FINAL REPORT MARCH 2005

# Consultation on financial compensation initiatives for family caregivers of dependent adults.

*Janice Keefe, Pamela Fancey & Sheri White*

*Maritime Data Centre for Aging Research & Policy Analysis*
*Department of Family Studies & Gerontology*
*Mount Saint Vincent University*

*An initiative of Theme 3, "Hidden Costs/Invisible Contributions: The Marginalization of Dependent Adults" Research Program.*

Hidden Costs Invisible Contributions

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# Acknowledgements

The consultation on financial compensation initiatives for family caregivers of dependent adults was held on November 8, 2004 in Ottawa. The idea grew out of discussions between researchers and partners within the policy theme of the *Hidden Costs/Invisible Contributions: The Marginalization of Dependent Adults* research program, funded by the Social Sciences and Humanities Research Council of Canada, about how to make our research results more relevant to the policy community. This resultant consultation was an additional activity, not part of the original project. It would not have come to fruition without the support of researchers, partners and staff of the HCIC project and interest, energy and financial commitment of others.

**FIRST**, an expression of thanks is extended to the representatives from national level government departments and agencies as well as organizations who willingly gave time from their busy schedules to attend. Their engagement and contribution to the discussion demonstrates their interest in policy development for Canada's caregivers.

**SECOND**, a thank you to those involved in the program - the facilitating skills of Susan Weagle, Director of Policy & Standards, NS Dept of Health, the comprehensive presentation by Lynn Friss Feinberg, National Centre on Caregiving, Family Caregiver Alliance (US) and the organizing skills of staff at the Maritime Data Centre for Aging Research and Policy Analysis, Mount Saint Vincent University. Combined these individuals ensured a well-organized and valuable experience for participants.

**FINALLY**, this event or the range of participants would not have been possible without the financial contributions of:

- Institute of Aging, Canadian Institutes of Health Research
- Institute of Health Services & Policy Research, Canadian Institutes of Health Research
- A Healthy Balance: A Community Alliance for Health Research on Women's Unpaid Caregiving, a CIHR funded Community Alliance for Health Research

# Executive Summary

This report summarizes the findings of the "*Consultation on Financial Compensation Initiatives for Family Caregivers of Dependent Adults*" held on November 8, 2004 in Ottawa, Canada. The consultation was an opportunity for national level policy makers and stakeholder organizations to critically assess the strengths and limitations of other countries' financial compensation programs and discuss their suitability for Canada's caregivers. Countries reviewed include: Australia, France, Germany, Israel, Norway, Netherlands, Sweden, United Kingdom and the United States.

The consultation format included plenary sessions, break out sessions, networking opportunities and a poster display. Policy Profiles developed for each of the ten countries were reviewed and discussed. The Profiles provided information on the country's policy context and available financial compensation policies (*e.g. allowances, tax relief, paid leave, credits*).

Participants review of the countries' policies suggest that financial compensation should be part of a menu of options, be broader than tax relief and also include labour policy to target employees with caregiving responsibilities. Also, an approach that considers immediate (*e.g. allowance, paid leave*) and longer term compensation (*e.g. pension credit*) should be considered. Ensuring adequate levels of compensation was noted so not to perpetuate caregiver poverty. Finally, differences in government jurisdictions were noted when reviewing the other countries. While some are administered nationally, others have national level legislation that is administered locally. Either model would prove challenging for Canada given its socio-political system.

Germany, Netherlands, Sweden and the United Kingdom were the four countries identified with elements of most interest and relevance to the Canadian context. As well, carer allowances and pension credit schemes were identified as important policy options to examine further. Issues related to implementation of similar models/initiatives in Canada include: federal-provincial-territorial jurisdictional responsibility for health/social services, program financing, labour market structure and political will. To this end, participants identified further information needed on other countries' approaches to support policy development in Canada. This includes: rationale, infrastructure, utilization, financing, integration with services, ethical considerations and evaluation.

The results from the in depth analysis will be transferred to key stakeholders during 2005-06 to help advance policy development on financial compensation in Canada.

The consultation was an initiative of the "*Hidden Costs/Invisible Contributions: The Marginalization of Dependent Adults*" research program and funded by CIHR's Institute of Aging and Institute of Health Services and Policy Research and A Healthy Balance CIHR funded community alliance research program.

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# 1.0 Overview

This report is a synthesis of proceedings from a consultation held on November 8, 2004 with decision making representatives from several federal government departments and national level stakeholder organizations on the topic of financial compensation for family caregivers. The consultation was organized by Janice Keefe, Associate Professor and Canada Research Chair in Aging and Caregiving Policy, Mount Saint Vincent University as part of a larger program of research titled "*Hidden Costs/Invisible Contributions: The Marginalization of 'Dependent Adult'*" (HCIC). The consultation was funded by the Canadian Institutes of Health Research Institute of Aging and Institute of Health Services and Policy Research and a CIHR funded project, A Healthy Balance: A Community Alliance for Health Research on Women's Unpaid Caregiving.

The overall objective of this consultation was to provide an opportunity for Canadian policy makers and stakeholder organizations to critically assess financial compensation programs as a public policy option for caregivers in Canada. Specific objectives were:

- To transfer information on financial compensation programs from ten countries, including Canada, to decision makers and stakeholders.
- To become familiar with other countries' approaches to caregiver compensation.
- To examine the potential transferability of other programs to Canada.
- To obtain a consensus on four countries/approaches that are of most interest and relevance to decision makers and stakeholders in Canada.
- To identify priority information areas for decision makers and stakeholders to assist with further analysis of the four countries/approaches.

# 2.0 Process

Twenty-four individuals from across Canada attended the consultation (*see Appendix A*). These individuals were invited to participate because of their interest in policy development for Canada's family caregivers. Participants received a package in advance of the event that included background materials and a Policy Profile for each of 10 countries (*see Appendix B*). The Policy Profiles were developed in 2004 through the HCIC project. Information presented in the Profiles is the result of a systematic review of articles, reports, and websites. The Profiles were reviewed by decision makers and researchers familiar with the country's public policy. Countries included in the study were: Australia, France, Germany, Israel, Norway, Sweden, The Netherlands, United States, United Kingdom and Canada.

The day included two plenary sessions, two break-out sessions and a poster display (*see Appendix C*). This multi-method format allowed for information transfer to the whole as well as opportunities for active engagement and networking at a group level. Groups were structured to enable a cross section of participants working together (*e.g. government, non government, researchers*). Susan Weagle, Director of Policy and Standards, Nova Scotia Department of Health assisted with the organization of the event and facilitated the day. Her involvement was valuable as it ensured that the program was relevant for policy makers. Plenary sessions were given by Theme 3 Leader, Janice Keefe and Lynn Friss Feinberg, Deputy Director, National Centre on Caregiving, Family Caregiver Alliance (US) (*see Appendix D*). These plenary sessions provided background information and context for the day's discussion on financial compensation.

In small groups, participants were asked to discuss the strengths and weaknesses of each country's approach and prioritize their applicability for the Canadian context. The prioritizing exercise was done by participants affixing color dots on a wall poster to mark the countries and policies of their choice.

A poster presentation that was given at the Canadian Association of Gerontology Annual Scientific and Educational Meeting in Victoria, BC in October 2004 was also on display. In addition to the presentation by Dr. Keefe, this presentation provided participants with a visual snapshot of the available policies across the ten countries.

The following provides highlights from the day.

# 3.0
# Setting the Stage

## *3.1 Caregiver Compensation Programs. An Overview by Janice Keefe*

There are a range of options to support caregivers including direct services. Financial compensation is one such public policy approach. Financial compensation initiatives may be categorized into three types – direct, a cash benefit in the form of wage, salary or allowance paid to the care receiver or caregivers; indirect, non direct benefits such as tax relief or third party payment of pension credits or insurance premiums; and, labour policy, paid leave from work to provide care. Some of these initiatives offer immediate financial relief while others are much more delayed. Currently at the national level in Canada, tax relief and paid leave from work are available.

A cross national review of policies in 10 countries suggests that most countries take a mixed-model approach to financial compensation. For example, at the national level Australia, France, Germany and United Kingdom offer direct and indirect financial compensation. Israel, the Netherlands, Norway and Sweden have similar offerings as well as national policy for paid leave. Across the countries, however, program particulars vary significantly in terms of eligibility criteria, value of compensation and administration processes (*see Appendix E*).

When considering financial compensation initiatives, there are several issues worth noting. With respect to direct compensation, payment directly to the care recipient facilitates his/her autonomy but at the same time, if awarded to the care receiver it may not be transferred to the caregiver. With respect to indirect compensation, tax relief that is non refundable has limited value to low income caregivers. Moreover, while pension credit accumulation will help reduce long term financial consequences of caregiving, unless the credit's value is indexed, it will have little value upon retirement. Finally, labour policy only supports employed caregivers and is limited to those who have sufficient other financial resources to endure the typical wait period and reduce their income as most are not securing 100% of the employee's income.

## *3.2 Caregiver Compensation Programs: The U.S. Experience by Lynn Friss Feinberg*

The United States is grappling with ways to improve quality of care, address the shortage of direct care workers and increase consumer choice. As such, financial compensation is becoming increasingly linked with direct services but the approaches are as diverse as the States. This diversity is fueled by the range of funding sources. For example, two major federal funding sources are the National Family Caregiver Support Program and Medicaid. State funding for support programs includes general funds, lottery and tobacco funds. A recent report details the range of services and supports by funding source by State (www.caregiver.org). An emerging trend across the states is the adoption of a "family centered" approach to policy development rather than focusing on the care recipient or the caregiver individually.

No federal policy on financial compensation exists and states differ widely in their approaches to financial compensation. For example, federal law prohibits spouse or parents of children to be paid, but some states allow this. As well, in some states, the caregiver is the client while in others payment is given to the care recipient. An examination of four states' approach – Illinois, North Dakota, Texas, Hawaii - demonstrates the wide variance in program particulars such as eligibility, value and funding source (*see Appendix F*). A common element, however, is the use of such money for home support services and caregiver respite.

Demonstration projects of the Cash and Counselling program reveals high consumer satisfaction, no major reports of fraud and abuse, and program costs are no more than traditional services. Tax relief is available but eligibility requirements and other restrictions limit its usefulness. Unpaid leave to care for a family member is available in the US but due to stipulations related to size of workplace, about 40% of US workforce cannot access this policy. For this reason, about 19 states have enacted family and medical leave laws that exceed national legislation entitlement. California has enacted the most comprehensive approach to caregiver support. It views caregivers as a client for most of its programs and services. It offers tax relief, partial paid family leave, and direct services such as resource centres, in-home assessment, family consultation and care planning, respite and in-home support services.

# 4.0
# Critical Assessment

Following the plenary sessions, participants were asked to consider five questions about select countries. Groups were pre-determined to ensure a balance of perspectives (*e.g. government, stakeholder organization, research*). Each group was assigned two countries and had the option of choosing a third country. Groups were asked to review the Policy Profiles for their assigned countries and discuss strengths and limitations of these other countries' approaches to compensation. It was expected that this exercise would provide an opportunity to initially assess the countries' policies on their own and then begin to consider how their approaches may or may not be relevant for the Canadian context. Reporting back to the larger group followed from this break-out session. Below is a summary of these discussions by country.

## *4.1 Australia*

Australia's approach to financial compensation was considered comprehensive because it offers both direct compensation and an array of home and respite care cases. There are two types of direct compensation offered – a universal allowance and a payment for low income caregivers. These programs are coordinated at the national level. Australia's approach, however, does not include compensation in the form of pension credits and thereby does not recognize the long term implications of caregiving. As well, there are no specific provisions for employed caregivers via labour policy. Thus, caregivers who must leave their work to provide care may incur significant financial consequences. Moreover, despite its emphasis on direct payment, the amount of payment available may contribute to ghettoizing caregivers, many of whom are already low income, and may exclude others who do not meet restrictive eligibility (*e.g. hours per week of caregiving, income and asset testing*). Despite these limitations, Australia's emphasis on direct payment may be relevant to the Canadian context. The two countries are similar in demography, geography and commitment to a social welfare state, conditions which may support the implementation of like policy in Canada.

## 4.2 France

France's approach was considered comprehensive because it allows for direct allowances, tax relief and a pension benefit. As well, the eligibility criteria for direct allowances include non relatives which broaden the potential pool of caregivers accessing this benefit. Conversely, a main limitation with France's allowances is that they exclude payment to spouses. Another limitation is that France does not offer labour policy to support employed caregivers. On a positive note, France's contribution to caregivers' old age insurance during the period of caregiving was of interest. Currently, in Canada if an individual leaves employment for caregiving their contributions to the Canada Pension Plan discontinue. Adopting France's approach would mean that the government would continue to make CPP contributions during their absence from the labour force for caregiving responsibilities.

## 4.3 Germany

Germany's program was considered progressive on several fronts. Through its Long Term Care Insurance program (LTCI), caregivers are able to register as employees providing them additional rights and recognition, including an allowance via the care receiver, provision for respite coverage and contributions to statutory pension insurance. The allowance program employs a gradient compensation system based on functional need of the care receiver. As opposed to a flat-rate, this approach recognizes the time/effort of caregivers (*e.g. increased care level classification, increased compensation*). It does not recognize the needs of caregivers through their own assessment but does provide an allowance to the care receiver to cover his/her regular caregiver's respite break. This component helps to sustain the caregiving situation by enabling a period of respite without financial hardship. In addition to these provisions, the LTCI program pays contributions towards the caregiver's statutory pension insurance. Thus their approach not only provides for immediate compensation but also recognizes the long term implications of caregiving. A limitation noted within Germany's LTCI involves paying the care receiver rather than caregiver directly as it may detract from the caregiver's recognition and may present challenges if there is an imbalance of power in the relationship or presence of cognitive impairment. Of interest was Germany's coverage of statutory pension insurance contributions while caregiving because of Canada's contributory pension system.

## 4.4 Israel

Israel's approach to financial compensation was considered limited in comparison to others reviewed. While it does provide an allowance for non elderly disabled adults through which family members may be paid, a similar program does not exist for the elderly population. On a positive note, Israel has labour policy to support employed caregivers. For example, caregivers are entitled to six days of paid leave to care for an ill relative and Israel's Severance Compensation Act enables access to unemployment benefits if leaving employment for caregiving. This latter policy was of interest because Canada also has an unemployment benefit program. Unlike Israel, Canadian workers who discontinue their employment for caregiving are not entitled to Employment Insurance benefits unless within the auspices of the Compassionate Care Benefit.

## 4.5 Netherlands

The Netherlands' labour policy approach was considered comprehensive as it provides for three separate caregiving scenarios enabling employees to provide assistance without significant financial hardship. In addition to labour policy, the Netherlands administers a direct allowance to its care receivers based on functional need. A positive aspect of this program is that its benefit is based on standard national rates of professionally delivered care. It was noted, however, that this country's policy approach assumes an available informal support network and thereby does not recognize the needs and realities of caregivers.
The assumptions made are relevant to the Canadian context as current policy focuses on the care receiver's needs and assumes family members are available and able to provide assistance. Further, caregivers are not considered clients or entitled to an assessment.



## 4.6 Norway

Norway's approach to compensation was considered comprehensive because it provides for an allowance and wage, paid leave from employment, and a pension credit. It was noted that both the allowance and care wage were generous but would not be considered income substitution. The pension credit benefit was automatically attached to the care wage assuming administrative ease for both the system and caregivers. Norway's approach was of interest to participants because it provides direct compensation options and recognizes both immediate and long term consequences.

## 4.7 Sweden

Sweden's program was considered progressive because it offers direct payment options, pension credit accrual and a comprehensive paid leave policy. In particular, it was noted that the Carers Allowance enabled payment equal to that of a formal home help service provider. This was considered important to recognizing the value of the caregivers' time/effort. Further, Sweden's Care Leave Act allows for up to 60 days at 80% salary for care of a terminally ill relative which will enable access by a greater pool of caregivers. It was noted, however, that Sweden's caregivers may face portability challenges because the programs are administered at the local level. Sweden's paid leave policy is relevant to Canada because of Canada's newly established Compassionate Care Benefit which has similar eligibility criteria but differences in entitlement. Understanding employer's response to Sweden's policy would be helpful in advocating the need for expansion of Canada's Compassionate Care Benefit

## 4.8 United Kingdom

The United Kingdom's approach was considered progressive because of its comprehensive emphasis on caregivers. Provision exists for a direct allowance, premium and pension protection for caregivers. As well, the allowance may continue up to 12 weeks even if caregiving situation changes (*e.g. hospitalization, respite*). This is important because it allows for sustainability of the caregiver who otherwise would incur financial consequences due to changes in situation. Further, both the allowance and premium are available to caregivers up to 8 weeks after death of care receiver. This is important because it recognizes that the involvement of the caregiver does not necessarily cease at the time of care receiver's death. Noted limitations with the UK's direct compensation programs are the restrictive eligibility criteria (*e.g. 35 hours of care a week, income levels*) thereby making the generous program inaccessible by many caregivers. The United Kingdom's new State Second Pension for Carers was of interest, particularly because it targets caregivers whose labour force participation may be impacted by caregiving resulting in longer term consequences. The UK is funding this initiative through contributions and accrual now, but no benefit will occur until 2050. It was suggested that a similar approach may be relevant for Canada.

## 4.9 United States

The United States' approach to financial compensation was considered limited at the national level because, similar to Canada, it is mostly limited to tax relief. This approach limits who benefits through restrictive income levels and the inability to refund. The strengths of the United States approach to compensating family caregivers lay in its current state-level programs enabled by the Family and Medical Leave Act. Through these programs states may offer financial compensation to caregivers. As well, at the state-level a number of demonstration programs for self-managed care exist. The programs provide payment to care receivers and caregivers as well as fund caregiver resource centers to educate and support caregivers. Similar to Canada, the US has a national health and welfare mandate which is administered at the state level. The national funding strategy in the US has relevance for Canada because a similar application could be undertaken in Canada through the federal government with stipulations to the provinces responsible for administering the program.

## 4.10 Summary



Based on the discussions of the nine countries and their policy implications for the Canadian context, several common points were identified. First, the scope of a country's approach to supporting caregivers is important if equity across caregiving groups is a concern. For example, financial compensation should be part of a menu of options that includes services, and not the only choice available to support caregivers. Financial compensation should be broader than tax relief and include labour policy to target employees with caregiving responsibilities. Second, an approach that considers immediate short and longer term compensation is important. Caregivers often incur direct expenses or lost wages due to caregiving. Policies that address both short and long term make a value statement on time spent caregiving. Third, adequate levels of compensation are an important consideration which is linked to whether the compensation model is universal or a social welfare model. For example, a social welfare model is important if low income caregivers are the target because it is helping those who need it most. However, this model may also be viewed as a limitation because it may perpetuate low income status if compensation levels are inadequate. Finally, inter-governmental jurisdictional issues were a prominent discussion point when reviewing the other countries. While some are administered nationally, others have national level legislation that is administered locally. Either model would prove challenging for Canada given its socio-political system.

# 5.0
# Priority Setting

Participants had the opportunity to become familiar with other countries' approaches to caregiver compensation and consider their potential transferability to Canada. In order to manage the wealth of information, it was necessary to streamline subsequent research activities to focus on countries which would be most relevant for consideration by Canadian policy makers. The next step in the consultation process was for participants to identify which four of the nine countries' approaches (*Canada not included*) were ones that Canadian policy makers should consider. In addition, of the 41 individual policies across the countries (*Canada not included*), they were asked to identify one specific policy worthy of further investigation. This priority-setting exercise was important because it enabled those in decision making positions to have a direct role in setting the research agenda. They were able to direct the researchers on what evidence was necessary to support change in caregiver policy.

Germany, the Netherlands, Sweden and the United Kingdom emerged as the most commonly identified countries whose approaches should be further examined. Two specific policy options – direct allowance and pension credits - rather than one were selected. It was felt that further analysis of both was warranted given the extent of their availability in other countries and because neither are currently available in Canada.

# 6.0 Constructing a Framework for Analysis

Following the priority-setting exercise, participants were assigned to groups and asked to explore what types of challenges/barriers may be faced if trying to adopt these countries' approaches in Canada. This discussion was important because it helped identify information that should be gathered on these policies in the next phase of the analysis. Reporting back to the larger group followed from this break-out session. Below is a summary of these discussions by country.

## *6.1 Challenges to Implementation*

### 6.1.1 Germany

A major challenge with implementing Germany's approach in Canada is difference in jurisdictional structure. Germany has a national health and social structure through which its financial compensation programs are administered and monitored. In Canada, the federal and provincial governments would need to work together to administer a similar initiative that would satisfy issues of accountability from all perspectives.



### 6.1.2 Netherlands

Major challenges with implementing the Netherlands approach in Canada include: differences in jurisdictional structure, concerns about program financing and cost incurred by employers. For example, the Netherlands direct payment approach is administered at the national level through its national care fund for long term care. A similar structure does not exist in Canada. Further jurisdictional issues exist related to assessment and compensation level. A unified assessment mechanism to comprehensively assess care receiver's needs does not exist in Canada because home care is provincial jurisdiction and varies from province to province. Further, implementing a standardized hourly rate of pay for caregiving work in Canada would be challenging considering the differential cost of living across the country. Salary inequity, for example, already exists for paid home support workers. Finally, the Netherlands offers a number of leaves for employed caregivers ranging from short term to long term (*up to 18 months*). While income security for parental leave is guaranteed in Canada, there is currently only a short term benefit available to family members of a terminally ill relative. Canadian employers may not be as accepting of mandated legislation to increase length or number of leaves. Employers would incur direct costs associated with recruitment and training of replacements and concerns exist in certain sectors about pending labour market shortages.

### 6.1.3 Sweden

Major challenges Canada would face with trying to implement Sweden's approach: differences in jurisdictional structures and concerns about program financing. For example, Sweden has a national level policy for health and social services, its programs are administered at the municipal level. This allows for financial compensation and direct services to be accessed at the local level, but variations across municipalities exist regarding administrative processes. A similar approach may be feasible in Canada but significant negotiation would be required to have provinces on board and even further significant restructuring to provide both payment and services at the local level. Moreover, Sweden's programs are financed through their tax system. Whether Canadians would be willing to accept significant tax increases to support such programs is questionable.

### 6.1.4 United Kingdom

A major challenge with implementing the United Kingdom's approach in Canada pertains to differences in jurisdictional issues and concerns about program financing. For example, the UK has national level legislation that governs community care, including caregiver support. The programs arising from such legislation are administered at the local authority level. Such legislation does not currently exist in Canada.



Another challenge may involve finding support among the younger population to fund a pension program, such as the State Second Pension for Carers, which would not be accessible until 2050.

### 6.1.5 Carer Allowance

The implementation of a direct allowance program for caregivers in Canada may face challenges related to program financing, ensuring quality of service, and administration of the program. Similar to challenges noted previously with individual countries' approaches, how such a program may be administered in Canada would be challenging in view of existing federal-provincial jurisdictional responsibilities. Moreover, embedded in administrative challenges are issues related to accountability and monitoring to ensure proper spending of public funds and to ensure needed quality care is received. Finally, unless additional money was allocated to fund this new initiative, a reallocation of existing dollars may impact the availability of formal home care services.

### 6.1.6 Pension Security

The main challenge when considering implementing pension security program for caregivers in Canada is political will. For example, public financing of a new pension may not garner full support of Canadians who would not benefit from it for years to come. There may be hesitancy on the part of decision makers to restructure the Canada Pension Plan program to accommodate this new addition and to introduce another mechanism to administer another pension initiative may be too expensive. Further, employers and individuals may be dissatisfied with a further increase to their contribution rates to support a program from which they may not benefit because they do not have caregiving responsibilities.

## *6.2 Required Information to Support Policy Development in Canada*

In view of the challenges discussed above, moving forward with policy alternatives in Canada requires further understanding of these initiatives. The following broad categories provide a framework for the kinds of information decision makers identified as necessary to further policy development.



1. Rationale/Objective
2. Administration infrastructure
3. Utilization patterns/profiles
4. Assessment/case management process
5. Program financing
6. Integration with direct services for caregivers
7. Ethical considerations/debates
8. Program evaluation

Between January and December 2005, the following questions will be used to explore these areas further through document analysis and key informant interviews. The results from this in-depth research of the four countries' approaches and two policies will be transferred to key stakeholders to help advance policy development in Canada.

- What was the impetus for implementation? What were the social and economic influences behind the policies? What was the process for creating the policy? What was the time frame from conception to implementation?
- Who are the individuals using the program (e.g. gender, age, income, location)? How long do they use the program? What is the money used for?
- How is the program administered? Who has authority/responsibility? Why is it structured this way? How do caregivers access the program? Who is eligible and why? What is the current entitlement? How often is it increased? Is the entitlement taxable or not, deductible or not, indexed or not? How many caregivers utilize/access the program? What monitoring/accountability structures are in place?
- What is the assessment process? What tool(s) are being used for assessment? How do assessment results inform access to the program? Are case manager services available?
- How is the program financed? From what entity does the caregiver receive the benefit? What are the costs (direct and indirect) to finance the program?
- What publicly financed services/supports are available for caregivers in terms of health care coverage and other benefits (whether universal or not)? How is the financial compensation program integrated with these services? Is there flexibility in switching from compensation to service to compensation?
- What is the impact of the policy on the labour market and formal service sector? What is the role of the employer in labour policy development?
- Does payment for care affect intrinsic motivation? Do caregivers have a choice to care? Do care receivers have a choice in caregiver?
- What is the satisfaction level of program users? What should be changed and why? What is the impact on direct services? Impact on quality of care? Impact on labour market? What are the results of cost-benefit analysis?

# 7.0
# Summary & Next Steps

In summary, the one-day consultation provided an opportunity for decision makers and stakeholder group representatives from across Canada to consider financial compensation as a policy option to support Canada's caregivers. The day was structured such that participants received information about other countries' approaches and then critically assessed them in terms of their relevancy for Canada. At the end of the day, the research team had consensus from the group that approaches employed in Germany, Netherlands, Sweden and the United Kingdom are worthy of further investigation and they identified the kind of information about these countries' approaches that would be valuable. Also pension credits and carer allowance were specific initiatives across the countries that should be further examined.

Both informal and formal feedback from participants suggests that the event met its objectives and was of value to decision makers (*see Appendix G for participants' evaluation*). The Policy Profiles developed as part of the *Hidden Costs/Invisible Contributions* project were considered by all to be a valuable tool to advance this topic (*see Appendix B or www.msvu.ca/mdcaging*). They also appreciated the opportunity to network with others and engage in dialogue about this policy option. Moreover, all participants expressed an interest in attending a follow-up workshop on supportive policies for caregivers in the tax/transfer system planned for 2005. This workshop is a collaborative initiative among the Canadian Policy Research Network, the Hidden Costs/Invisible Contributions: The Marginalization of Dependent Adult SSHRC funded project, and A Healthy Balance: A Community Alliance for Health Research on Women's Unpaid Caregiving CIHR funded project.

The results of the November 8 consultation will drive the research agenda of the HCIC Theme 3 team at Mount Saint Vincent University in 2005. Areas of inquiry as outlined in Section 6.0 will be researched through a comprehensive review of documents and by interviews with key informants. A synopsis of this work is expected to be available in December of 2005.

# *Appendices*

Appendix A – Participant List
Appendix B – Policy Profiles
Appendix C – Agenda
Appendix D – Biographical Sketches
Appendix E – Caregiver Compensation Programs: An Overview, presentation by Janice Keefe
Appendix F – Caregiver Compensation Programs: The US Experience, presentation by Lynn Friss Feinberg
Appendix G – Participants' Evaluation

# *Appendix A – Participant List*

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# *Appendix B – Policy Profiles*

Policy Profiles for these countries follows:

Australia
Canada
France
Germany
Israel
Netherlands
Norway
Sweden
United Kingdom
United States

The profiles are available in pdf format from:
**www.msvu.ca/mdcaging**

or by contacting the Maritime Data Centre for Aging Research and Policy Analysis - **mdc_aging@msvu.ca**

## *Appendix C – Agenda*

Date: Monday, November 8, 2004
Time: 8:30 am – 4:00 pm (8:00 am light breakfast served)
Location: York/Albion Rooms
Marriott Hotel Ottawa, 100 Kent Street, Ottawa
Tel: 613-238-1122
Fax: 613-783-4229

# Agenda

8:00 – 8:30 Breakfast and Registration

| | |
|---|---|
| 8:30 | Welcome and Opening Remarks – Janice Keefe |
| 9:00 | Plenary – Caregiver Compensation Programs: Overview – Janice Keefe |
| 9:45 | Plenary – Caregiver Compensation Programs: The US Experience – Lynn Friss Feinberg |
| 10:30 | Break |
| 10:45 | Small group discussion A |
| 11:45 | Reporting Back |
| 12:30 | Lunch |
| 1:30 | Plenary - Overview of Priorities – Janice Keefe |
| 2:15 | Small group discussion B |
| 3:00 | Reporting Back |
| 3:30 | Next Steps – Janice Keefe |
| 4:00 | Adjourn |

This event has been made possible by:

- *Institute of Aging, Canadian Institutes of Health Research*
- *Institute of Health Services and Policy Research, Canadian Institutes of Health Research*
- *Healthy Balance Research Program, Atlantic Centre for Excellence in Women's Health & Nova Scotia Advisory Council on Status of Women*
- *Hidden Costs/Invisible Contributions: The Marginalization of Dependent Adults Project, University of Alberta*

# *Appendix D – Biographical Sketches*

**Janice Keefe, Ph.D.**, *Associate Professor & Canada Research Chair in Aging and Caregiving Policy, Mount Saint Vincent University, Halifax, Nova Scotia*

Janice Keefe, has a PhD in Family Relations and Human Development from the University of Guelph and is an Associate Professor in the Department of Family Studies and Gerontology at Mount Saint Vincent University. In July 2002 she was selected as the Mount's first Canada Research Chair in Aging and Caregiving Policy and has been awarded funding from the Canadian Foundation of Innovation to develop the Maritime Data Centre for Aging Research and Policy Analysis which is a teaching and research facility (www.msvu.ca/mdcaging).

Dr. Keefe's research areas are rural elderly, continuing care policy and caregiving, including work and elder care, caregiver assessment and financial compensation, and human resource issues in home care. She currently is a Principal or Co-investigator on research funded by the Canadian Institutes for Health Research, Social Sciences and Humanities Research Council, United States' Alzheimer's Association, Nova Scotia Health Research Foundation and Health Canada. In 1998 she authored work for Health Canada entitled Financial Compensation versus Community Supports which included an international review of financial compensation policies for family caregivers. Her commitment to knowledge translation is instrumental to her invitations to speak at national and international meetings on home care and caregiver policy and participate on interdisciplinary research teams.

Dr. Keefe has published over 50 peer-reviewed articles, technical reports and scholarly presentations. She is Chair of the Social Science Division of the Canadian Association on Gerontology and a Member of the Advisory Board for the Canadian Institutes of Health Research, Institute of Aging.

# *Appendix D – Cont.*

**Lynn Friss Feinberg, MSW**, *Deputy Director, National Center on Caregiving*
*Family Caregiver Alliance, San Francisco, California*

Lynn Friss Feinberg is Deputy Director of the National Center on Caregiving at the San Francisco-based Family Caregiver Alliance (www.caregiver.org). The Center works to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Currently, she is directing a 50-state survey, funded by the U.S. Administration on Aging, to profile "The State of the States in Family Caregiver Support." In recent years, her research has also focused on choice and decision-making for persons with cognitive impairment and their family caregivers. She now serves as co-investigator for a longitudinal study, funded by the National Institute of Mental Health, to develop interventions for caregiver mental health.

Prior to 2001, Ms. Feinberg was FCA's Director of Research and Information Programs. She also directed the "Statewide Resources Consultant" contract with to coordinate the cross-site replication of FCA's model family support program through a statewide system of 11 non-profit Caregiver Resource Centers in California. Previous positions included serving as area agency on aging planner and evaluator, and conducting aging policy research at the University of California, San Francisco.

She is the author or co-author of over 40 publications and has served on numerous national advisory committees and expert panels to address caregiving and long-term care issues. Ms. Feinberg has lectured widely on family caregiving, long-term care systems development, and the interface of research and practice. She is a member of the Board of Directors of the American Society on Aging (ASA), and a member of ASA's Generations Editorial Board. Ms. Feinberg holds a master's degree in social welfare and gerontology from the University of California at Berkeley.

# *Appendix E – Caregiver Compensation Programs: An Overview, presentation by Janice Keefe*

## CAREGIVER COMPENSATION PROGRAMS, AN OVERVIEW
November 8, 2004

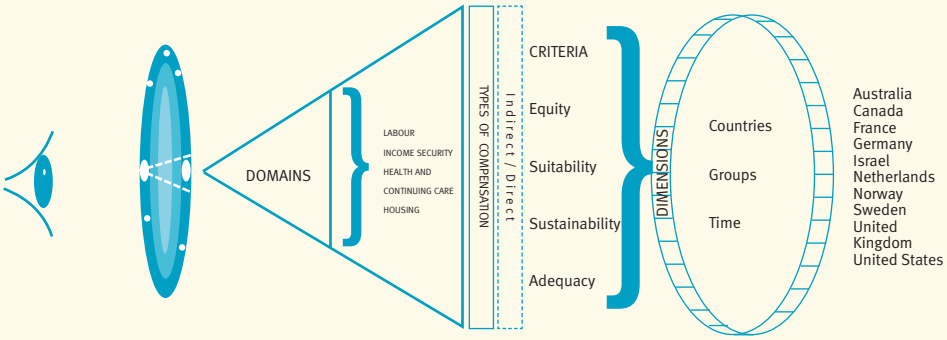
*Janice M. Keefe, Ph.D.*
*Canada Research Chair in Aging and Caregiving Policy*
*Presented at the Stakeholder Consultation on Financial Compensation Initiatives for Family Caregivers of Dependent Adults, Ottawa.*

### ➜ Background & Rationale

- Caregivers are essential.
- Trends community care = increased expectations.
- Value their role and recognize the costs and consequences.
- Range of options to support caregivers.
  - › Direct services such as respite care
  - › Financial compensation is one public policy approach.
- Financial Compensation in Canada
  - Taxation
  - Employment Insurance
- HCIC Project 3.2 - International review
  - › Valuable in understanding strengths and limitations of others' approaches.
- Why these 10 countries?
  - › Mix of welfare and health systems
  - › Range of approaches to compensation

## ➜ Project 3.2 - Method

Comprehensive review of literature (expanded, 1998-2004).
Policy Profile developed for each country.
Review of Profiles by key informants.
Analysis of policies by 4 criteria.




## ➜ Types of Financial Compensation

### Direct

- Cash benefits paid to the caregiver or care receiver to pay caregiver.
- May take the form of a wage, salary, allowance or voucher.

### Indirect

- Non-direct  benefits that have a delayed monetary or economic value.
- May take the form of tax relief or third party payment of pension credits or insurance premiums.

### Labour Policy

- Enable employees to take leave from work to provide care.

## ➜ Direct Compensation

### Cash benefit paid to the caregiver or care receiver to pay caregiver

| | Payment to CG | Payment to CR |
|---|---|---|
| Australia | Y | |
| France | | Y |
| Germany | | Y |
| Israel | | Y |
| Netherlands | | Y |
| Norway | Y | Y |
| Sweden | Y | Y |
| United Kingdom | Y | |
| United States | | |

## ➜ Direct Compensation

### Comparison

- Vary in the value.
- Vary in who it is paid to.
- Some are flat fees, others are hour wage based on identified need, while Germany offers a gradient system based on care needs.
- Cash or service option.
- Level of monitoring varies.
- Taxable or not.

### Issues

- Cash benefit to CR facilitates autonomy.
- Cash benefit to CR may not be transferred to CG.
- Cash benefit directly to CG sends important message - values caregiving and provides some immediate financial relief.
  - Does it devalue the autonomy of the CR?
- Non taxable aspect is important if benefit has low dollar value.

## ➜ Indirect Compensation

### Delayed benefit for either caregiver or care receiver

| | Tax Relief | Pension Security |
|---|---|---|
| Australia | Y | |
| France | Y | Y |
| Germany | Y | Y |
| Israel | Y | |
| Netherlands | Y | |
| Norway | | Y |
| Sweden | | Y |
| United Kingdom | | Y |
| United States | Y | |

### Tax Relief

- Comparison
  - "credit" or "deduction".
  - eligibility criteria.
  - who is the claimant (*e.g. CG or CR*).
  - value of tax relief (*e.g. $600 to $6000*).
  - refundable or not.

- Issues
  - Limited access by low income.
  - "Inverse Care Law"

### Pension Security

- Comparison
  - Different approaches (*accrued credits, state-paid pensions, drop out provisions*).
  - Eligibility criteria varies (*attached to program, leaving labour force*).
- Issues
  - Reduces long term financial consequences for caregivers.
    › No impact on immediate situation
  - Type and level of indexation important.

## ➜ Labour Policy

### Income support/substitution; paid leave from workplace

| | Paid Leave | Other |
|---|---|---|
| Australia | | |
| France | | |
| Germany | | |
| Israel | Y | Y |
| Netherlands | Y | |
| Norway | Y | |
| Sweden | Y | |
| United Kingdom | | |
| United States | | |

## ➜ Labour Policy

### Comparison

- Eligibility criteria; most are primarily for "terminal care" situations.
- Length of leave (*e.g. 6 to 120 days*).
- Amount of income support (*e.g. 70% of income, $762/month, full wage*).

### Issues

- Income security for "employed caregivers" only.
- Typically not directly from employer but must apply to insurance program.
  - Wait period varies.
- Supports healthy workplace as employee not trying to balance "work" and "caregiving".
- Limited in terms of who may be able to reduce income to supported levels.

## ➜ Summary

| | Direct | Indirect | Labour |
|---|---|---|---|
| Australia | Y | Y | |
| France | Y | Y | |
| Germany | Y | Y | |
| Israel | Y | Y | Y |
| Netherlands | Y | Y | Y |
| Norway | Y | Y | Y |
| Sweden | Y | Y | Y |
| United Kingdom | Y | Y | |
| United States | | Y | |

# *Appendix F – Caregiver Compensation Programs: The US Experience, presentation by Lynn Friss Feinberg*

## CAREGIVER COMPENSATION PROGRAMS: THE U.S. EXPERIENCE

Ottawa, Canada
November 8, 2004
Presented at the Stakeholder Consultation on Financial Compensation Initiatives for Family Caregivers of Dependent Adults, Ottawa.

*Lynn Friss Feinberg, MSW*
*Deputy Director*
*National Center on Caregiving*
*Family Caregiver Alliance*
*www.caregiver.org*



### ➜ Overview

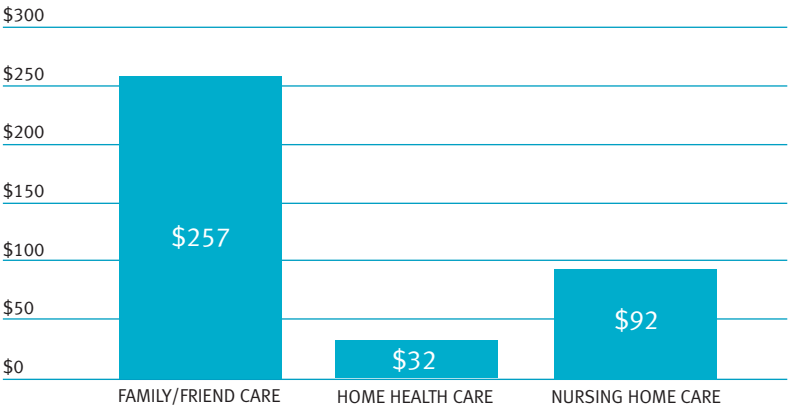
- Background
- Public Policy Strategies to Support Family Caregivers
- Program Examples
- State Case Study
  - California
- Conclusion

### ➜ Prevalence of Family Caregivers in the U.S.

**An estimated 44.4 million Americans provide unpaid care to another adult more than 1 in 5 adults in the U.S.**

*SOURCE: National Alliance for Caregiving and AARP Caregiving in the U.S., April2004*

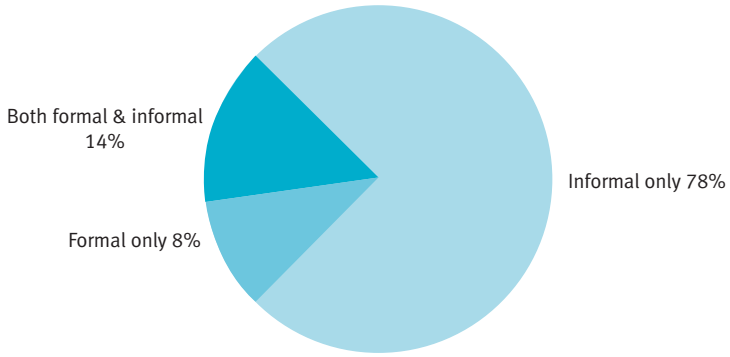
## ➜ Value of Family Caregiving




*SOURCE: Arno, P.S (February 2002). "The Economic Value of Informal Caregiving," updated figures presented at the American Association for Geriatric Psychiatry meeting, Orlando, FL.*

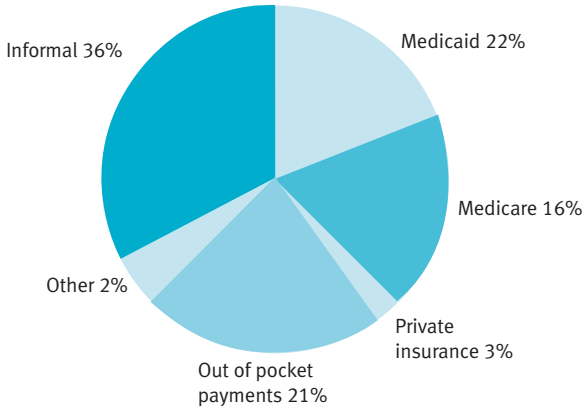
## ➜ Long-Term Care Is a Family Matter

### Distribution of Adults (age 18+) Receiving LTC at Home, by Type of Care




*SOURCE: Health Policy Institute, Georgetown University, analysis of data from the 1994 and 1995 National Health Interview Surveys on Disability, Phase II. In Thompson, L. (March 2004). Long-Term Care: Support for Family Caregivers. Issue Brief. Washington, DC: Long Term Care Financing Project, Georgetown University.*

## ➜ Estimated Percentage Shares of Spending on Long-term Care of the Elderly, 2004.




*SOURCE: Congressional Budget Office*

## ➜ Public Policy Strategies to Support Family Caregivers

- Four main strategies:
  - Direct Services
  - Financial Compensation
  - Tax Incentives
  - Family and Medical Leave

- *Approaches are as diverse as the States*

## ➜ Direct Services: Funding Streams

- Major federal funding streams in the U.S. to support family caregivers:
  - National Family Caregiver Support Program
  - Medicaid HCBS waivers
- State funding streams to support family caregivers:
  - State general funds
  - Lottery, tobacco settlement, other funds

## ➜ Direct Services: National Family Caregiver Support Program (NFCSP)

- NFCSP was enacted under the reauthorization of the Older Americans Act in 2000.
- First federal law to acknowledge the service needs of family and informal caregivers who provide support to older persons (*age 60+*)

## ➜ Direct Services: NFCSP

- Formula grants to the States based on population
- NFCSP is funded at $159 million USD in FY 2004
  - Likely to experience modest increase in FY 2005
  *($163 million approved by appropriations panel)*
- NFCSP has 5 categories of services in which States provide services:
  1 Information about available services
  2 Assistance in gaining access to services
  3 Individual counseling, support groups, education & training
  4 Respite care
  5 Supplemental services, on a limited basis, to complement the care provided by caregivers
- The family or informal caregiver is the client
- No mandated assessment of caregiver needs
- All income groups eligible
  - Priority to those in greatest social or economic need



## ➜ Direct Services: Medicaid Program

- Medicaid dominates long-term care (LTC) spending in the U.S.
  - National spending on LTC was $139 billion USD in 2002
- Medicaid home and community-based services (HCBS) waivers have become the primary vehicle through which the Medicaid program finances care in the community
- Medicaid waiver expenditures have grown dramatically over the last decade as a share of Medicaid's community-based services benefits
  - Increasing from 37% in 1992 to 67% in 2002

## ➜ Direct Services: Medicaid Waivers

- Under federal Medicaid rules, States have the option to develop waivers
  - The consumer (care receiver) is the identified client
  - Care receiver must be at risk of institutional care and meet financial requirements
  - Can provide services in the home or community
  - Services do not have to be statewide

- Can provide services considered to be caregiver supports (*e.g., respite care, family education & training)*

- Despite a focus on the consumer, Aged/Disabled Medicaid waivers are a major funder of respite care in the U.S.
  - $84.5 million USD in FY 2001
  - $101.4 million USD in FY 2002
- Data comparisons hard across States
  - Different respite definitions
  - Data collection varies across, as well as within, programs

## ➜ Direct Services: State General Funds

- Many States also operate caregiver support programs financed primarily through state general funds
  - Programs operate according to state rules
  - Highly variable from State to State and often within States

## ➜ Financial Compensation

- Emerging trend in consumer-directed care
- Programs that:
  - Provide families with cash grants or vouchers to purchase needed goods or services
  - Have $ follow the individual
  - Allow payment to family caregivers to provide care
- States are grappling with ways to improve quality of care, address the shortage of direct care workers, and increase consumer choice
- One strategy to achieve these goals: pay family members to provide care
- This practice is subject to debate in the U.S.
- Consumer-directed options are allowable under the NFCSP, Medicaid waivers, and state-funded programs
- Each State, and programs within States, structure options differently

## ➜ Financial Compensation
### Program Examples

- Illinois NFCSP
  - Administered by the Illinois Dept. of Aging
  - Family caregiver is the client
  - AAAs can offer vouchers (*up to $1,000 USD per year*) to family caregivers for goods or services ranging from respite to home modifications to lawn care
  - Family members can be paid to provide care in some areas of the state, but not in others

### Program Examples (cont.)

- North Dakota Family Home Care Program (state-funded)
  - Administered by the ND Dept. of Human Services
  - Consumer is the client; must be nursing home eligible and live in the caregiver's home
  - Provides up to $700 USD per month to provide personal care to a relative
  - Family caregivers are also eligible for up to $550 USD per month for respite assistance
  - Family members can be paid to provide respite or personal care

- Texas In-Home and Family Support program (state-funded)
  - Administered by Texas Dept. for Aging & Disability Services
  - Consumer is the client
  - Voucher for up to $2500 USD for respite, home care, home modifications, and other services
  - Family members cannot be paid providers of care

- Hawaii Nursing Homes Without Walls (Aged/Disabled Medicaid Waiver)
  - Administered by HI Dept. of Human Services
  - Consumer is client; nursing home level of care
  - Choice of respite care providers
  - Families can be paid to provide respite or personal care
    - › Under the consumer-directed option, families members provide about 90% of care



## ➜ Financial Compensation

### Cash & Counseling

- To determine feasibility of offering a cash allowance option in lieu of traditional agency services to Medicaid beneficiaries receiving personal care services
- Cooperative effort of:
  - CMS, Robert Wood Johnson Foundation, ASPE, AoA
- Launched in 1995, enrollment began in 1998
  - Experimental design
- Originally implemented in 3 states: Arkansas, New Jersey, Florida
  - Recently expanded to 11 more States
- Provides consumers with a monthly cash allowance based on an individualized budget
- Consumers can choose between:
  - Traditional agency-provided services, or
  - Managing their personal assistance services
    *(can hire, fire personal assistance workers, including family members)*
- Bookkeeping and counseling services available

### Outcomes:

- Consumer satisfaction high
- No major reports of fraud and abuse
- Data from Arkansas shows that allowing consumers to manage personal

assistance services costs no more than traditional services
  - Also improved access to authorized services
- Consumer direction is not for everyone

## ➜ Strategies: Tax Incentives

- Tax Credits
  - Most popular
  - Political appeal among lawmakers but no federal law has been enacted
- Tax Deductions
  - Tend to favor higher income families
- 26 States provide some tax breaks

## ➜ Tax Incentives

- Dependent Care Tax Credit (DCTC)
- Dependent Care Assistance Program (DCAP)
  - These tax benefits are claimed mainly by working parents of children
  - Co-residency requirements and other restrictions limit the usefulness of these benefits for employees caring for adults
  - Of no value to: caregivers who must quit their jobs to give care; long-distance caregivers; middle income families; older spouses
- Federal caregiving tax incentives have been proposed
  - Credits or deductions range from $1,000 to $5,000
  - Generally a component of "omnibus" caregiving or LTC bills *(e.g., Ronald Reagan Alzheimer's Breakthrough Act of 2004)*
  - Some bills target dementia-only population (S. 2029)



## ➜ Family & Medical Leave Policies

- The Family & Medical Leave Act (FMLA)
  - Created in 1993
  - Sets a federal "minimum" requiring employers (*with 50+ employees*) to provide:
    - 12 weeks of unpaid leave to care for a newborn child; an immediate family member (spouse, child, or parent) with a serious health condition; or to take medical leave when the employee is unable to work because of a serious health condition
- At least 19 States have enacted family and medical leave laws
- States have expanded the FMLA provisions in several ways:
  - Allowing leave in workplaces with less than 50 employees (*Oregon, Vermont*)
  - Expanding definition of "family" (*Hawaii, Oregon, Rhode Island, Vermont*)
  - Offering paid leave (*California*)

## ➜ Family & Medical Leave Policies (cont.)

- California: Enacted the most comprehensive paid family leave provisions in the nation in 2002 (SB 1661).
  - Expands the state's disability insurance program to provide up to 6 weeks of paid leave a year for workers who take time off to care for an ill child, spouse, parent, or domestic partner.
  - Workers receive 55-60% of wage replacement, up to $728 per week.
  - 100% employee funded (average of $27 per year per employee).

## ➜ Case Study: California

- State has a $500 caregiver tax credit
- Offers partial paid family leave
- Caregiver support services funded through a range of programs and agencies
  - Caregiver Resource Centers (CRCs)
  - NFCSP
  - Multi-Purpose Senior Services Program (*Medicaid waiver*)
  - In-Home Support Services
- CRCs administered by the CA Dept. of Mental Health
  - Replicates FCA's model program and operate locally by 11 regional, nonprofit agencies
  - Caregiver is the client
  - $11.7 million in state general funds (2002)
- Range of services: I&A, in-home assessment, family consultation and care planning, and range of respite options (*e.g., voucher program up to $3,600 a year per family client)*.
- NFCSP administered by CA Department of Aging
  - Caregiver is the client
  - $12.6 million in federal funds (2002)
- NFCSP services include a range of respite options, I&A, education & training, consumable supplies
- MSSP (Med. Waiver) is operated through the CA Department of Aging
  - Consumer is the client
- Caregiver support services include only respite care
- $1.9 million towards respite in 2002
- IHSS operated by the CA Dept. of Social Services
  - Funded through Medicaid personal care services program
  - Consumer is considered the client
- Through the "residual program" allows family members to be paid providers of care, including parents and spouses

| Major Programs | Consumer Direction? |
|---|---|
| CRCs | Yes |
| NFCSP | Allowable, but varies across the state |
| MSSP | No |
| IHSS | Yes |

## ➜ Conclusion

- Support for family caregivers is highly variable in the U.S.
  - States differ widely in their approaches to caregiving and services provided
- A partial national caregiver strategy is in place
  - National Family Caregiver Support Program (*direct services*)
  - Family and Medical Leave Act (*employer-based mechanism*)
- No federal policy on financial compensation
- Emerging trend: viewing consumer direction as a consumer and "*family-centered*" approach
  - The involvement of family and informal caregivers is widespread in consumer-directed programs



## ➜ Biggest Gap: Financing the Long-Term Care System

- Individuals who need LTC must pay out-of-pocket until they are impoverished and before they can get help through the means-tested Medicaid program
- Middle income families are hit the hardest
- National, cohesive LTC system is still a dream…

# *Appendix G – Participants' Evaluation*

Nineteen of the potential 24 participants completed the evaluation form. Feedback indicates that the event was successful in meeting its objectives of knowledge transfer and advancing dialogue on the topic of financial compensation. Results are as follows:

| | Strongly Disagree | Disagree | Agree | Strongly |
|---|---|---|---|---|
| The consultation was stimulating | 0 | 0 | 2 | 17 |
| The Policy Profiles and Background Document were helpful in preparing for my participation at the workshop | 0 | 0 | 7 | 12 |
| The Policy Profiles are a valuable tool to advance this topic | 0 | 0 | 5 | 14 |
| The presentations provided useful information | 0 | 0 | 3 | 15 |
| The opportunity to dialogue on this policy option was beneficial | 0 | 0 | 4 | 15 |
| The networking opportunities were valuable | 0 | 0 | 7 | 12 |
| I have significantly increased my understanding of financial compensation and its relevancy for Canada | 0 | 0 | 8 | 11 |



## Is there anything that could have been done differently to make this meeting more beneficial?

A number of respondents indicated that there was nothing further that could have been done. Comments included: "No, excellent organization and background materials," and another "Meeting was extremely well planned – can't think of anything to change" and "No, it was great!" A few, however, offer some suggestions. For example, one suggested that the focus could have incorporated a discussion of approaches from the perspective of the caregiver and the care receivers and others offered that agenda could have been modified to allow more time for discussion, longer breaks for networking, or shorter "reporting back" session in the afternoon. Other suggestions included sending a copy of presentations to participants and holding the workshop in space with windows.

## What follow-up activities would you recommend come out of the workshop?

Respondents indicated that they would benefit from receiving a synthesis of the consultation discussions and an action plan. Moreover, one respondent suggested continuing the dialogue through a conference on caregiving focusing on social, economic and health issues. Otherwise, several expressed interest in remaining involved in the ongoing review and analysis of selected countries' policies and programs and, when available, receiving results from the next phase of the research. At that time, it was also suggested that such results should be communicated with Federal-Provincial-Territorial decision makers.

All but one respondent expressed interest in attending a workshop on supportive policies for caregivers in the tax/transfer system co-sponsored by the Healthy Balance Research Program and Canadian Policy Research Network being planned for 2005.

Other comments offered by participants that attest to the success of the event include:

- Greatly enjoyed the presentations and discussion. Packed a tremendous amount of information into a single day. Lots to think about comparatively.
- Great team!
- Well done – there was a lot of ground to cover in a short period. Not easy but you succeeded!
- Excellent initiative and opportunity for dialogue. We look forward to next steps.
- A great day! I learned a lot and really enjoyed the process. The facilitator and speakers were excellent.
- The afternoon session came up with excellent information and questions for further work on the 6 areas, very good process for meaningful feedback.
- Very well done. Policy profiles were very handy.
- Excellent! Well organized – well done. Very relevant for policy analysis.
- Great job!
- Well organized – useful format to get through the day's workload expectations.
- Excellent workshop, logistics and food.

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