

*Emil and Sonja are in their late-fifties. They immigrated to Canada from Yugoslavia in the 1970s, shortly after they were married. Until recently they rented and managed a small grocery store that they had planned to run until their old age; however, changes in Sonja's health have necessitated a change of plans. Over the last year Sonja has become increasingly forgetful. She has recently been diagnosed with early onset Alzheimer's disease and is showing many signs of dementia. The couple has no children and Emil has thus become Sonja's primary caregiver. For part of this year Emil continued to work at the store on his own. Sonja's dementia has now progressed such that it is neither possible to leave her alone at home for lengthy periods of time nor bring her to the store. Emil has made inquiries regarding a long-term care facility for Sonja, but he has not been able to find suitable care for his wife, who has lost her ability to speak English and now only understands the Slavic languages of her childhood. The cost of private care may be more than Emil can afford on his current income, as he will have to hire another employee to help with the store as well. The couple is now facing a complete loss of employment income, as Emil contemplates entering early retirement in order to care for Sonja full-time. The couple is financially unprepared for these circumstances.*

## **CHAPTER 8 – Conclusion**

### **I. Overview**

This study considers the needs of a broad community of unpaid family caregivers. It analyzes to what extent existing laws in BC assist caregivers to balance paid employment and unpaid caregiving labour. In doing so, this project investigates whether current public policy recognizes the social and economic value of family caregiving to families, communities, the health care system, employers and the economy.

*Care/Work* surveys approaches taken to respond to the needs of caregivers in other jurisdictions in order to shed light on options for reform in Canada. This is because the ultimate purpose of this paper is not only to provide a thorough summary of the current law, but also to lay a foundation for law reform. The underlying concern is that many changes have occurred in social and labour demographics over the last century, and that the law, which has been revised in a piecemeal fashion, has not evolved sufficiently to respond to the challenges facing family caregivers.

The bulk of this paper is comprised of chapters that consider different aspects of the legal system and assess their responsiveness to the needs of family caregivers. *Care/Work* reviews employment law, human rights, tax law, health policy on caregiver allowances, as well as the pension regime. This structure is a useful strategy in terms of narrowing down a broad subject for the purpose of analysis. However, this fragmentation obscures the reality that

caregivers experience the legal system as a network of intersecting areas of law. An accurate and comprehensive portrait of how the law impacts caregivers requires us to consider the legal framework as a whole. It is for this reason that each chapter of this paper concludes with problems to consider rather than formal recommendations. To attach specific recommendations to each chapter would in a sense mimic the problematic piecemeal approach to law reform that has been taken to date.

The other challenge we must meet in this conclusion is the impossibility of making sense of family caregiving policy in the abstract. Reflecting on the strengths and weaknesses of the legal system requires some insight into the practical reality of how balancing care and work impacts caregivers. However, a comprehensive analysis is difficult given the diversity and variety of both caregiving and employment relationships.

As we discussed in chapter 2, caregiving relationships vary greatly. Some, such as those involving a child with disabilities, may be sustained throughout the working life of a caregiver. In comparison, a caregiver assisting a friend or family member after surgery or in recovery from an illness may require accommodation for days, weeks or months. Some caregivers experience the employment consequences of caregiving on an episodic basis, as a loved one may be quite independent when a health condition is in remission. People providing care for someone with a degenerative condition may experience increasing caregiving demands until the context becomes palliative. Caregiving relationships are short and long-term, caregiving is non-linear, and caregiving needs fluctuate even within a single relationship. Caregivers also maintain different kinds of employment relationships including self-employment, unionized and non-unionized work, part-time and full-time work, casual and long-term arrangements, and precarious labour attachment characterized multiple part-time, short-term positions.

The goal of this final chapter is to provide a summary of our research and identify some options for reform that will both respond to a variety of caregiving and employment circumstances, and consider the impact of multiple areas of law. This paper provides a starting place for more detailed law reform work in each of the areas we explore: in some areas further study will be required to clarify the best method for implementing our suggestions. In some areas the next step may be to develop draft legislation. In other areas, the question of valuation of caregiving labour requires further consideration of the appropriate dollar amount to attach to tax credits and allowances accessible to, and pension contributions made on behalf of, unpaid family caregivers.

With the above commitment to holism in mind and a sense that analysis must as much as possible be embedded in the practical reality of caregiving, this conclusion frames options for reform in relation to the caregiver portraits that introduce each chapter. This final chapter integrates the portraits and the various summaries of areas of law to explore how each of these caregivers fares in terms of access to rights and benefits under the current legal system. Given the infinite specificity of caregiving relationships our eight caregivers by no means represent all caregivers or encompass all the consequences of juggling work and care; however, this approach should ground our thinking in the lived experience of caregiving and ensure a degree of comprehensiveness.

This conclusion contains an overview of existing rights under BC current legislation,

a recapitulation of the circumstances of our eight caregivers, an analysis of how these caregivers fare under the existing regime, and a discussion of options for reform that would render the system more responsive to the challenges facing family caregivers. This conclusion is both a complement to this paper and a self-contained reference tool. Though mentioned briefly in aspects of this analysis, the international research is described in greater detail in the appendices to this paper: appendix B contains a comparative table and appendix C provides more lengthy country profiles.

## II. The Law of Family Caregiving

There is no single law in BC or Canada that addresses the circumstances of working caregivers. Rather, this area is primarily impacted by legal provisions found in employment and labour law, human rights, pensions, tax policy and health law. Existing legal recognition of the circumstances of family caregivers falls into roughly three categories: (a) employment leave provisions; (b) family responsibilities accommodation; and (c) measures that offset income loss.

### A. Employment Leave Provisions

Under the British Columbia *Employment Standards Act*, eligible employees are entitled to five days unpaid family responsibility leave to address the care needs of children and other immediate family members (s.52), and eight weeks unpaid compassionate care leave to provide end-of-life care to family members (s.52.1), the latter of which also may also trigger entitlement to six weeks of employment insurance benefits under the federal employment insurance system. Our review of this area of law identifies BC and Canada as leaders in providing workers with income replacement for end-of-life caregiving as well as maternity and parental leave benefits, but providing little recognition of other forms of family caregiving.

### B. Family Responsibilities Accommodation and Workplace Flexibility

Family responsibilities accommodation in the workplace is a somewhat uncertain area of law in Canada. Subject to the prohibition against discrimination against employees in the terms and conditions of employment contained within the BC *Human Rights Code*, there is no employee right to work flexibility in relation to family caregiving obligations. Accommodation of caregiving responsibilities is generally at the discretion of employers, unless the employee makes a successful human rights claim.

The leading BC case on when a conflict between workplace and family responsibilities will give rise to discrimination under the *Human Right Code* has established a test that is very difficult for employees to meet.<sup>362</sup> Although there exist very few cases that deal with the caregiving of adult family members – most cases pertain to childcare – recent case law indicates a pattern of controlling the floodgates and limiting human rights protection to extraordinary, not common, caregiving responsibilities. In practice, while human rights

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<sup>362</sup> *H.S.A.B.C. v. Campbell River & North Island Transition Society*, 127 L.A.C. (4th) 1 (B.C.C.A.).

provides the only legal framework for accessing work flexibility and accommodation of family responsibilities, it has proven itself to be a poor vehicle for exercising these rights.

### **C. Measures that Offset Income Loss**

Measures to offset income loss include tax incentives, as well as pensions and direct stipends or wages paid to the caregiver in recognition of caregiving labour. This is an area Canada has not explored significantly. The last ten years has witnessed a proliferation of studies on the needs of caregivers, all of which highlight the financial strain associated with caregiving and indicate a need for reform to address the short and long-term income security of caregivers; however, few programs exist in BC to support family caregivers.

#### **(i) Income Tax Measures**

The tax system currently includes a number of tax credits that are available to taxpayers who reside with family members who have a physical or mental disability and are dependent on the taxpayer for financial support. A major problem is that due to the non-refundability of existing tax measures – including the Caregiver Tax Credit – most are accessible only to higher income earners. One of the other problematic features from the perspective of caregiver policy is that eligibility is linked to financial dependency rather than caregiving labour. There is no BC or federal tax credit that compensates or recognizes caregiving labour.

#### **(ii) Payments to Caregivers**

In BC, payments to caregivers are only possible indirectly and by way of exceptions to health policy. The Choice in Supports for Independent Living program provides eligible people with disabilities with access to funds that they may spend at their discretion on their own care; however, payments to caregivers who are also family relations are permitted only in very limited circumstances. No BC program provides direct payments to family caregivers in recognition of their labour.

#### **(iii) Pension Security**

Public pension measures that take into account the impact of caregiving activity on earnings and pension security exclusively address the care of young children. The Child-Rearing Provision permits a parent to exclude years during which she was not engaged in paid employment in the determination of Canada Pension Plan entitlement. This measure allows an individual to discount her earnings during the first seven years of a child's life. There is no parallel measure with respect to other forms of caregiving. In BC there is also no caregiver-specific pension. Caregivers who reduce their earnings in order to provide caregiving possess no pension security protection.

## The Current Legislative Regime At a Glance

LEGISLATION	BENEFIT	DETAILS	LIMITATIONS
<i>Employment Standards Act</i> , s.52	Family Responsibility Leave	5 days unpaid leave per year May take 1 day at a time	* Many workers are not covered by the Act * Narrow definition of family excludes some caregiving relationships
<i>Employment Standards Act</i> , s.52.1	Compassionate Care Leave	8 weeks unpaid leave per year to care for a family member with a serious medical condition if a significant risk of death within 26 weeks	* Many types of workers are not covered by the Act * Limited to end-of-life caregiving
<i>Employment Insurance Act</i>	Compassionate Care Leave Benefits	6 weeks of income replacement benefits during the 26 week window of caregiving	* Must be eligible for EI * Excludes many work arrangements (self-employed individuals) * Benefit amount is tied to employment earnings
<i>Human Rights Code</i> s. 13(1)	Protection against discrimination in a term or condition of employment based on family status	An employer's unwillingness to allow an employee to change working arrangements in order to balance work and care may amount to discrimination. If so, an employer may be required to accommodate schedule or other changes.	* Strict legal test * Must frame employer rule as discrimination * Must file a complaint (cost, time, litigation) * Currently seems to apply only to extra-ordinary or unusual caregiving obligations
Federal <i>Income Tax Act</i> , s.118(1)(c.1) & BC <i>Income Tax Act</i> , s. 4.3(d)	Caregiver Tax Credit (In-home Care of a Relative Credit)	May deduct \$627 (federal credit) plus \$209 (provincial credit) from income tax payable (amount changes over the years)	* Care recipient must reside with caregiver but in a separate suite * Excludes care of friends * Value of credit is low * Non-refundable, regressive measure * Eligibility is tied to financial dependency not caregiving labour
<i>Canada Pension Plan</i> , s.48(2)	Child Rearing Provision	May exclude time spent out of the paid workforce caring for children (under 7 years of age) from the time used to determine pension entitlement	* There is no parallel provision with respect to caregiving for adults * A drop-out provision is not helpful to caregivers whose reduced income is not temporary

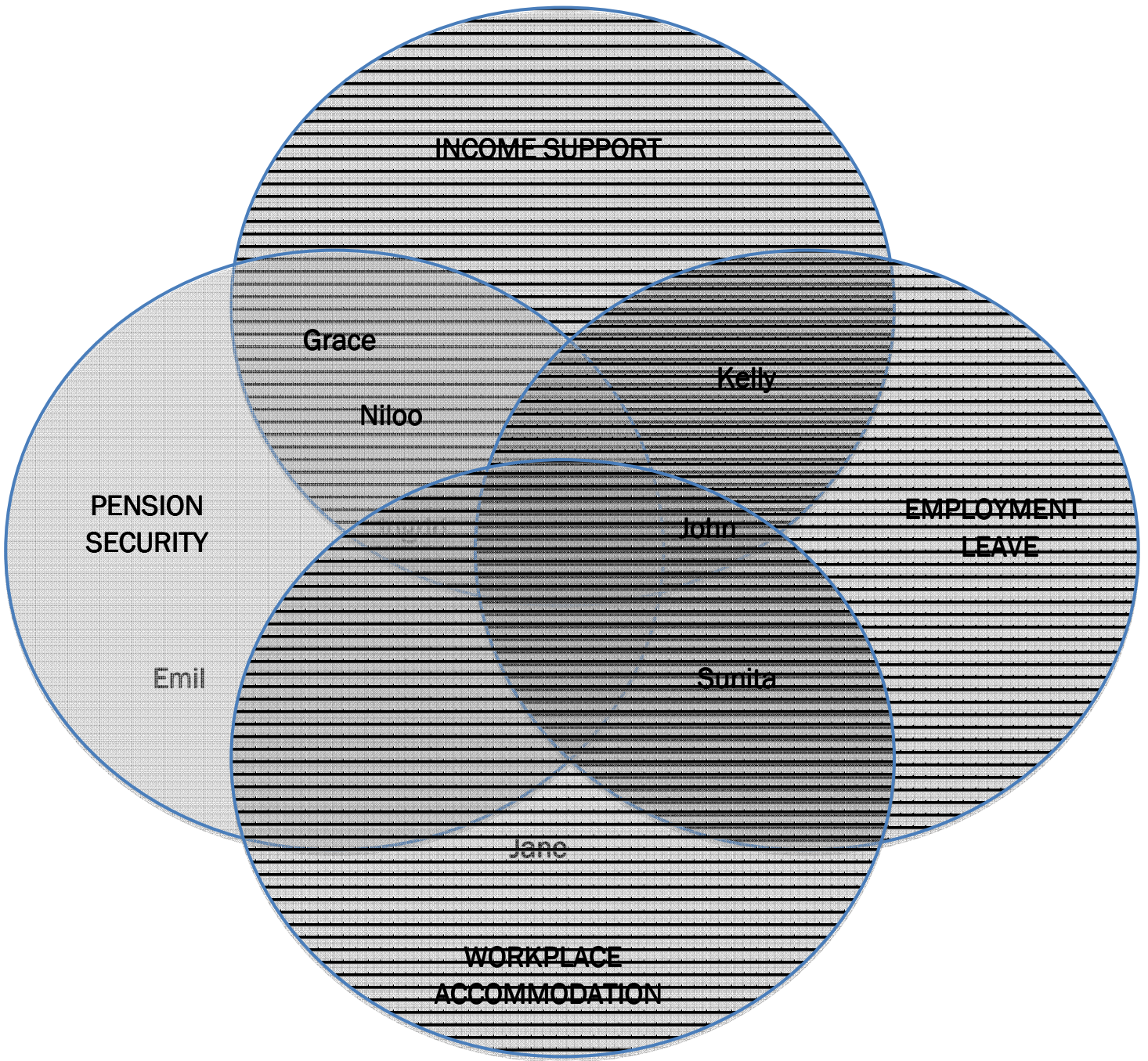
### III. Recap: Summary of our “Fictitious” Caregivers

How do our eight caregivers fare under the current regime? First, to refresh your memory, the following table summarizes the varied circumstances of the caregivers introduced in this paper.

<b>CAREGIVER</b>	<b>CAREGIVING RELATIONSHIP</b>	<b>EMPLOYMENT CIRCUMSTANCES</b>
Grace	Divorced woman caring for both school-aged children and aging mother. Long-term caregiving required for her mother.	Works part-time due to caregiving responsibilities. Short-term work history: out of the paid work force until her divorce.
Sunita	Caring for her father-in-law following a stroke. Likely long-term care.	Unionized employee working a full-time rotation that includes nights. Requires schedule changes to maintain caregiving (e.g. no night).
Kelly	Assisted her sister until her cancer was in remission. Short-term care (8 months). Could become her sister’s caregiver again if she goes through another period of treatment	Precarious employment. She is a non-unionized teacher without employment benefits and an artist. Must negotiate her course load every school term. Income is an erratic combination of employment and grant income.
Jane	Caregiver of an aging mother with a mental illness. Care needs are fluctuating, episodic and unpredictable.	Earns significant salary as a lawyer. Work culture expects significant hours – 60 hours/week – which is incompatible with care needs when her mother is particularly ill.
Ingrid	Single, low-income parent of an adult child with a disability. Long-term caregiving needs.	Income is a mix of welfare and occasional part-time work in child care and housecleaning.
John	Primary caregiver and parent of young children and an adult child with disabilities. Long-term care needs uncertain. Short-term care needs demanding.	Family requires his income. Non-unionized employee without job security. Requires short-term leave and long-term accommodation.

Niloo	Life-long caregiver of a close friend with a physical disability. Long-term and increasing care needs.	“Chosen” low-income and reduced standard of living in order to make caregiving possible. No retirement savings.
Emil	Sole caregiver of his wife, who has a degenerative condition. Is himself close to retirement age.	Self-employed with little prospect of continuing employment due to his wife’s caregiving needs. Financially unprepared for early retirement.

As the following diagram illustrates, given the current legal framework, each caregiver presents a unique mix of unmet needs:





## **IV. Impact of Current Laws on our Caregivers**

### **A. Leave**

Kelly, John and Sunita would benefit from access to paid leave. However, only Kelly will have access to paid leave under the *Employment Insurance Act*, and the nature of EI is such that Kelly's employment circumstances trigger entitlement to minimal benefits.

Although the Canadian Compassionate Care leave program characterizes Canada as an international leader in palliative and end-of-life family caregiving, provincial and federal employment standards and employment insurance legislation provide no recognition of economic consequences of other ongoing and short-term caregiving on the worker. In BC, family responsibility leave, allowing workers to take up to five days off work per year, falls far short of the reality of the demands imposed by most caregiving relationships.

### **B. Workplace Accommodation**

Jane, Sunita, John and Ingrid require accommodation of their caregiving obligations by their employer (potential employer in the case of Ingrid) in order to effectively balance work and care. Each of them foresees long-term caregiving needs on the part of the family member for whom they provide care. As a result of this challenge, Ingrid is only periodically employed. Jane, Sunita and John must negotiate alternative working arrangements and may have to find alternative employment if their employers are not supportive. No law exists to require an employer to consider flexible working arrangements. These workers would have to pursue their right to accommodation via a human rights argument, if their employers are not supportive. Given the state of the law it is not clear that any of them would be successful.

### **C. Income Support**

The financial consequences of caregiving are significant for most of our eight caregivers. This is particularly the case for: Grace, who must support and care for school-aged children and her mother simultaneously; Ingrid, who has been unable to secure ongoing employment given her child's significant care needs and as a result has largely relied on welfare as a means of support; and Farnaz, who has chosen to reduce her hours and work in a flexible, low-paying position in order to free up her time to provide ongoing support to her friend.

Tax incentives are most accessible to our least needy caregiver, Jane, due to her elevated income, and indirectly to John, who is the lower income-earner of a spousal partnership, via his partner. Due to non-refundability, tax measures are effectively unavailable to Ingrid, whose income is so low that she does not pay taxes, and to Farnaz, who does not live with Niloo, the care recipient, and also because Niloo earns a reasonable income and is not financially dependent on Farnaz. Grace's tax payable may also be too low, and to access the credit she would be required to build a separate self-contained suite in which her mother would reside. Only Farnaz, as a non-biological family member, may have some success accessing the funds indirectly: if Niloo were able to access self-managed care funds through the Ministry of Health, Niloo may be able to use these funds to hire Farnaz as a caregiver.

However, in BC no provincial or federal program provides caregivers allowance in recognition of the social value of their unpaid labour.

#### **D. Pension Security**

Grace, Ingrid and Farnaz face the prospect of poverty in their old age. Given Ingrid's patchy work history, she will likely be completely reliant on publicly funded old age security, thereby surviving on little more than provincial welfare levels during her retirement years. Farnaz and Grace will receive very little by way of Canada Pension Plan benefits due to poor contributions caused by reductions in wage and hours of employment. The child-rearing drop out provision – the only pensions measure that addresses caregiving labour – is inadequate to address their circumstances as their caregiving encompasses more than the first seven years of a child's life. Emil will commence an unplanned early retirement at a substantially reduced standard of living due to the unexpected nature of his early retirement. There is no income-replacement program in Canada that recognizes the value of his care for his wife at a time when he had anticipated that he would be working and saving up for late life.

#### **V. Options for Reform**

Based on the above analysis, we put forward the following options for reform for consideration:

##### **1. Employment Leave**

The current compassionate care leave benefits could be expanded to include more than end-of-life and palliative care, and the duration of benefits could be lengthened such that part of the leave would trigger income replacement benefits. The following framework illustrates one approach to this problem:

- Amend the requirements for eligibility to compassionate care leave under the *Employment Standards Act* to include circumstances where a family member requires time off work to care for a family member who suffers from a serious illness or other serious health condition, regardless of the likelihood of death.
- Similarly amend the requirements for eligibility to compassionate care leave benefits under the *Employment Insurance Act*.
- Extend the duration of compassionate care leave under the *Employment Standards Act* to one year, in order to parallel the duration of leave available in the case of the birth of a child, subject to a requirement to periodically confirm the ongoing serious nature of the condition, for example, every three months.
- Extend the period of entitlement to benefits under the compassionate care leave program to up to 15 weeks under the *Employment Insurance Act*.

## **2. Workplace Accommodation of Family Responsibilities**

Consistent with recent amendments to employment legislation in the U.K. and New Zealand, the BC *Employment Standards Act* could be amended to create a right to request variations in the location and hours of work, including changes to part-time status, where an employee requires these changes in order to manage family caregiving obligations.

We also encourage consideration of amending the *Human Rights Code* by inserting a definition of family status. This definition could characterize family status as including the care of family members including children of any age, parents, persons related by biology, adoption, marriage or common law partnership, and anyone else a claimant considers to be like a close relation. The purpose of such an amendment would be to clarify that family caregiving responsibilities discrimination may arise as a result of the impact of family responsibilities on an individual's ability to meet terms and conditions of employment, and to define caregiving to include a diversity of caregiving relationships. This amendment would also reconcile the *Human Rights Code* with the expansive definitions of family member contained in the BC *Employment Standards Act* and the federal *Employment Insurance Act*.

## **3. Caregiver Tax Credit**

In order to create a tax credit that is accessible to low-income people and properly targets individuals who provide caregiving labour, we encourage the federal government to create a refundable tax credit that references the provision of caregiving labour as an eligibility criterion. Consideration should also be given to the value of the credit, currently very low in relation to the social and economic worth of caregiving labour, especially if this credit is to continue to be viewed as a measure, let alone the primary measure, to recognize the value of caregiving labour.

## **4. Direct Income Support**

We encourage the provincial and federal government to explore income replacement for low-income family caregivers either through the creation of a caregiver allowance payable both into the typical years of retirement and during the years of the life course when a caregiving maintains paid employment. As is the case with the tax credit, the determination of the amount of this allowance requires further study.

## **5. Pension Security**

In recognition of the impact of family caregiving on pension security we propose consideration of amending the *Canada Pension Plan Act* to include a drop-out provision parallel to the Child-Rearing Provision that would be applicable to all years of full-time family caregiving. In addition we encourage the federal government to commit to toping-up the contributions made on behalf of family caregivers where reduced hours of employment would otherwise result in a reduction in contributions and consequent pension entitlement. Under this latter proposal unpaid family caregivers would be treated like government employees with respect to the accumulation of public pension benefits.

## **6. Valorization of Caregiving Labour**

A number of the reforms described above – the Caregiver Tax Credit, direct income support for caregivers, government pension contributions payable on behalf of unpaid caregivers – require further consideration of the value attached to caregiving labour. The question of what dollar amount to attach to each of these reform options is a complex question requiring further study.

## **VI. Final Words: Law Reform to Support Family Caregiving**

The above reforms would have a significant impact on our caregivers. Employment leave would become available to Sunita and John. It would become easier for Sunita, John and Jane to access workplace accommodation of their family responsibilities. Ingrid would be in a better position to negotiate work flexibility with a new employer. Ingrid, John, Grace, Kelly and Niloo would likely have access to a tax credit. Niloo, Ingrid and Emil could apply for a caregiver allowance to supplement or replace employment income. Jane, Kelly and Sunita could make use of a drop-out provision to reduce the impact of caregiving intensive years on their public pension income. Ingrid, Niloo and Emil could supplement their otherwise very minimal retirement income with a caregiver allowance.

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 in order for caregivers to balance work and care in a healthy and sustainable manner, and to mitigate against the financial consequences of caregiving for the individual and her family.

This paper works forward from the proposition that, given recent social and demographic changes, it is timely to consider law reform measures that will support family caregivers to balance work and caregiving responsibilities and provide greater recognition of the social value of unpaid family caregiving labour. The question of how the costs of our aging population should be distributed between and amongst family, community, employers and the state raises complex public policy issues based in understandings of paid and unpaid work.

Historically family responsibilities accommodation has been constructed as a private issue to be addressed by individuals within the family sphere. However, this approach may no longer be tenable, if it ever was. Combined with an increasing life expectancy and a declining birth rate, the evolution in the characteristics of Canadian families over the last century, including the division of domestic labour, and the more recent impact of technological change on health care delivery and workplace structure, may require us to consider a paradigm shift in our thinking about the value of family caregiving and the role of legislation in supporting caregiving labour.

Problem solving in relation to family caregiving requires much more than law reform: while the law and policy inform our values, they form only a piece of the social and moral infrastructure that informs practices in relation to caregiver support. Still, the growing role

and impact of family caregiving makes this a pressing area for law reform. We invite you to consider the problems and solutions discussed in this paper and use this report as a springboard for further study.

The topic of caregiver support is vast, encompassing a number of complex areas of law, and so to some degree, although this report is lengthy, it remains but an early step in the law reform process. Greater research and analysis will be required to explore how to put the content of this study's conclusions into practice. *Care/Work* should provide a foundation of research to direct this next phase in the process and indicate other areas where amendments to legislation should be developed without delay.