. Survey responses indicate that a number of caregivers have employers that allow them to make adjustment as needed whereas other respondents switched to self-employment to acquire greater scheduling liberty: 20% changed jobs and 16% accepted lower-paying positions. However, detailed survey comments also reveal that some caregivers believe the magnitude of caregiving is incompatible with paid employment in their circumstances. Many respondents left work or “retired”. Other comments betray significant anxiety about revealing the scope of their caregiving activities. Over 25% of caregivers indicated that they require greater job flexibility.

Leave appears to be an issue for caregivers. Just over 8% of respondents were able to take a paid leave and slightly over 20% took unpaid leaves from employment. Close to 25% indicated they needed time off work and only 8% stated they had received employment insurance. Over twice as many caregivers (16%) went on income assistance at some point.

D. Income Assistance for Caregivers

The most recurring theme in terms of responses was the financial cost of caregiving. Over 75% of caregivers indicated that a caregiver allowance would significantly improve their lives. Close to 60% of caregivers felt they should be paid or provided with some kind of financial compensation for their caregiving labour. Tax credits were the most available form of financial assistance – over 85% of caregivers indicated they had received them – but close to 65% of respondents indicated greater tax credits would be a benefit that would significantly improve their lives as caregivers. Over 45% of respondents stated that pension credits would significantly improve their lives.

Close to 50% of respondents indicated that if it were affordable they would prefer to have their family member or friend cared for by a paid professional. However, the detailed comments of caregivers who completed the survey indicate ambivalence on this issue, revealing frustration regarding the lack of appropriate or reliable care. Caregivers appear to want options. This seems to be connected to the challenge of respite: while close to 45% of caregivers indicated they have access to respite and just over 55% stated that additional respite care would significantly improve their lives, their comments suggest that they do not get adequate time for respite, given the scope of their loved one's caregiving needs, and do not feel comfortable leaving their family member with available caregivers for a lengthy period of time.

In the context of the current healthcare system, caregivers see their labour as tremendously valuable to the state and intrinsic to the well-being of their loved one, and the majority of respondents believe they should be financially compensated for their labour.