

# Policy Profile for Compensating Family Caregivers

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## United Kingdom



October 2004



*A project of the "Hidden Costs/Invisible Contributions:  
The Marginalization of 'Dependent' Adults" research program.*



## 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 Kingdom, and summarizes the social policy context for supporting family caregivers.

### Home Care in the United Kingdom

The United Kingdom is a constitutional monarchy governed by an elected parliament, with a multicultural population of 60 million people. While many policies apply to all of the UK, each country (Northern Ireland, Scotland, England and Wales) also enacts health and social policy legislation.

The National Health Service and Community Care Act of 1990 provides for most community based long-term care services to be delivered by local authorities. It is estimated that between April 1, 2001 and March 31, 2002, 600,000 people were in receipt of home help/home care, with 500,000 of these people being aged 65 or older.

The National Health Service and Community Care Act (1990) was the first legislation to formally acknowledge the need to support family caregivers. The Carers (Recognition and Services) Act (1995), which applies only to England and Wales, gave caregivers the right to an assessment of their needs. In 1999, the UK Government announced its National Strategy for Carers, which aimed to enhance the quality of life of caregivers. Since this strategy, England and Wales have passed the Carers and Disabled Children Act (2000), giving local councils the power to supply certain services directly to caregivers.



### Highlights

- % 65 years and older – 16% (2003)
- % of 65+ institutionalized – 5.1% (Great Britain) (1998)
- % of disabled persons – 15% (2001)
- % of women in labour force – 44% (2000)
- % of people requiring daily care – 4.5% (2000)
- % gdp for long term care – 1.3% (Great Britain) (1992-95)

### Caregiver Highlights

In 2000:

- 1 in 6 people over the age of 16 were caregivers.
- 1 in 5 households contained a caregiver.
- 1 in 4 caregivers spent at least 20 hours per week caring, and 1 in 10 provide more than 50 hours per week.
- women were more likely to be caregivers than men and are more likely than men to provide care for someone in another household.
- 4 million caregivers combined work and care.



# National Compensation Initiatives for Caregivers

## Direct Compensation

<b>Initiative</b>	<b>Carer's Allowance (formerly Invalid Care Allowance)</b>
<b>Target Group</b>	<ul style="list-style-type: none"> <li>• Caregivers of a disabled child or adult who is a relative, neighbour or friend.</li> </ul>
<b>Eligibility Criteria</b>	<ul style="list-style-type: none"> <li>• Care receiver is a relative, neighbour or friend.</li> <li>• Care receiver is eligible for Attendance Allowance, Disability Allowance, or Constant Care Allowance.</li> <li>• Caregiver is aged 16 and over and provides at least 35 hours of care per week.</li> <li>• Caregiver may not be eligible if receiving a benefit paid at the same or higher amount such as State Pension.</li> </ul>
<b>Income Tested</b>	<ul style="list-style-type: none"> <li>• Yes, ceiling of £79 per week (\$182 CAD) after eligible deductions.</li> </ul>
<b>Entitlement</b>	<ul style="list-style-type: none"> <li>• Approximately £44 per week (\$108 CAD).</li> <li>• Payment is taxable.</li> <li>• May continue for up to 12 weeks if caregiver or care receiver is in hospital or if care receiver goes into respite care.</li> <li>• Continues for up to 8 weeks after death of the care receiver.</li> <li>• Recipients get a Christmas Bonus of £10 (\$22 CAD) in early December.</li> </ul>

<b>Initiative</b>	<b>Carer Premium</b>
<b>Target Group</b>	<ul style="list-style-type: none"> <li>• Caregivers who qualify for Carer's Allowance.</li> </ul>
<b>Eligibility Criteria</b>	<ul style="list-style-type: none"> <li>• Caregiver is in receipt of the Carer's Allowance or is entitled to Carer's Allowance as an "underlying entitlement".</li> </ul>
<b>Income Tested</b>	<ul style="list-style-type: none"> <li>• Yes.</li> </ul>
<b>Entitlement</b>	<ul style="list-style-type: none"> <li>• An extra amount of up to £25 per week (\$62 CAD) included in the calculation of means-tested benefits such as income support, income-based job seeker's allowance, housing benefit and council tax rebate.</li> <li>• Extended for 8 weeks after caregiving has ceased.</li> </ul>

<b>Initiative</b>	<b>Direct Payments</b>
<b>Target Group</b>	<ul style="list-style-type: none"> <li>• Older or disabled persons and caregivers of an older or disabled person or disabled child.</li> </ul>
<b>Eligibility Criteria</b>	<ul style="list-style-type: none"> <li>• Older person or a disabled person aged 16 and over.</li> <li>• Caregiver aged 16 and over who provides a substantial amount of care on a regular basis for someone aged 18 and over.</li> <li>• Cannot be used to pay a spouse or close relative who lives in the same household as the care receiver, unless the local council determines that this is appropriate.</li> <li>• Can be used to pay a close relative that lives outside of the care receiver's home.</li> </ul>
<b>Income Tested</b>	<ul style="list-style-type: none"> <li>• No.</li> </ul>
<b>Entitlement</b>	<ul style="list-style-type: none"> <li>• Local councils determine the amount of the payment based on an assessment of needs.</li> <li>• Amount must be equivalent to the reasonable cost of securing the needed services.</li> <li>• There are restrictions on what kinds of services can be purchased and who they can be purchased from.</li> <li>• Caregivers in receipt of direct payments must use the funds to purchase services for their own needs.</li> <li>• Payment is not taxable.</li> </ul>



# National Compensation Initiatives for Caregivers

## Indirect Compensation

Initiative	<b>Pension Protection (including Home Responsibilities Protection Program)</b>
Target Group	<ul style="list-style-type: none"> <li>• Caregivers who do not work or are low income earners.</li> </ul>
Eligibility Criteria	<ul style="list-style-type: none"> <li>• Caregiver in receipt of Carer's Allowance who is entitled to pension protection through the Carer's Allowance program.</li> <li>• Caregiver not in receipt of the Carer's Allowance can receive pension protection under the <b>Home Responsibilities Protection (HRP)</b> program if the following conditions are met:               <ul style="list-style-type: none"> <li>- Caring for someone at home.</li> <li>- Receives income support and does not need to register for work due to caregiving responsibilities or regularly spends at least 35 hours a week looking after someone who is getting Attendance Allowance, Disability Living Allowance, or Constance Care Allowance.</li> <li>- Must not work and have no qualifying earnings for the full tax year, or do some work but not earn enough to make it a qualifying year.</li> </ul> </li> </ul>
Entitlement	<ul style="list-style-type: none"> <li>• Recipients of the Carer's Allowance will be credited with a National Insurance contribution for each week receiving the Allowance.</li> <li>• HRP provides protection for the basic state pension whereby years in receipt of HRP are taken away from the number of qualifying years needed to calculate pension entitlement.</li> </ul>

Initiative	<b>State Second Pension for Carers</b>
Target Group	<ul style="list-style-type: none"> <li>• Caregivers who do not work or are low income earners.</li> </ul>
Eligibility Criteria	<ul style="list-style-type: none"> <li>• Caregiver must qualify for either Home Responsibilities Protection or be under State Pension age and entitled to Carer's Allowance.</li> <li>• Must not work at all, or earn less than the annual Lower Earning Limit of £4,108 for 2004/2005 (\$9,226 CAD).</li> </ul>
Entitlement	<ul style="list-style-type: none"> <li>• For additional State Pension purposes, the caregiver is treated as if his/her earnings are at the Low Earnings Threshold of £11,600 for 2004/2005 (\$26,050 CAD).</li> <li>• While caregivers began to accrue credits under this scheme in 2002, State Second Pensions for Carers will not be payable until 2050.</li> </ul>

Initiative	<b>Council Tax Discount for Carers</b>
Target Group	<ul style="list-style-type: none"> <li>• Caregivers caring for someone in their home.</li> </ul>
Eligibility Criteria	<ul style="list-style-type: none"> <li>• Caring for someone for at least 35 hours a week, in the same house, who is in receipt of a Attendance Allowance or Disability Living Allowance.</li> <li>• Care receiver is not the caregiver's spouse or child under the age of 18.</li> </ul>
Entitlement	<ul style="list-style-type: none"> <li>• Discount on Council taxes may be available.</li> </ul>



## Current Issues and Debates

There are a number of organizations in the UK that focus on the needs of caregivers, such as Age Concern, Help the Aged, Carers UK, and The Princess Royal Trust for Carers. These organizations provide a range of services and are actively involved in political lobbying and advocacy.

Individual countries in the United Kingdom have developed legislation to support caregivers. In 2002, Scotland's Community Care and Health Act extended new legal rights to unpaid caregivers. The Caring (Equal Opportunities) Act (2004), which extends only to England and Wales, was recently passed. The Act gives caregivers more choice and opportunities to lead a full life. The three primary aims of the Act are to ensure that caregivers are given the information they need, including information about their rights, to make informed decisions about their lives; to ensure that caregivers' health, in its broadest sense, is positively considered by social services; and help to give caregivers more opportunities in education, training and employment. There is currently no caregiver's legislation in Northern Ireland.

The introduction of the State Second Pension for Carers marks an important step in supporting caregivers. Caregivers will not be able to receive payments from the program until 2050, but the program is significant in that it acknowledges the impact of financial sacrifices made while caregiving on long-term financial security.

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### For additional information on the HCIC project, please visit

<http://www.hecol.ualberta.ca/rapp/mcri.htm>

*Thank you to the HCIC team members and external reviewers for their input and for the contribution of research staff - Jennifer Colepaugh, Pamela Fancey, Beth Rajnovich, and Sheri White.*

## Bibliography

### Publications

- Dair, A. (2004) Social security and related benefits that may be available to persons with disabilities and their carers. Staffordshire County Council, Social Care and Health Department.
- Keefe, J.M., & Fancey, P.J. (1998). Financial compensation versus community supports: An analysis of the effects on caregivers and care receivers. Final Report.
- Nolan, M., Barber, L., Edis, A., Brown, J., & McKee, K. (2004). Services for supporting family carers of elderly people in Europe: Characteristics, Coverage and Usage – National background report for the United Kingdom. EUROFAMCARE. Retrieved September 14, 2004 from [www.uke.uni-hamburg.de/institute/medizinsoziologie/ims2/gerontologie/eurofamcare/presentations.html](http://www.uke.uni-hamburg.de/institute/medizinsoziologie/ims2/gerontologie/eurofamcare/presentations.html)
- Montgomery, A., & Friss Feinberg, L. (2003). The road to recognition: International review of public policies to support family and informal caregiving. Policy Brief. Family Caregiver Alliance – National Center on Caregiving.

### Websites

- British Council, [www.britishcouncil.org](http://www.britishcouncil.org)
- Carers UK, [www.carersonline.org.uk](http://www.carersonline.org.uk)
- International Reform Monitor, [www.reformmonitor.org](http://www.reformmonitor.org)
- Department of Health, Government of the United Kingdom, [www.dh.gov.uk](http://www.dh.gov.uk)
- Department for Works and Pensions, Government of the United Kingdom, [www.dwp.gov.uk](http://www.dwp.gov.uk)
- Inland Revenue, Government of the United Kingdom, [www.inlandrevenue.gov.uk](http://www.inlandrevenue.gov.uk)
- National Statistics, Government of United Kingdom, [www.statistics.gov.uk](http://www.statistics.gov.uk)
- Multikulti, [www.multikulti.org.uk](http://www.multikulti.org.uk)
- Rochdale UK, [www.rochdale.gov.uk](http://www.rochdale.gov.uk)
- The Pension Service, Government of the United Kingdom, [www.thepensionservice.org](http://www.thepensionservice.org)
- The World Bank Group, [devdata.worldbank.org/genderstats/home.asp](http://devdata.worldbank.org/genderstats/home.asp)
- World Fact Book, [www.cia.gov/cia/publications/factbook](http://www.cia.gov/cia/publications/factbook)
- World Health Organization, [www.who.int](http://www.who.int)

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