

John and his partner have three adopted children. Their eldest son has been subject to many different diagnoses over the years as health professionals attempted to characterize the source of his behavioural problems and developmental delays. He is unable to read and write, and he has been expelled from many schools over the years. At the age of 20 their son has been diagnosed with schizophrenia, and he appears to be unable to take care of himself. John's partner has steady employment that involves a great deal of overnight travel, and so John is the primary caregiver for the boys. However, he must work outside the home as well in order to meet the family's financial needs. The couple is concerned about leaving their son either home alone, or with the younger children. John would like to take four to six months leave from work to help his son to develop a routine to manage his illness. John is a non-unionized employee. He does not appear to be eligible for Compassionate Care Leave or benefits. His employer has denied his request for an unpaid leave, and John is afraid of losing his job.

CHAPTER 6 – Direct Payments to Caregivers

I. Income Support for Family Caregivers

In this brief chapter we summarize international innovations in caregiver compensation. A number of countries compensate family caregivers directly for their labour. This is an approach that has never been explored in British Columbia and has been investigated extremely rarely in other parts of Canada. This chapter of *Care/Work* briefly outlines various legislative regimes in other countries that provide caregivers with a right to direct financial compensation. The purpose of this chapter is to present alternatives to the existing Canadian approach of responding to the dependency of adult family members through income tax policy that was reviewed in Chapter 5.

In some Canadian jurisdictions, family care recipients may be able to access financial benefits to pay for caregiving through the provincial Ministry of Health and transfer these funds to family caregivers. In this chapter Ministry of Health policies permitting payments to care-recipients will be reviewed briefly, largely to illustrate that they are ineffective vehicles for caregiver support, and again to place caregiver compensation within the larger framework of public policy in the area of family caregiving.

Each province and territory administers a general social assistance program through which unemployed low-income family caregivers, like all provincial residents meeting income assistance eligibility requirements, would have access to minimal welfare benefits. As a social

welfare state, Canada also requires the provinces and territories to maintain an income assistance benefits program.²⁸⁸ This is the closest thing to direct payments to caregivers that exists in Canada. However, this chapter will not evaluate the BC welfare system as a current source of support for caregivers: the efficacy of this infrastructure is an enormous project beyond the limited scope of this study.

We do note, however, that the social assistance regime replicates the lack of value attached to unpaid caregiving embedded within most legislative regimes in BC, for social assistance recipients must have a recent employment history and be actively in pursuit of “work” in order to be eligible for income assistance.²⁸⁹ Adult family caregiving is not considered work. We mention the welfare system strictly to dispel the impression that the absence of a caregiver support program leaves caregivers without any alternatives to zero income, and also to situate caregiver compensation within broader social policy in Canada. Social assistance payments to which caregivers have access in Europe and Australia are mentioned in this chapter only where they target caregivers specifically.

Direct compensation programs must be understood in the context of caregiver social policy more broadly. To this end Appendix C of to this paper provides country profiles for each of the countries mentioned in this chapter.

II. British Columbia Programs for Self-managed Care

British Columbia does not have a program designed to deliver payments to family caregivers in recognition of their labour. What exists in BC, like most Canadian provinces, is a self-managed care program according to which eligible individuals can receive funds directly from the Ministry of Health in order to purchase their own home support services.²⁹⁰ This is as an alternative to an agency or health care professional conducting an assessment to determine what care needs are required and funding service agencies to deliver this care.²⁹¹ Under the terms of these programs funds are provided to a care recipient, characterized as a consumer, and in some jurisdictions the funds may be used to pay for the services of a family caregiver.

The BC self-managed care program is called Choice in Supports for Independent Living (CSIL).²⁹² Under this program, which has been in existence for more than twenty years,²⁹³

²⁸⁸ The Canada Health and Social Transfer is a block of funding the federal government provides to the provinces to subsidize spending in the areas of health care, post-secondary education, early childhood development, social assistance and social services. Discretion in spending has resulted in differing access to services between provinces. See Department of Finance, Canada Health and Social Transfer, online: <http://www.fin.gc.ca/transfers/transfers_chst-eng.asp>.

²⁸⁹ *Employment and Income Assistance Act*, R.S.B.C. 2002, c.40, s.8 -10, s.13. Some individuals are excluded from the requirements in relation to recent employment history and the ongoing requirement to be seeking work under the regulation: Employment and Income Assistance Regulation, B.C. Reg 263/2002.

²⁹⁰ Karen Spalding, Jillian R. Watkins & A. Paul Williams, *Self-Managed Care Programs in Canada: A Report to Health Canada*, Report to the Home and Continuing Care Unit of the Health Care Policy Directorate (Ottawa: Health Canada, 2006) at 4 and 5 [Spalding, Watkins & Williams].

²⁹¹ *Ibid.* at 9.

²⁹² Ministry of Health, “Community Care Services”, online: <<http://www.health.gov.bc.ca/hcc/csil.html>>.

²⁹³ Spalding, Watkins & Williams, *supra* note 290 at 14.

consumers essentially become an employer of a caregiver, and assume responsibility for hiring, training and administering payroll.²⁹⁴ The CSIL program is administered by regional health authorities, and each authority determines the amount of funds available to a consumer to pay for care. A second option in BC is for a person requiring care to assemble a group of at least five individuals to form a non-profit society called a Microboard and access funding through the Ministry of Health and other branches of government.²⁹⁵ Receiving funds through a Microboard thus requires the group to assume all the legal responsibilities associated with running a non-profit society.

A report completed for Health Canada in 2006 indicated that few self managed care programs permit consumers to use funds to compensate family caregivers for their labour, concluding that only Vela Microboards allow general freedom, by virtue of allowing the society's board to choose the care provider, and identifying only three provincial programs that allow payments to family caregivers in exceptional circumstances: BC, Manitoba and Nova Scotia.²⁹⁶

Current BC Ministry of Health policy with respect to payments to family caregivers is that “[a] family member, except an immediate family member, may be paid to provide care for a CSIL or family care home client.”²⁹⁷ The immediate family member restriction is defined to exclude parents, children and spouses from receiving government funds. This policy took effect in 2007 subsequent to a review of the CSIL program that took place after the greater restriction on hiring family members was found to be discriminatory by the BC Human Rights Tribunal.²⁹⁸ According to the policy, an exception may be made to hire a family member in the following limited circumstances:

1. the client or client support group wishes to pay an immediate family member to provide assessed services that the health authority would otherwise provide either through CSIL or a family care home.
2. the health authority has determined there is no appropriate and available caregiver to provide for any extraordinary or unique needs of the client for one or more of the following reasons:
 - nature and degree of care required.
 - rural or remote location.
 - cultural barriers.
 - communication barriers.
3. the family circumstances of the client have been considered.
4. the client's care plan includes appropriate respite for the immediate family member.²⁹⁹

At the time of writing, the government of Nova Scotia has announced the creation of the only existing direct allowance for family caregivers in Canada. The Allowance to Aid Caregivers is a \$400 monthly benefit for eligible caregivers who perform 20 hours or more

²⁹⁴ Ministry of Health, *supra* note 292.

²⁹⁵ Spalding, Watkins & Williams, *supra* note 290 at 15.

²⁹⁶ *Ibid.*

²⁹⁷ Ministry of Health, *Home and Community Care Policy Manual*, Chapter 8, Section H [*Home and Community Care Policy Manual*].

²⁹⁸ *Hutchinson v. British Columbia (Ministry of Health)*, 2004 [B.C.H.R.T] No. 55, upheld by the Supreme Court of BC.

²⁹⁹ *Home and Community Care Policy Manual*, *supra* note 297.

of care per week.³⁰⁰ This is an income-tested benefit that will only be available to caregivers earning less than \$18,785 and the benefit is a form of taxable income.³⁰¹

III. International Innovations in Direct Compensation of Family Caregivers

Direct compensation programs are a common aspect of caregiving policy in a number of countries we reviewed. Australia, the United Kingdom, France, Germany, the Netherlands, Sweden and Norway all maintain some kind of program that can be accessed by family caregivers. The programs vary significantly in terms of the monetary value of the payment, the eligibility requirement for benefits, and the framework within which they are situated. Some programs are framed as social assistance and income security measures; others are aspects of health and home care policy – the latter is usually the case with payments to care recipients for caregiving services which may be used to fund informal family care or professional assistance.

A. Care Allowances

Direct financial support has been a component of the U.K. government's National Carers' Strategy, for over a decade.³⁰² The U.K. supports its family caregivers directly through its social security program and has not created a caregiver specific tax incentive. Like the Australian system discussed below, the caregiver support program and the disability assistance system are interwoven in terms of eligibility criteria. The U.K. Carer's Allowance³⁰³ is a payment to caregivers of individuals who qualify for state-funded benefits designated for people with disabilities.³⁰⁴ The caregiver must provide at least 35 hours per week of care and earn no more than £95.00 per week from paid work.³⁰⁵ In this sense the benefit targets low income caregivers who are essentially working full-time as unpaid caregivers as an alternative to paid employment. The benefit is valued at £53.10 per week;³⁰⁶ however, a low-income caregiver may be entitled to an additional Carer Premium.³⁰⁷ The

³⁰⁰ Department of Health, Government of Nova Scotia, "Caregiver Allowance", online: <http://www.gov.ns.ca/health/ccs/caregiver_allowance.asp>.

³⁰¹ *Ibid.*

³⁰² U.K. Government, Department of Health, National Carers' Strategy, *Carer's at the heart of 21st –century families and communities: 'A caring system on your side. A life of your own'* (2008), Summary, online: <http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345> [2008 Strategy].

³⁰³ The benefit was referred to as the "Invalid Care Allowance" in the *Social Security Contributions & Benefits Act 1992 (U.K.)*, which created the benefit. However, the title of the benefit was changed to 'Carer's Allowance as per *Regulatory Reform (Carer's Allowance)*, S.I. 2002/1457. Office of Public Sector Information, *Regulatory Reform (Carer's Allowance)*, S.I. 2002/1457, online: <<http://www.opsi.gov.uk/si/si2002/20021457.htm>>.

³⁰⁴ *Regulatory Reform (Carer's Allowance)*, *ibid.*

³⁰⁵ *Social Security Contributions & Benefits Act 1992 (U.K.)*, c. 4 and *Social Security Benefits Up-rating Order 2008*, S.I. 2008/632, Sch. 1 Part III.

³⁰⁶ This is equivalent to the cost of purchasing one week of groceries in London for a family of three: Andreas Hofert, Daniel Kalt & Christian Hilberath, *Prices and Earnings: A Comparison of Purchasing Power around the Globe*, 9th ed. (Vancouver: UBS Wealth Management Research, 2009) online <<http://www.ubs.com/research>> [*Prices and Earnings*]. See Appendix D for more information on the comparative methodology used in this report.

³⁰⁷ *Social Security Contributions & Benefits Act 1992 (U.K.)*, c. 4, s. 124 and *Income Support (General Regulations) 1987*, S.I. 1987/1967, Sch. 2, Part III, 14ZA.

state also funds respite for the caregiver, initially through the *Community Care (Direct Payments) Act 1996*. This program has included eldercare since 2000 and the care of disabled children since 2001.³⁰⁸

Australian caregiver policy constitutes one of the most longstanding and comprehensive responses to the challenge of caregiver support. Its payment program recognizes both low-income and higher-income caregivers through separate initiatives. The Carer Pension, renamed the Carer Payment in 1997, provides a bi-weekly benefit to caregivers.³⁰⁹ As with the U.K. allowance, caregivers must be full-time caregivers prevented from engaging in full-time employment as a result of the demands of care. The Carer Payment is a means-tested benefit that targets low-income caregivers. It provides AUD \$569.80 to single caregivers³¹⁰ and AUD \$475.90 to each spouse³¹¹ of a couple engaged in constant caregiving. Caregivers performing up to 20 hours per week of care are eligible for the Carer Allowance, a bi-weekly payment of AUD \$105.10.³¹² The Carer Allowance is not a means-tested benefit. Recipients of the Carer Payment or the Carer Allowance are entitled to an annual Carer Supplement of AUD \$600; more financially needy caregivers, who are receiving both benefits, are entitled to a payment of AUD \$1,200.³¹³

Australian payments to carers, delivering approximately AUD \$1,450 in monthly support plus an annual bonus to the most financially needy caregivers, provide significant compensation to caregivers compared with most of the countries we reviewed. Assuming a family size of three, the payments would cover the costs of rent, groceries and transportation.

In contrast, in the U.S., there exist extremely modest direct payment programs in the states of Maryland and Virginia. Both grant caregivers \$500 annually.³¹⁴

³⁰⁸ *Health and Social Care Act 2001*. See U.K., Directgov, “Direct Payments for Carers”, online: <http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG_10018517> and *Explanatory Notes: Health and Social Care Act 2008 (U.K.)*, c.14 at 57 & 60, online: <http://www.opsi.gov.uk/acts/acts2008/en/ukpgaen_20080014_en_1>.

³⁰⁹ *Social Security Act 1991 (Cth.)*, s. 197. See also Centrelink, *Guide to Australian Government Payments Booklet*, “Carer Payment”, online: <<http://www.centrelink.gov.au/internet/internet.nsf/publications/co029.htm>> [Carer Payment].

³¹⁰ This is equivalent to the cost of purchasing six weeks groceries in Sydney for a family of three.

³¹¹ This is equivalent to the cost of purchasing one month of groceries for a family of three plus three train tickets in Sydney (1 journey of 200 km).

³¹² *Social Security Act 1991*, No. 46, 1991 at s. 952 (Volume 2), online: <<http://www.comlaw.gov.au/comlaw/Legislation/ActCompilation1.nsf/0/D4FCFC450AB7DB74CA25760B0001DDB9?OpenDocument>>. See Centrelink, “Carer Allowance”, online: <http://www.centrelink.gov.au/internet/internet.nsf/payments/carer_allow_adult.htm> [Carer Allowance].

This benefit’s value is equivalent to the cost of purchasing one month of groceries for a family of three in Sydney or two, three course restaurant meals.

³¹³ Centrelink, “Carer Supplement”, online: <http://www.centrelink.gov.au/internet/internet.nsf/individuals/ssp_carer.htm#>. The dollar amount is equivalent to the cost of one month’s rent for a family of three in Sydney.

³¹⁴ Md. Ann Code art. HU, §10-701 et seq.; Va. Code Ann. §63.2-2201 et seq.

B. Family Caregiver Wage

In Northern European social democracies the approach is to provide the family caregiver with a payment that more approximates the wage provided to paid caregivers; however, the eligibility criteria limit access to the benefit to a subset of caregivers. In Norway, the Care Wage is a taxable wage available to caregivers who are providing extraordinarily burdensome care to severely disabled persons.³¹⁵ The amount of the wage is based on care needs but the average pay is kr. 4600/month.³¹⁶ However, this salary would purchase one month's groceries plus seven train tickets in Oslo but is not adequate to cover the cost of rent in Norway.³¹⁷

The Swedish *Care for the Elderly* law, entitles caregivers to an allowance and social security protection comparable to what exists for care personnel in the formal caregiving sector.³¹⁸ The municipality reimburses the caregiver of an elderly dependent with a salary equal to that of municipal formal home care worker. This salary is subject to income taxes. In addition, the Attendance Allowance is an untaxed cash payment to a care recipient to compensate a family caregiver.³¹⁹ Eligibility is usually based on level of dependence/amount of caregiving (calculated care hrs/week) and payment is around kr. 5000/month (~550 Euro).³²⁰ Each municipality has authority over the Attendance Allowance and whether and how it is offered is within their discretion – there is no federal or state regulation – and availability, payments, eligibility criteria, and maximum payment vary by municipality.

Based on our research, although all the sources we reviewed described the northern European approach as providing family caregivers with a wage comparable to that of a paid formal home care worker, the actual value of the wage translated into purchasing power suggests that this approach may be problematic. Home care may be an extremely low-paying occupation, delivering a salary inadequate to cover housing costs in an urban centre. Translated into purchasing power the Australian payment system may be more generous. In any event our findings in this area are very preliminary. They caution us that the language of a wage versus a social assistance payment that appears in international caregiving literature may be misleading, and remind us that the amount of a benefit provided to caregivers must be determined taking into consideration both the goal of the benefit and the actual cost of living in the province, which varies across BC.

C. Transferable Payments to Care-Recipients

Germany and the Netherlands have put in place care recipient benefit programs that acknowledge the role of family caregiving in health policy by permitting recipients to use the

³¹⁵ Janice Keefe, *Policy Profile for Compensating Family Caregivers: Norway* (Halifax: Maritime Centre for Aging Research & Policy Analysis, 2004) [Keefe, PP Norway].

³¹⁶ *Ibid.*

³¹⁷ *Prices and Earnings*, *supra* note 306.

³¹⁸ *Care for the Elderly 1990*, cited in Interministry Committee on Compensation for Family Caregivers, *Public Funds, Family Commitment: A review of Government policy concerning public compensation to family caregivers in British Columbia* (2002) [ICCFC].

³¹⁹ *Care Leave Act (1989)*, cited in National Alliance For Caregiving - A National Resource on Caregiving, online: <www.caregiving.org/intcaregiving/sweden/sweden1.htm>

³²⁰ This is 75% of the cost of rent for a family of three in Stockholm or 6 weeks of groceries.

benefits to compensate family caregivers. In 1995, Germany adopted a compulsory Long Term Care Insurance (LCTI) scheme, which provides long-term care allowance benefits to persons who are “frail”, as defined in the Social Security Code “as a person who requires for a minimum period of approximately six months, permanent, frequent or help in performing a special number of ‘Activities of Daily Life’ and ‘Instrumental Activities of Daily Life’ due to physical, mental or psychological illness or disability”.³²¹ LCTI pays monthly care allowances. There are 3 levels and kinds of care (family care, professional homecare, informal care).³²² Individuals who choose informal care receive a cash allowance; otherwise the allowance is paid by the care insurer directly to the professional care provider. Caregivers can register as employees under the employment category “Informal Caregiver”. Registration through the LCTI entitles the caregiver to an allowance, respite coverage, and statutory pension contributions (see below for details). Family caregivers who have provided home care for at least one year are entitled under the LCTI to 4 weeks paid respite.³²³

The Home Care/Domiciliary Care Benefit is a monthly payment to care-receivers that may be transferred to family caregivers. The value of the benefit is:

- Level 1 - € 205 – 90 min. average care every day (1/2 must be basic care)³²⁴
- Level 2 - € 410 – 3 hrs. average care every day (2 hrs. must be basic care)
- Level 3 - € 665 – 5 hrs. average care every day (4 hrs. must be basic care)³²⁵

In the Netherlands, the *Exceptional Medical Expenses Act (AWBZ)* provides persons who are entitled to care under the Act, with the option of a personal care budget, which allows the care recipient the freedom to choose how, when and from whom they obtain care (such as an individual care provider, including a caregiver of their choice (ex. care organization, family member)).³²⁶ A professionally developed care plan is created with set hours, and the care recipient is paid based on the prescribed hours at standard nationally set rate.

In France, the *Personalized Allowance of Autonomy (Allocation personnalisée d'autonomie)* (APA) is a payment for caregivers of eligible adults over age 60.³²⁷ The *Prestation de compensation du handicap* (PCH) is a payment to care-recipients that may be used to compensate caregivers.³²⁸

³²¹ Institute for the Study of Labor, “The German Social Long-Term Care Insurance: Structure and Reform Options”, IZA DP No. 2625 (Germany: February 2007) at 2-5.

³²² Melanie Arntz, Ralf Sacchetto, Alexander Spermann, Susanne Steffes & Sarah Widmaier, *The German Social Long-Term Care Insurance: Structure and Reform Options* (March 2007) IZA Discussion Paper No. 2625, online: <<http://ssrn.com/abstract=944780>> at 6 & 9 [Arntz et al].

³²³ Netherlands Ministry of Health, Wellbeing and Sports, “Summary and Overview of Care Allowances in Seven Countries” (Survey, 1 May 2007), online: <<http://www.minvws.nl/en/reports/lz/2007/summary-and-overview-of-care-allowances-in-seven-countries.asp>>.

³²⁴ This is equivalent to the cost of three weeks of groceries in Munich.

³²⁵ Arntz et al, *supra* note 322. One month’s rent for a family of three in Munich is approximately € 880.

³²⁶ Netherlands Ministry of Health, Welfare and Sport, Host Country Report, “Long-term care in the Netherlands - The Exceptional Medical Expenses Act”, online: <<http://www.minvws.nl/en/folders/lz/2009/host-country-report.asp>>.

³²⁷ France, Code de l’action sociale et des familles, *Article L232-1, Allocation personnalisée d’autonomie*, Légifrance, online: <http://www.legifrance.gouv.fr/affichCode.do?sessionid=358FF38B378E5ECD5C6ACA4E72A7467B.tpdjo16v_1?pidSectionTA=LEGISCTA000006174428&cidTexte=LEGITEXT000006074069&dateTexte=20090820>.

IV. Conclusion

The most direct method of providing financial assistance to volunteer family caregivers or recognizing the value of caregiving labour is for the state to make payments to caregivers. In Canada only the province of Nova Scotia currently follows this approach by providing eligible caregivers with a \$400 monthly benefit.

An international review reveals very divergent approaches, ranging from the US states of Maryland and Virginia, which have created a \$500 annual caregiver allowance, to Australia, which provided significant social assistance payments to caregivers, to Norway and Sweden, which provide caregivers delivering significant care with a wage equivalent to the salary of a paid caregiver, as well as pensions benefits, the latter of which is discussed in the following chapter.

Payments to caregivers may be appropriate for those family caregivers whose circumstances cannot be addressed through leave and work flexibility options discussed in, respectively, Chapters 3 and 4 of this paper. However, the notion of direct government payments to caregivers raises a number of challenging questions:

- Considering the array of approaches described in this chapter, do any approaches fit the Canadian context in terms of prevailing community values and the existing government infrastructures available benefit administration?
- What is the appropriate approach for Canada to take, e.g., a living wage versus a nominal allowance?
- What is the appropriate method of administration and delivery?
- Is it appropriate to relegate volunteer unpaid family caregivers to relying on income assistance, given the benefits families, communities and the government gain from this pool of labour?
- Is a caregiver allowance an appropriate way to supplement the income of family caregivers compelled to reduce their employment to part-time work?

These problems and other dilemmas remain, many of which present difficult questions that may require further study as they involve consideration of notions of work, volunteerism and the role of the state in supporting families.

³²⁸ France, Code de l'action sociale et des familles, *Article L245-1 (2007), Prestation de compensation*, Légifrance, online: http://www.legifrance.gouv.fr/affichCode.do;jsessionid=2256F8F99C821606150D1E973A7EAB48.tpdjo16_v_1?idSectionTA=LEGISCTA000006157603&cidTexte=LEGITEXT000006074069&dateTexte=20090825. The PCH replaced the *Compensatory Allocation for Third Person Benefits (L'Allocation Compensatrice Tierce Personne)* (ACTP) in 2006. At the time recipients of the ATCP were able to choose whether to continue with the old ATCP benefits or switch to the new PCH compensation benefits.