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To Pay or Not to Pay: Examining Underlying Principles in the Debate on Financial Support for Family Caregivers*

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RÉSUMÉ

De nombreux pays offrent un soutien financier ou monétaire direct aux membres de la famille ou aux amis dispensateurs de soins familiaux. Les débats sur les avantages et les désavantages de cette politique abondent dans la documentation. D'après l'hypothèse voulant que les valeurs sous-tendent les politiques publiques, l'article examine quatre paradoxes politiques relevés dans la documentation et illustre, à l'aide de certains exemples provenant d'une analyse politique internationale, les objectifs et les valeurs sur lesquels repose l'élaboration de nombre des politiques. Il s'agit de la responsabilité des soins, des objectifs économiques ou sociaux, de l'équité de genre, et de l'autonomie des bénéficiaires de soins. Les auteurs mettent en garde les décideurs au sujet des effets pervers d'une politique de soutien financier et proposent des programmes et des services destinés à appuyer les dispensateurs de soins. La politique futur au Canada doit permettre des choix appropriés tout au long de la vie et faire en sorte que ni le dispensateur de soins, ni le bénéficiaire des soins, n'éprouveront de difficultés financières à court ou à long terme en raison de leur choix.

ABSTRACT

In many countries one approach to supporting family-and-friend caregivers is direct financial or monetary support. Debates about the benefits and consequences of such policies pervade the literature. Building on the premise that values underlie public policy, the paper examines four policy paradoxes in the literature and uses selected examples from an international policy analysis to illustrate the underlying objectives and values upon which many of the policies were developed. These include the responsibility to care, economic or social objectives, gender equity, and the autonomy of care receivers. The authors conclude that policy makers need to be cautious about the unintended effects of financial support policy and develop a menu of policies and services to support caregivers. Future policy development in Canada must enable legitimate choice across the life course and ensure that neither the caregiver nor the care receiver will experience short- or long-term financial consequences of his or her choice.

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Introduction

Values underlie public policy. The debate about how to best support family caregivers is not immune to fundamental questions about what values underlie public policy initiatives from Canada and other countries. Providing cash to caregivers has been more hotly debated in the policy research literature than policies such as tax credits and paid leave from work (Holstein & Mitze, 1998; Kunkel, Applebaun, & Nelson, 2003–2004; Osterbusch & Linsk, 1987). Paying families to provide care touches on key social values and elicits strong opinions. This paper analyzes international policies that financially support caregivers by examining their underlying values and objectives and the extent to which these policy objectives are transferable to the Canadian context.

Interest in developing appropriate caregiver policy is fuelled by increased demand for informal caregivers at the same time as concern about their decreased supply is raised. The demand for these caregivers results from factors related to population aging, including increased co-morbidity resulting in need for assistance, as well as policies emphasizing community care and acute care substitution, resulting in increased burden on family caregivers (Jenson, 2004). Concerns about decreased availability of informal caregivers emanate from women's increasing involvement in the labour market and, in the future, from the decreasing availability of surviving children to provide such care (Carrière, Keefe, Légaré, Lin, & Rowe, in press). In response, researchers and advocates have recognized a need for improved caregiver policy in Canada (Armstrong & Kits, 2001; Canadian Caregiver Coalition, 2005).

One suggested policy approach has been financial support for caregivers. Reviews of international policy approaches by Keefe and Fancey (1998) and Keefe (2004) indicate that other countries have taken a wide range of approaches to this kind of policy. Financial support policies can be classified into three broad categories. First, direct financial support policies provide monies in the form of wages, allowances, or vouchers and are paid directly to the caregiver or to the care receiver to pay the caregiver. Second, indirect financial support policies offer delayed monetary support and take the form of tax relief or pension security. Third, public labour policies provide employment leave and a proportion of employment earnings to eligible caregivers. This paper will focus on direct support policies, as this approach "brings the debates into sharper focus" (Kunkel et al., 2003–2004).

In Canada, there are currently no national direct financial support policies for caregivers, as we rely on

indirect and delayed financial support through taxation. There are currently five tax relief measures that can be claimed by caregivers at the federal level, although they provide only minimal amounts that are not accessible by many caregivers.¹ Canada also has recently introduced a labour policy, the Compassionate Care Benefit, which provides financial support in the form of six weeks paid leave to employed caregivers to provide palliative care or palliative care management.² Given the limited value and accessibility of these programs, they represent only a minor foray into providing financial support to caregivers and cannot be seen as a comprehensive caregiver support strategy.

Internationally, there has been considerable debate around financial support policies, particularly direct financial support (Holstein & Mitze, 1998; Keigher, 1991; Kunkel et al., 2003–2004; Ungerson, 1997). Questions abound. Is it appropriate for the state to provide financial support for caregivers? Is this approach the best mechanism for supporting caregivers? Is it in the best interest of care receivers? Are the primary objectives of such policy to support caregivers or to save costs? These are the fundamental questions that need to be discussed to inform debate in Canada. In so doing, we need to begin with the values that we espouse as a country and identification of our priorities. Consequently, this policy analysis focuses on an assessment of how policies reflect certain values. The practical issues of program evaluation – for example, how such a program would be administered, who should be eligible, and how abuse and unsustainable costs can be prevented (Blasser, 1998; Keigher, 1987, Osterbusch & Linsk, 1987; Simon-Rusinowitz, Mahoney, & Benjamin, 1998) – while important issues to consider, are beyond the scope of this research.

In Canada, there have been calls for new ways of thinking about public policy in general. Kenny (2004) suggests policy should be based not only on empirical evidence but also on an ethical framework, given that policy-making is laden with values. In our increasingly pluralistic population, we need to think carefully and make more transparent the values underlying policy, and who will be advantaged and who will be disadvantaged by policy decisions (Kenny). Evaluation of the appropriateness and transferability of international approaches for the Canadian context requires not only developing an understanding of the objectives underlying international policies and the Canadian appetite for public policy in this area, but also examining broader ethical and moral issues in different policy approaches.

Methodology

This paper will report analysis of financial support policies in terms of three values – family/state responsibility, gender equity, and autonomy of the care receiver – by referencing approaches from 6 countries. The research draws on an international review of policies to support family-and-friend caregivers in 10 countries. The policies were reviewed in 2004–2005 as part of a larger research endeavour to analyze financial support policies for family-and-friend caregivers. Countries included in the initial policy scan were Australia, Canada, France, Germany, Israel, the Netherlands, Norway, Sweden, the United Kingdom, and the United States. Descriptive information (target group, eligibility, entitlement) of direct, indirect, and labour policies at a national level in each country is available in individual country profiles (Keefe, 2004). Information and policy documents were collected using a multi-method approach. Policies were obtained using government Web pages. Detailed information of the policies and their analysis was collected through systematic peer-reviewed databases, Google scholar searches, and key informants in selected countries. For the purposes of this paper, highlights of policies from six countries – the United Kingdom, Australia, Germany, France, Norway, and the Netherlands – were chosen because analysis revealed common and divergent threads in their underlying values. (see figure 1)

Analytical Approach

Stone’s (2001) classic textbook, *Policy Paradox: The Art of Policy Decision-making*, admirably presents the

challenges to policy-making when the ideals on which policies are based conflict with the ways in which the policies are implemented. Such paradoxes result from attempts to address one problem without concern for the larger systems that influence our choices. A comparative social policy analysis approach is used to investigate the countries’ polices, specifically identifying evidence of underlying values related to inherent paradoxes in the delivery of policies to support family caregivers financially. These include the responsibility to care, economic or social objectives, gender equity, and the autonomy of the care receiver. These key ethical debates emanate from a comprehensive literature review, and this discussion is enhanced by the illustration of divergent values through the analysis of financial support policies from specific countries. Consequently, analyses are organized around the following questions: (a) Should the family or state be responsible for the care of older people? (b) Should economic or social values drive policy objectives? (c) Do financial support policies help or hinder gender equity? (d) Should the autonomy of the care receiver supersede the rights of the caregiver? (see figure 1)

Policy analysis cannot occur in a vacuum. Attention must be given to the unique political and historical context, as well as the structure of the population of each country. One example of pervasive context is the fact that both public and political institutional values play a vital role in policy; choices are not simply a matter of logic (Pestieau, 2003). Demographic, cultural, political, and economic factors affect the relationship between the state

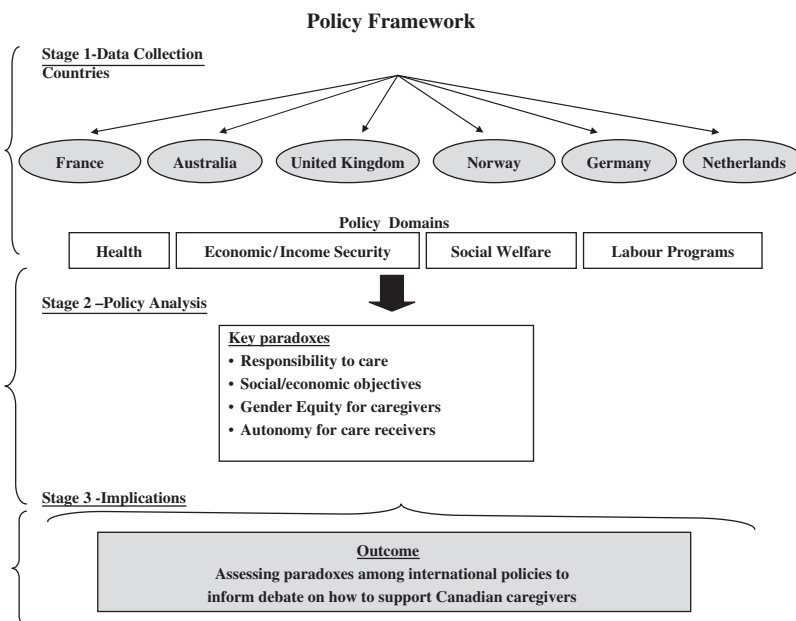


Figure 1: Policy framework

and the family and must be considered when conducting an international comparison of caregiver supports (Jegermalm, 2002). Table 1 provides an overview of the demographic and caregiver policies in each country and the types of policies that directly and financially support caregivers. Comparative social policy analysis contributes to policy discourse by framing issues and defining questions and thereby informs policy debates (Pestieau). The ultimate goal of this research is to inform Canadian policy debates on financial support for caregivers by assessing and learning from the approaches to this policy elsewhere.

This paper will contribute to the discussion by uncovering the values, objectives, and principles underlying financial support policies in other countries and informing international policy debates in an effort to address whether financial support policy may be appropriate for Canada's caregivers.

Debates Surrounding Family Obligation versus State Responsibility for Care

Each country has a social architecture – a set of values, beliefs, and principles – that informs decision-making and development of social policy on how responsibilities will be distributed among the four sectors of society that provide for individual well-being – the family, market, community, and state (Jenson, 2004; Pijl, 1994). While each country's social architecture is unique, reflecting diverse historical, economic, political, and cultural contexts that have shaped the underlying values of the society, there are trends and commonalities. As part of the debate on financial support policy for caregivers, countries must first decide who is responsible for providing care to dependent adults – family or the state – and, having determined who is responsible, whether or not financial support will be introduced for economic reasons (maintaining costs) or social reasons (valuing the care provided).

Some countries have taken a conservative approach to this issue, rooted in a longstanding belief that families, and particularly women within families, are the appropriate source of care for dependents and that families have a responsibility to provide this care (Evers, 1994). Conservatives argue that “from the very moment such allowances are understood by the people concerned as the establishment of new rights for support and relief, the conventional notion of family care as a private self-sustaining system comes into question” (Evers, 1994, p. 36). Those taking this approach have supported a minimal role for public and formal care services and offer little support for paying family members to provide care, as they

see caregiving as a natural extension of kinship responsibilities (Evers, 1994).

This conservative approach is embedded within an individualist perspective on public policy and rooted in cultural beliefs about family, care, and work. Kunkel and colleagues illustrate the concern in the United States that paying family caregivers might undermine social values, since there is “deep concern over tainting lines between the work we do for love and the work we do for money, between ‘care’ and ‘work’” (Kunkel et al., 2003–2004, p. 79). Introducing money into family relations is thought to be problematic. It is argued that as care provided by family caregivers is done out of love, providing payment for this care will alter the quality of the relationship between the caregiver and care receiver, and generally the nature of family relationships, leading to emotional distance. It is also argued that paying family caregivers would result in a major shift away from caring as part of normal family responsibility (Kunkel et al.). Others have gone so far as to argue that payment can lead to abuse of the care receiver (Blasser, 1998), although there is no evidence to support this connection.

Other voices support direct payment policy and argue that money does not necessarily taint love. Indeed, research on programs that provide economic aid to caregivers has indicated that it can change the caring relationships in positive ways. Adamek (1992) notes that in one qualitative study, caregivers and care receivers were positive about financial payment. For example, care receivers reported being happy to have a way to reciprocate for the care received. Similarly, in research on clients and caregivers of a Nova Scotian program that enabled caregivers to be paid, care receivers expressed their satisfaction at being able to reciprocate (Keefe & Fancey, 1997, 1998). Furthermore, Keigher and Murphy (1992) found that payment did not reduce the feelings of obligation for providing care. Rather, respondents reported that the payment allowed them to provide better care and reported an “intense sense of responsibility” (p. 264).

While countries that emphasize family obligation to care may be unlikely to implement financial support policies, there are also cases where financial support policies do exist and/or reinforce the belief that families have a responsibility to provide care. Germany's longstanding belief in *Subsidiaritätsprinzip* (“principle of subsidiarity”) means that families and communities are responsible for care. This value is rooted in Roman Catholic ethics and was ingrained in German social law more than 30 years ago (Schneider, 1999). Remnants of this belief can be seen within current long-term care policy in Germany, which is an

Table 1: An overview of six countries and their national direct financial support policies available to eligible care receivers (CR) and/or their caregivers (CR)

	Germany	France	Norway	United Kingdom	Netherlands	Australia
Population (2006) ¹	82.4 million	60.9 million	4.6 million	60.6 million	16.5 million	20.3 million
% 65 and Older (2006 est.) ¹	19.4%	16.4%	14.8%	15.8%	14.3%	13.1%
Economic GDP per Capita (thousands) (2005 est.) ¹	\$30.1	\$29.6	\$42.8	\$30.1	\$30.3	\$31.6
Caregiver Policy Context ²	<ul style="list-style-type: none"> - Long-term care insurance program since 1994 - Registration of caregivers 	<ul style="list-style-type: none"> - Caregiver strategy is part of a larger program for elderly/disabled - Concern about ability to sustain numbers of people accessing programs 	<ul style="list-style-type: none"> - Norway's Social Services Act (1991) outlined supports for caregivers such as respite services and caregiver wages - Municipalities administer programs 	<ul style="list-style-type: none"> - National legislation recognizing need to support family caregivers. - Certain countries provide caregivers right to assessment. 	<ul style="list-style-type: none"> - Universal long term care. - Personal budget & several leave options. - Significant policy change underway – "own responsibility." - Devolution to locales. - Cash payment to CR 	<ul style="list-style-type: none"> - Caregivers recognized as clients - National respite program. - \$461 M Carers Package announced.
Direct Financial Support Policies ²	<ul style="list-style-type: none"> - Long-term care insurance (LTCl) - Cash option of LTCl (CR) - Stand-in care/ respite under LTCl 	<ul style="list-style-type: none"> - Compensatory allocation for third person benefits (ACTP) (age <60) - Personalized allowance of autonomy (APA) (age 60+) 	<ul style="list-style-type: none"> - Attendance allowance given to care receivers who are disabled or ill - Care wage for caregivers of severely disabled persons 	<ul style="list-style-type: none"> - Carers Allowance; Carer Premium; payments from councils to purchase services (CG) 		<ul style="list-style-type: none"> - Carer payment: Cash payment to CG. - Carer Allowance: Cash supplement for low income working age carers.

¹From *World fact book*, retrieved November 30, 2006, from <https://www.cia.gov/cia/publications/factbook/index.html>

²From J. Keefe, *Policy profiles for compensating family caregivers: Australia, France, Germany, Netherlands, Norway, United Kingdom*, retrieved May 1, 2005 from <http://www.msvu.ca/mdcaging/policyprofiles.asp>

insurance-based program that offers the choice of cash or services to those in need of care. Those who choose the cash option in order to pay a caregiver, which can include family members, receive significantly less than the value of formal care services offered through the program (Evers, 1998). The state provides less cash to support family care arrangements, as there is felt to be an obligation for these people to provide care (Evers, 1994). This is also the case in the Netherlands, where those choosing a Personal Budget, which pays cash to arrange services, receive 25 per cent less than the value of regular care services (Kremer, 2004). What constitutes “normal informal care” (that families are obliged to provide and that should not be compensated) and “irregular, unusual informal care” (above and beyond what families can reasonably be expected to do and that should be compensated) is still debated (Kremer, p. 10).

The exclusion of particular family relationships from financial support policies reveals beliefs about family responsibility (Evers, 1994). For example, financial support may be available to informal caregivers but not be used to pay spouses or other close family members. Both of France’s direct support programs, the APA and ACTP (see Table 1), exclude spouses from compensation, suggesting a belief that spouses have a natural obligation to provide care (Jani-Le Bris, 2005). A direct payment program in British Columbia (BC) excludes close relatives, including spouses, parents, and children regardless of residence, and also excludes other relatives living in the same household as the care receiver (Ministry of Health Services, BC, 2002). However, recently the BC Supreme Court upheld a Human Rights Tribunal decision that the BC government discriminated in this policy in the case of a father caring for his severely disabled daughter (BC Supreme Court, 2005).

Other countries have taken a more collectivist approach to financial support policy. In these countries, family and state responsibility for care are rooted in social democratic values. Those operating from this approach commonly see caregiving as a shared social responsibility and operate under the belief that policy should reduce the burden on caregivers. These states have tended to focus on the extension of professional services as the best way to provide care and reduce burden on family caregivers, and for women in particular. Financial support programs have played a limited role, as they can be seen as off-loading state responsibility onto families (Evers, 1994). This has commonly been the case in countries with a strong welfare state such as Norway. A recent “Action Plan for the Elderly” does not call for increased expectation for families to provide care, but does recognize the importance of supporting

families. Compared with those in other countries, families provide relatively less care in Norway (Ingebretsen & Erikson, 2004). Furthermore, the Norwegian Social Services Act specifies that “persons who are unable to care for themselves due to illness or disability, or who are completely dependent on practical or personal help to manage their daily tasks, are entitled to help” (Ingebretsen & Erikson, p. 37). In another Norwegian government document, entitled “Better Quality of the Services of Care in the Community”, the focus rests on national strategies for the development of formal services, although the paper also stresses the importance of strengthening ties between formal and family care. It should also be noted, however, that even in a country like Norway that has stressed social responsibility for care, there is a strong sentiment among the population that families have responsibilities to provide care (Ingebretsen & Erikson).

The provision of professional services over financial support for family caregivers is advocated for other reasons. First, it has been argued that informal caregivers may not be the appropriate source of care. Kunkel et al. (2003–2004) note that this concern is rooted in “values of beneficence and avoidance of maleficence, the desire to do good and to do no harm” (p. 77), which in the United States has translated into a policy approach to caregiving with a core goal of risk reduction and protecting receivers of services provided by the government. Concerns have been raised about the quality of care that family caregivers may provide, given a lack of training and the sometimes complex care required (Keigher, 1987). Proponents argue that rather than paying family members, government efforts and funds should be directed toward ensuring availability and affordability of professional care.

Social versus Economic Objectives of Financial Support Policy

Financial support policies for caregivers mirror most other social policies in that they have multiple objectives and are often one component of a larger policy agenda. For example, Australia’s Carer Allowance is part of a larger strategy to promote community care and is intended to provide some compensation for the costs incurred by the caregivers (Jenson & Jacobzone, 2002). France’s ACTP is intended to help the elderly stay in their own homes and create jobs in the home help sector as a strategy to reduce unemployment. Similar to that of France and Australia, the long-term care program in Germany is aimed at helping the care receivers remain at homes; however, additional objectives involve reducing social

assistance expenditures and assisting caregivers (Jenson & Jacobzone). Underlying objectives of financial support policies are frequently both economic and social. Policies with economic objectives aim to “reduce or delay the institutionalization of the person with care needs and thereby decrease the cost to the health care system” (Keefe & Fancey, 1998, p. 4). Discourse has tended to focus on cost containment. Policies with a social objective have as their first goal recognition of the contribution of caregivers and support of the informal care system (Keefe & Fancey, 1998). These policies acknowledge that caregiving is valuable and caregivers should be supported. Many countries frame their policies in terms of supporting caregivers, but the economic objectives are the impetus to develop such support. Few countries state social objectives without references to containing cost.

Many countries are facing concerns about their ability to maintain the welfare state, given global demographic changes of declining birth rates and an aging population. In response, economic objectives have come to take a central role in the development of financial support policies for caregivers (Glendinning & McLaughlin, 1993). Governments continually attempt to provide care efficiently and cost-effectively. One approach to cost reduction has been to focus on care delivered by the community, and by families within the community, in particular. Changes in France over the last two decades demonstrate this shift to looking to family as a source of care. In France in the early 1960s, the “Rapport Laroque” emphasized professional care for seniors. However, with concerns about the ability to maintain the welfare state, there was a “rediscovery” of informal care in the 1980s (Joel & Martin, 1994). This shift can be seen in increasing policy debate around “intergenerational solidarity” and “help for helpers,” which had not previously appeared in social policy debates in France (Joel & Martin, 1994). Glendinning and McLaughlin argue that payment for care programs in France have had the objective of sustaining informal caregiving and delaying the move toward residential care, thereby reducing costs. Jani-Le Bris (2005) highlights the lack of a strong national advocacy voice for caregivers as limiting policy innovation in this area.

Similarly, in the Netherlands, the government is looking for more affordable approaches to providing care. This has resulted in limiting the AWBZ, an insurance program for long-term care, increasing out-of-pocket-expenses for care, and tightening needs assessment rules, leading to increased responsibility and costs being placed on informal caregivers (Visser-Jansen & Knipscheer, 2004).

The low monetary amounts paid through many of these programs support economic objectives more than social objectives, as governments attempt to secure care services for less cost from family members who are willing or conscripted to do the work for little financial support. These programs are also not intended to compensate family caregivers for their work, as the amount provided is commonly well below the market rate paid to formal service providers (Blasler, 1998; Ungerson, 1995). Sweden is a notable exception; it has a program that pays family members at the same rate as formal home care providers. Under this program, no distinction is made between formal and informal care providers (Johansson, 2004).

While many direct financial support programs appear to have an underlying objective of cost containment by encouraging community care by family members, explicit goals of some programs are to attribute social value to caregiving work and to support caregivers. For instance, Australia offers a Carer Allowance of CAN\$89 biweekly to caregivers who are either living with the care receiver or providing a minimum of 20 hours of care per week. Eligibility is not limited by income. Given the small amount offered, this policy is aimed primarily at recognizing the caregiver’s work and offering some support, rather than at ensuring sustainability of community-based caregiving (Keefe, Fancey, & White, 2005). A relatively new program in the United Kingdom also appears to be based on social objectives; this direct payment program offers funds to caregivers to meet their own needs. The funds can be used to purchase a range of services for the caregiver; for instance, taxi rides to reduce an elderly caregiver’s sense of social isolation, or admission to art galleries to allow a young adult caring for a parent to pursue personal interests. It should be noted, however, that this program is being accessed by only a small number of caregivers (United Kingdom, Department for Work and Pensions, 2004).

Positive or Negative Effects of Financial Support for Women

Another policy paradox emanating from financial support policies for caregivers is that the very policy designed to support all caregivers, many of whom are women, may have the undesirable life course effect of poverty, limited pensions, and dependency. Researchers who challenge the assumption that financial support policies help women argue that these programs may encourage women to leave work to provide care (Ungerson, 1995). As women often have lower incomes than men, it may appear more

advantageous for women to leave work to provide care, thus losing short- and long-term employment income. Ungerson (1995) argues that payments can entrap women into caregiving. Financial programs that provide only limited support do not take into account the long-term financial needs of women providing care, who are more likely to live in poverty throughout their lives. Programs may provide some immediate financial relief, though this can be at the expense of long-term financial security. Additionally, programs may push women back into the home, reinforcing the gendered division of labour. This underlying assumption of "male breadwinner/female caregiver" rationalizes providing low remuneration for care work (Colepaugh, 2004). For example, Austria's introduction of a payment for care program has perpetuated the gendered division of labour within the family, because, according to Hammer and Osterle (2003), this policy does not have the potential to emancipate or to reduce gender inequalities.

On the other hand, Simon-Rusinowitz, Mahoney, and Benjamin (1998) argue that financial support is important for women, particularly those who are low wage earners, for the very reason that they are among the most vulnerable groups in society at risk of becoming impoverished in their later years. Women are giving up or reducing employment to provide care, even when financial supports are not available. They do it out of a sense of duty, social pressure, or a lack of other sources of care. As a result, they are incurring significant financial costs. When financial support is offered, the current and future economic needs of women providing care can be addressed.

Australia and the United Kingdom offer income maintenance benefits to low-income family caregivers. The Australian Carer Payment, in addition to the allowance discussed previously, is available only for caregivers who provide full-time care and whose household income is low. Similarly, the U.K. Carers Allowance is payable to caregivers who provide a minimum of 35 hours of care per week; whose personal earnings are low, regardless of the income or asset levels of a partner or spouse; and who are not receiving other social security benefits. Logically, income replacement benefits are available only to family carers of working age. However, following pressure from carers' organizations, the U.K. Carers Allowance has been extended to older carers who have no other state pension entitlement (Keefe, Glendinning, & Fancey, in press).

Such approaches typically provide amounts similar to social assistance payments, which may provide a minimum standard of living but may not sustain

the caregiving relationship and may not take into account long-term financial needs of caregivers. Such programs have income and asset tests, intended only for low-income caregivers, not to support all of those providing care. Moreover, as is the situation within Germany's Long Term Care Insurance Policy, the cash allowance is often less than the value of in-kind benefits offered at the same care level, thus reinforcing the undervaluing of the care work. Specifically, those who choose the in-kind service option receive benefits at nearly twice the value of the cash payment option. It is only in rare cases that the policies are intended to *compensate* caregivers for their work and provide payment based on the amount of care provided through means such as an hourly wage (Keefe & Fancey, 1998). Among the six countries in this review, only the Care Wage program in Norway gives wages, and they were for caregivers of severely disabled persons.

Proponents of direct payment argue that financial support is a matter of gender justice. Traditional care work discourse identifies it as women's work, as part of their role, and done out of love, thus not requiring compensation (Guberman, 2003). By contrast, financial support policies assign value to the unpaid work done by women and enable a degree of economic independence for women. Financial support facilitates choice, and in some countries such policies lead the way to ensuring that women have access to other social rights of citizenship, such as unemployment benefits and pensions, and safe working environments (Guberman). Among financial support policies in the United Kingdom and Germany, for example, state contributions to pensions and other social security pensions have been introduced in recognition of the long-term consequences of care work and its differential effect on women.

Valuing the Care Receiver's Autonomy

Direct financial support policies often attempt to enhance the autonomy of persons needing assistance by directing the payment to them to compensate and manage their own caregivers. Evers (1994) argues that the growth of this policy approach marks a shift in thinking about care to a market-liberal approach, in which care is seen as a personal choice. Care receivers are able to hire their own workers and determine what type of care they want. This approach is advocated by the Independent Living Movement and has resulted in the emergence of self-managed care programs. While in Canada these programs seldom allow for payment of family members, such is not the case internationally in programs such as France's ATCP and APA and Germany's Domiciliary

Care Benefit under the Long Term Care Insurance program. This approach has also taken hold in the Netherlands, where the Personal Budget program has moved from a demonstration project to a readily available option under the Exception Medical Expenses Act (Schreuder Goedheijt, Visser-Jansen, & Pijl, 2004; Visser-Jansen & Knipscheer, 2004). This approach is also evident in the United States' Cash and Counseling demonstration project in four states. Under this program the state has a responsibility to provide funds to the care receiver, but it becomes the care receiver's choice to secure services through family, friends, or formal service providers (University of Maryland Center on Aging, 2002).

Direct payments can provide autonomy and flexibility for both caregivers and care receivers to decide how to use the funds. Pijl and Ramakers (n.d.) have conducted interviews with recipients of the Personal Budget and their caregivers in the Netherlands that support this claim. Both parties reported that they were satisfied with the program. Care receivers reported that they were able to choose their own caregivers and had more of a voice in their care. Caregivers reported that they received reasonable wages and had more legal rights under the program. However, criticisms have been raised about the complex bureaucracy involved in the program.

Self-managed care programs can also support families in providing care. Such policies support choice among family caregivers and allow for private family decision-making (Osterbusch & Linsk, 1987). These policy approaches are also a reflection of changing social realities that have resulted in reconsideration of traditional perspectives on financial support policy. Evers (1994) writes, "The idea of a universal and highly standardized public-services network presupposed rather highly integrated societies" (p. 26). In a society with increasingly diverse family forms and cultural and ethnic pluralism, such an approach may be inadequate. Cash-based approaches to care provision by the state are increasingly seen as an appropriate solution for diverse needs of caregivers, allowing for "group-specific solutions in the organization of care" (Evers, 1994). Effectiveness and efficiency, as well as "democracy by individual choice", are underlying values of this approach (Evers, 1994, p. 26).

It must be questioned, however, to what extent these programs support caregivers. While the money can be used to pay family members for the care they provide, concern has been raised about how much of this money actually gets transferred to family caregivers. When the system of support is accessed only through the entitlement of the care receiver and is

dependent upon on the discretion of the latter to pass the payment on to a family carer (as in Austria and Germany), it potentially introduces an employer–employee arrangement, or considerable financial dependency, into the caring relationship (Keefe et al., in press). These policies appear to offer little choice or social protection for the caregiver. In fact they can detract from the caregiver's recognition and may create a financial dependence on the person to whom they give care (Keefe et al., in press).

Ungerson (2004) notes that such direct payment programs vary greatly. Some include regulations around work hours and require holiday pay, while others of this type have no regulations and do not monitor how care receivers use the money. This means that care receivers can save the funds for themselves instead of transferring them to a family caregiver. While this approach has the potential to provide financial support to caregivers who were previously doing the work without compensation, it can also have severe consequences for family caregivers, for it can create a grey labour market, low-paid employment, and lack of entitlement to social benefits normally associated with a lack of regulated employment (Ungerson, 2004).

It is out of this concern of creating a grey labour market that the Personal Budget in the Netherlands is highly regulated and monitored. Care receivers are required to make employment contracts with caregivers, including family, and are required to pay at least minimum rates. Payment of caregivers' wages is handled either by a government organization or by caregivers who must account for their expenses. Caregivers also have legal rights, such as vacation time. This strict monitoring was put in place in the Netherlands out of concern that without regulation the money would be used to hire care workers on the black market and that care workers might not be ensured appropriate working conditions (Pijl & Ramakers, n.d.).

In contrast, family caregivers in Germany have no entitlement to any benefits of their own. Rather, they are available only through the person needing care. It is generally assumed that care receivers who have taken the cash option will direct at least some of the money to the family caregiver. However, there is no evidence indicating how much of the money is transferred to family caregivers.

Perspectives on the Netherlands' Personal Budget program vary significantly. While the program allows care receivers to hire and pay family members and provides family caregivers with reasonable wages and other protections, there is an aspect of this program that, according to Pijl and Johansson (2003),

reveals that it is not intended to support caregivers. The care assessment used to determine the amount of budget to be allocated includes the current amount of care by the family as a given and allots funding only for additional needed tasks. Should family caregivers take on these additional professional tasks, they will be taking on the burden of both paid care and unpaid care (Pijl & Johansson). In the Netherlands, caregiver advocates are asking that the assessment tool be made “carer-blind” – that it evaluate and provide for the total amount of care required by the care receiver, regardless of the availability of family.

Others represent a very different perspective. The Care Insurance Board in the Netherlands has recently reviewed the program and guidelines regarding what kinds of family-provided care should be compensated. The board concluded that family caregivers in the Netherlands are decreasingly willing to provide care without pay. They have termed this change the “monetisation of informal care” and have identified this as highly undesirable shift. The board has advised the government to consider altering the Personal Budget to disallow payment to family members living with the care receiver (Pijl & Ramakers, n.d.).

While some analysts hold hope that the self-managed care model will enable the transfer of money to caregivers, thereby empowering care receivers and supporting caregivers, others express concern. Indeed such policy has the potential to reflect the three previous paradoxes. First, this approach may reinforce social expectations of family to provide care – that it is a family responsibility, and results in women being coerced into caregiving work and incurring related costs (Keigher, 1987; Ungerson, 2004). Second, such models in the guise of providing autonomy to the care receiver may represent a challenge to gender equity and represent a double-edged sword for women:

On the one hand, cash payments for family carers do recognize and attempt to ameliorate the direct and opportunity costs associated with caregiving and provide some formal recognition of the caregiving role. On the other hand, these programs can entrap women into caregiving roles by offering financial support in place of other care options. (Keefe et al., in press, p. 8)

Third, researchers have argued that the policies of self-managed care are embedded in the economic objective of saving costs rather than social objectives of supporting quality care. Such policies result in the decreased responsibility of the state in family care and shift responsibility to people who need care for recruiting, training, and ensuring quality of their

care needs. While some embrace this independence from state decisions, others are cautious about downloading on individuals and their families.

Experiences from countries such as Germany and the Netherlands will need to be evaluated further as to the consequences of these approaches on caregivers in general, and women in particular, to find whether such an approach can ensure that both care receiver and caregiver have choices about the provision of care and have their needs met, and what impact they have on attitudes about caregiving and financial support.

Conclusion: Thinking Through Caregiver Policy in Canada

While other countries have embraced financial compensation as an approach to support caregivers, this has not been a popular policy approach in Canada. What financial support does exist comes largely through the tax system or for a limited number of eligible employees whose family member is near death – the Employment Insurance program. Federal forays into financial support for caregivers is complicated by jurisdictional issues, since home and continuing care programs are under provincial/territorial jurisdiction, not federal. Such policies focus almost exclusively on the need of the care receiver and do not typically recognize caregivers as clients with needs in their own right.

Recent research has brought attention to the costs and consequences incurred by caregivers of dependent adults (Aronson & Neysmith, 2001; Fast, Eales, & Keating, 2001; Pederson & Huggan, 2001). These costs can be related to the provision of unpaid labour; out-of-pocket expenses incurred through purchasing equipment, supplies, and services; or reduction in employment income through reduced hours or missed time, turning down promotions or training, or even leaving the labour market to provide care (Fast, Williamson, & Keating, 1999; Shillington, 2004). As a result, caregivers may find themselves without immediate and long-term financial security, and the sustainability of the caregiving relationship may be threatened. Income security is essential to the quality of life of a nation’s citizens yet in isolation cannot address the looming need to support care in the community.

Financial support policies are but one approach to the development of a supportive community policy. One of the reasons why policy paradoxes occur is that there is an attempt to introduce a single policy solution to respond to a complex issue that crosses multiple domains. The limited success of the Compassionate Care Benefit is an example of an

attempt, albeit admirable, to address a huge need within a narrow labour domain. To be truly supportive of caregivers we need to develop policies across multiple domains. We need to recognize that financial support is one component of the solution, but not the only one. In order for there to be choice in whether to become a caregiver, a menu of support options needs to be available.

Discussion and debate about developing financial support policies should not remain rooted in the dichotomies outlined here. While looking at state versus family, individual versus collective, or social versus economic might be a useful approach to highlight the issues that have shaped policies in other countries, their application is rarely as true dichotomies. For example, to propose policies to meet social objectives without considering their economic consequences would be irresponsible, whether this is the personal economic impact for a woman leaving the labour force to provide care; the economic cost to society from losing a member of a productive economy; or the public cost of compensating her for her work. Values as well as economic and political contexts are fluid, changing in response to one another, yet we lack sufficient research to assist us to navigate the value issues or to inform policy decisions based on values.

Consequently, a more complex and comprehensive framework for sorting through these layers is needed in order to develop responsive policies. Thus, the debate should focus less on whether family or state should be responsible for providing care, and focus more on how caregivers can be supported if they choose to be a caregiver, while ensuring that the choice does not carry short- and long-term consequences. Policy must be based on the needs of persons of all ages in a society, not just those in need of care. It must also consider the interconnections among individuals and families and how social policy affects these relationships (Kenny, 2004).

If we embrace an approach that connects economic and social objectives, consideration of Kenny's (2004) policy lens of intergenerational equity will be paramount – neither caregiver nor care receiver should be negatively affected by policy, either in the short-term or long-term. Policy should not benefit today's citizens at the expense of future generations. Such an approach may be particularly beneficial in revaluing the work done by women and ensuring that both their immediate and long-term needs are addressed through caregiver policy. Recognition of the importance of care decisions across the life course and the need for policy that supports, and does not disadvantage, individuals from engaging in care work will

go a long way to creating a Canadian society that values the contribution of caregivers. Such an ideal will mean an integrated approach to policy development across multiple domains and across different jurisdictions. At present the leadership to move this policy agenda forward is noticeably absent from the conservative policy agenda in Canada; however, pressure from individuals, communities, and advocacy groups is increasing, as are the looming needs of the next generation. Future demands will force action, regardless of political will. Canadians will be best served if the course of action is informed by sound research – research that assists us to make the best decisions based on values.

Notes

- 1 These tax credits have been criticized on numerous grounds. All of these credits provide minimal amounts of money (in the range of a few hundred dollars) and therefore do not adequately compensate for the financial losses associated with caregiving. Also, because the credits are non-refundable, those with no or low income, which is often the case for women caregivers, do not have sufficient income to receive any financial support through these credits (Shillington, 2004). Care receiver income tests, co-residency criteria, and eligibility based on type of relationship between the caregiver and care receiver also severely limit who can benefit from these credits (Fast et al., 2001; Shillington, 2004).
- 2 This program is available only to caregivers who have at least 600 work hours in the last 52 weeks, and provides 55% of income up to a maximum of \$423 per week. There are no programs that provide direct financial support for those providing long-term care or any type of care that is not considered palliative.

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