Policy Profile for Compensating Family Caregivers

Janice M. Keefe, Ph.D. Mount Saint Vincent University

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Introduction and Overview

'Hidden Costs/Invisible Contributions: The Marginalization of "Dependent" Adults' (HCIC) is an international, collaborative program of research designed to create a deeper understanding of the place of those characterized as "dependent" in society, specifically, older adults and those persons with disabilities or chronic illness.

The research is divided into four Themes. Theme 3 – Impact of Public Policy on Costs and Contributions – includes a critical examination of national level policies and programs aimed at financially compensating caregivers of dependent adults in ten countries. Policy Profiles have been developed for Australia, Canada, France, Germany, Israel, Netherlands, Norway, Sweden, United Kingdom, and the United States.

These Policy Profiles describe national level direct compensation (e.g. allowances) and indirect compensation (e.g. tax relief) policies for family caregivers. National labour policies that support employed caregivers are also included. Information presented 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.

This Profile describes national level policies and programs that offer compensation for family caregivers in the United States, and summarizes the social policy context for supporting family caregivers.

Home Care in the United States

The United States is a constitution-based federal republic with a population of over 290 million people. It is divided into 50 states and one district. English is the official language and Spanish is spoken by a sizable minority.

There is no national home care program in the United States. Medicaid, a joint federal-state entitlement, is the largest single payer for long-term care services in the United States. Most Medicaid funds pay for institutional care; home and community-based services account for 29.5 % of spending.

There is currently no reimbursement or payment available at the national level for the direct costs for caregiver services. Assistance is available to caregivers through tax relief and the Family and Medical Leave Act (1993) which sanctions unpaid leave of up to 12 weeks during a 12 month period to care for an immediate family member with a serious health condition. The National Family Caregiver Support Program under the Older Americans Act Amendments of 2000, provides states with funds for five direct services to caregivers: information, assistance, counseling and training, respite, and supplemental services.



Highlights

% 65 years and older - 12.4% (2000)

% of 65+ institutionalized - 5.7% (1998)

% of disabled persons age 5+-19.3% (2000)

% of women in labour force – 46% (2000)

% of people requiring daily care – 4.1% (2000)

% gdp for long term care - 1.32% (1992-95)

Caregiver Highlights

In 1996:

- · 73% of caregivers were female.
- 69% of caregivers cared for one person, 23% for two people, and 8% for three or more people.
- 85% of caregivers cared for a relative, and 15% cared for a friend or neighbour.
- 64.2% of caregivers were employed full- or parttime.
- just under half of working caregivers adjusted their work schedules to accommodate caregiving.

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National Compensation Initiatives for Caregivers

Indirect Compensation

Initiative	Federal Child and Dependent Care Tax Credit
Target Group	Employed caregivers of children or dependent adults.
Eligibility Criteria	Caregiver who paid for care of a child under 13 or a spouse or dependent of any age who is physically and mentally incapable of self-care.
	Caregiver must have earned income.
	If married, both parties must have earned income unless one spouse was a full-time student, or was incapable of self-care.
	Care receiver must live with the caregiver.
Entitlement	 Offsets a portion of dependent care expenses against federal income tax liability. The credit is a percentage (20% to 35%) of the amount of work related care expenses paid to a care provider based on income. For 2003, up to \$3,000 USD (\$3,798 CAD) of expenses paid for one qualifying individual can be used, and up to \$6,000 USD (\$7,597 CAD) of expenses paid for two or more qualifying individuals can be used.
	• For 2003, this credit provides up to \$2,100 USD (\$2,700 CAD) (35% of \$6,000 USD – see above) for families with incomes under \$15,000 USD (\$18,995 CAD) and two or more dependents, and up to \$1,200 USD (\$1520 CAD) (20% of \$6,000 USD – see above) for families with incomes under \$43,000 USD (\$54,458 CAD) with two or more dependents.
	These amounts must be reduced by the amount of dependent care benefits provided by an employer that the caregiver excludes from income. (See DCAP below).

Initiative	Dependent Care Assistance Program (DCAP)
Target Group	Employed caregivers of children or dependent adults.
Eligibility Criteria	 Employed caregiver incurs care expenses in order to continue working. If the employee is married, the care must be provided to allow the employee and the employee's spouse to work or look for work, or the spouse must be a full-time student, or unable to care for himself or herself.
Entitlement	 Federal Internal Revenue Code allows an employer to provide an employee with up to \$5,000 USD (\$6,333 CAN) each year in child and dependent care benefits tax free. Benefits may take several forms including cash reimbursements, vouchers, or free or subsidized care. If a taxpayer receives benefits through a DCAP, the amount of the benefits must be subtracted from the child and dependent care expenses used to calculate the Child and Dependent Care Credit.

National Compensation Initiatives for Caregivers

Indirect Compensation

Initiative	Medical Expenses Tax Deduction
Target Group	Caregivers or care receiver.
Eligibility Criteria	 Allowable expenses include the cost of diagnosis, cure, mitigation, treatment. Medical expenses also include dental expenses, premiums paid for insurance that covers the expenses of medical care, and amounts paid for transportation to get medical care. Expenses must be primarily to alleviate or prevent physical or mental illness. Medical expenses also include amounts paid for qualified long-term services and limited amounts paid for any qualified long-term care insurance contract. If the taxpayer either the caregiver or the care-receiver - has medical expenses that exceed 7.5% of their adjusted gross income, medical expenses are deductible.
Entitlement	Caregivers can generally include medical expenses they pay for themselves as well as for someone who was their spouse or dependent either when the services were provided or when the caregiver paid for them. If the caregiver is considered to have provided more than half a person's support under a multiple support agreement, they can include medical expenses they paid for that person, even if they cannot claim an exemption for that person.

Note: No national-level direct compensation initiatives, such as caregiver allowances or wages, were found for the United States.

Current Issues and Debates

While there has been increased recognition of the needs of caregivers in the United States, compensation for caregivers vary considerably from state to state. Many states offer tax relief, and some, such as Georgia and Illinois, are using the National Family Caregiver Support Program to offer informal caregivers options such as vouchers to purchase services, and direct payments to family members. In July 2004, California put its Paid Family Leave law into effect. The law provides replacement of 55% of wages when leave is taken to care for an ill family member or a new baby. Additionally, a Cash and Counseling Demonstration program is underway in three states: Arkansas, Florida, and New Jersey. The program provides cash allowances and information to disabled persons allowing them to purchase and arrange for services that best meet their needs.

At the national level, the focus has been on using the tax system to support caregivers. Two pieces of legislation, the Senior Eldercare Relief and Empowerment (SECURE) Act, introduced in February 2004, and the Ronald Reagan Alzheimer's Breakthrough Act of 2004, introduced in June 2004, would see new tax relief for caregivers.

For more information contact:

Janice Keefe, Ph.D.
Associate Professor &
Canada Research Chair in Aging and Caregiving Policy
Mount Saint Vincent University
Halifax, NS B3M 2J6 janice.keefe@msvu.ca

For additional information on the HCIC project, please visit http://www.hecol.ualberta.ca/rapp/mcri.htm

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Websites

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Caregiver's Home Companion, www.caregivershome.com

Internal Revenue Services, United States Department of the Treasury, www.irs.gov

International Reform Monitor, www.reformmonitor.org

National Alliance for Caregiving, www.caregiving.org

National Association for Homecare, www.nahc.org

National Family Caregiver Support Program Resource Room, www.aoa.gov/prof/aoaprog/caregiver/caregiver.asp

National Governors Assocation, www.subnet.nga.org/ci/4-caregivers.html

National Women's Law Centre, www.nwlc.org

Office of Legislative Policy and Analysis, olpa.od.nih.gov

United States Census Bureau, www.census.gov

United States Department of Health and Human Services, www.hhs.gov

United States Department of Labor, www.dol.gov

United States Senate Special Committee on Aging, aging senate gov

University of Maryland Center on Aging, Cash and Counseling Demonstration, www.hhp.umd.edu/AGING/CCDemo

State Action, www.stateaction.org

The World Bank Group, devdata.worldbank.org/genderstats/home.asp

World Fact Book, www.cia.gov/cia/publications/factbook

World Health Organization, www.who.int

Personal Communications

Friss Feinberg, L., National Caregiver Alliance

Gleason, T., United States Department of Veterans Affairs

Knapp, P., United States Department of Veterans Affairs

The author accepts full responsibility for any errors or omissions in the information presented in this profile.