

Policy Profile for Compensating Family Caregivers

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*A project of the "Hidden Costs/Invisible Contributions:
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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 Sweden, and summarizes the social policy context for supporting family caregivers.

Home Care in Sweden

Sweden is a constitutional monarchy governed by an elected parliament. It is divided into 21 counties and 290 municipalities and has a population of almost 9 million. Swedish is the official language.

In Sweden, the national level government sets policy and directives, while the county councils are responsible for providing health care, and the municipalities provide social services. Home help, which includes help with activities of daily living and personal hands-on care, is the core service provided to those in need of care. In 2003, 128,000 persons aged 65 and over received home help, and almost half of these also received home nursing care. As both the counties and municipalities have a high degree of autonomy, there is significant variation in how they interpret their responsibility to provide services and care.

A number of national measures exist to support family caregivers. The 1989 Care Leave Act provided caregivers with a period of paid leave to care for an ill elderly relative. In 1998, an addition was made to the Social Service Act that encouraged local municipalities to support family caregivers. In 1999, the National Action Plan on Policy for the Elderly was implemented. One of the major initiatives was a national grant to increase caregiver support.



Highlights

- % 65 years and older – 17.3% (2003)
- % of 65+ institutionalized – 8.7% (1998)
- % of disabled persons age 16-64 – 20.8% (2003)
- % of women in labour force (age 16-64) - 49% (2000)
- % of people requiring daily care – 4.6% (2000)
- % gdp for long term care – 2.7% (1992-95)

Caregiver Highlights

A 2001 study indicates that in 1998-99:

- 79% of persons aged 16-64 and 65% of persons aged 65-84 who needed practical help and lived at home received only informal help.

National Compensation Initiatives for Caregivers

Direct Compensation

Initiative	Attendance Allowance
Target Group	<ul style="list-style-type: none"> Elderly persons who requires assistance from a family member.
Eligibility Criteria	<ul style="list-style-type: none"> No age restriction for family caregiver. Based on level of dependency/amount of caregiving, calculated in hours of help needed/given per week. Many municipalities have 17 hours of caregiving per week as a cut-off criteria. Eligibility criteria vary by municipality.
Income Tested	<ul style="list-style-type: none"> No.
Entitlement	<ul style="list-style-type: none"> This is an untaxed payment that goes to the care receiver to be used to pay the family caregiver. Maximum payment is about SEK 5000 per month (\$860 CAD). Payment amounts vary by municipality.

Initiative	Carers' Allowance
Target Group	<ul style="list-style-type: none"> Caregivers of elderly dependents.
Eligibility Criteria	<ul style="list-style-type: none"> Caregiver must be under 65 years of age. Eligibility criteria vary by municipality.
Income Tested	<ul style="list-style-type: none"> No.
Entitlement	<ul style="list-style-type: none"> Salary equal to that of a formal home help service provider employed by the municipality. Provides similar social security protection as for formal caregivers.

Initiative	Assistance Allowance
Target Group	<ul style="list-style-type: none"> Persons with disabilities requiring personal assistance from a family member.
Eligibility Criteria	<ul style="list-style-type: none"> Care receiver must be under the age of 65. Care receiver is severely disabled and requires personal assistance with the activities of daily life (personal hygiene, dressing, eating, communication with others) for an average of more than 20 hours per week. Care receiver's needs are assessed to determine amount of allowance.
Income Tested	<ul style="list-style-type: none"> No.
Entitlement	<ul style="list-style-type: none"> Based on the number of hours of care needed. Payment is taxable.

National Compensation Initiatives for Caregivers

Indirect Compensation

Initiative	Pension Credits
Target Group	<ul style="list-style-type: none">• Caregivers.
Eligibility Criteria	<ul style="list-style-type: none">• Caregiver is in receipt of Carer's Allowance or Care Leave.
Entitlement	<ul style="list-style-type: none">• Credits accrue with credits from other kinds of income.

Labour Policies

Initiative	Care Leave Act (1989)
Target Group	<ul style="list-style-type: none">• Caregivers of a terminally ill relative.
Eligibility Criteria	<ul style="list-style-type: none">• Caring for a close relative in a terminal care situation.• Caregiver must be under the age of 65.
Entitlement	<ul style="list-style-type: none">• Paid absence from work for up to 60 days, with number of days being contingent on the care receiver.• Payment is made by National Social Insurance and is taxable.• As of 1998, the level of payment is 80% of the income qualifying for sickness insurance benefit.

Current Issues and Debates

Supports for family caregivers in Sweden vary significantly by municipality. In 2003 only 47% of municipalities offered the Attendance Allowance, and only 28% offered the Carers' Allowance. Financial support is seen as a last resort solution to be used in situations where the cost of providing services greatly exceeds the cost of employing a family member as a caregiver.

The three-year National Action Plan for Policy on the Elderly (1999-2001) provided funding to municipalities to develop infrastructure to support caregivers, and resulted in a significant expansion of services. Respite services are now available in almost all municipalities and counseling and personal support services have expanded at the municipal level. Evaluation of this initiative also revealed that there is a great deal of work that needs to be done to improve the quality of supports offered to caregivers.

Support for caregivers continues to be part of the political agenda in Sweden. If and how support for family caregivers should be legislated as an entitlement is an issue of growing importance for the Ministry of Social Affairs in Sweden. In addition, an organization called Carers Sweden, founded in 1996, is becoming a significant voice for caregivers. This organization's goals are to be a national umbrella organization and to promote the needs of caregivers through advocacy, information and awareness-raising activities.

For more information contact:

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

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- International Reform Monitor, www.reformmonitor.com
- National Alliance for Caregiving, www.caregiving.org
- Peer Review Program of the European Employment Strategy, www.almp.org
- Swedish National Board of Health and Welfare, www.socialstyrelsen.se
- Statistics Sweden, www.scb.se
- 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 Communication

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