

Care provision within families and its socio-economic impact on care providers across the European Union

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Across Europe family members provide by far the largest amount of care for older, disabled and chronically ill people; family care is essential for the sustainability of many countries' long-term care arrangements. This study provides up-to-date evidence from across the European Union (EU) on the numbers and characteristics of carers and the consequences of caring.

- In 2005 it was estimated that, across the European Union, 19 million people aged 25 and over provided at least 20 hours a week care for an elderly, disabled or chronically ill person. Around 9.6 million of them provided at least 35 hours a week care. There are also thought to be 2 to 4 million young people with additional care responsibilities.
- Patterns of informal care, society attitudes towards family responsibilities and the availability of services to support older and disabled people and/or carers all vary widely between member states. These differences are reflected in the lower quality of life reported by carers in Mediterranean and eastern European countries, compared to countries with developed welfare services like the UK and Sweden.
- Across Europe, women predominate both as carers and care recipients. The gender bias of carers is even more marked when physically intimate and/or emotionally demanding care is involved.
- Care-giving is associated with adverse health and socio-economic effects. Carers living in the same household as the person they care for provide more intensive care and are less likely to be employed than carers looking after someone living elsewhere.
- Across the EU there are different policies and service initiatives aimed at supporting carers, but few have been independently evaluated for evidence of their effectiveness.
- There is a lack of comprehensive or comparable national and EU-wide evidence on carers. Studies use different definitions to identify carers. Most evidence is on carers of older people or elderly parents; there is also a growing body of research on relationships between paid work and care-giving. There is much less evidence on carers of younger people, older carers, carers from ethnic minority communities, or other groups of carers.

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Background

Informal and family care has developed a high profile across EU policies. Given EU-wide demographic trends, family care plays a critically important role in keeping down the costs of long-term care services in member states. Family care also has major implications for the European employment strategy; for EU actions on Social Services of General Interest; for gender equality actions; and in other EU policy domains.

This study aimed to collate evidence on:

- the prevalence of family care-giving within member states and across the EU
- the socio-economic impact of care-giving on the households of carers, focusing on carers with the heaviest responsibilities and on gender inequalities
- measures aimed at alleviating pressures on family carers by:
 - supporting them in providing care
 - compensating for the adverse socio-economic consequences of care-giving.

Findings

Numbers of carers across the EU

Estimates vary according to the methods used to identify carers with more than minimal care responsibilities; estimates also vary because different countries have been included as the EU has enlarged over recent years. It was estimated in 2005 that, if only those providing 20-plus hours a week care are included, there were 19 million carers aged 25-plus, of whom 9.6 million had heavier responsibilities of 35-plus hours care per week. Numbers of carers are expected to grow by 13 per cent by 2030, with marked increases in older carers. However, it is not clear whether new member and accession states have been included in these estimates. In addition, there are an estimated 2 to 4 million young people with additional care responsibilities for a disabled person.

What carers do

EU-wide research in 2007 found carers reported carrying out on average three care-related tasks, including at least one involving personal care. In addition, half reported visiting or keeping the care recipient company. One in five carers reported helping by organising professional care. Periods of care-giving last on average five years, but may be much longer where conditions such as dementia are involved.

Carers of older people

Across the EU, carers of older people are the most extensively researched. Three-quarters are women; their average age is 55; almost half are daughters or sons of the older person. On average they provide 45.6 hours per week; the median (middle value) is 24 hours per week. Two-fifths of carers of older people are also in paid work. A perceived absence of any alternative – that is accessible, good quality, public, long-term care services – is a common reason for providing care. Adverse physical, psychological and social consequences of caring are commonly reported.

Carers of non-elderly people

The study examined evidence from England, Flanders (Belgium), Netherlands, Austria and Italy about carers of non-elderly people. Evidence is sparse and fragmented; differences in sources of information and definitions of carers make comparisons between countries virtually impossible.

Box 1: Meeting Centres Support Programme (MCSP), Netherlands

There are 46 Meeting Centres across six provinces in the Netherlands. The Programme integrates different types of support for people with mild or moderate dementia and their carers:

- Special activities and psychosocial programmes for people with dementia.
- Information, emotional, social and practical help for carers.

Each person with dementia and their carer is looked after by the same staff worker.

Evaluations of the MCSP have found:

- 82 per cent of carers report lower felt burdens
- MSCP is more effective than standard dementia day care in decreasing the psychological problems of lonely carers
- significantly fewer people with dementia enter institutional care compared with those using standard dementia day care.

Again the majority of carers are female and aged 45-plus. Most live with the care recipient, an indicator of more intensive care-giving and a reflection of the prevalence of care for disabled or ill spouses and children among this group. Negative impacts on carers' physical and emotional health are again apparent. Those providing over 20 hours a week care are particularly likely to reduce their paid work; women are more likely than men to work part-time or stop work altogether.

Older carers

Currently the most common age of carers across the EU is 50–64. However, the prevalence of carers who are themselves over retirement age will increase as more spouses of older people become carers; their ages will also increase along with population ageing.

Care and gender

Across the EU, women provide the bulk of care. This gender bias is even clearer in relation to provision of intimate personal and/or emotionally demanding care. However, with population ageing, more men are likely to become carers in their own old age.

Care and paid work

There is consistent evidence on relationships between care and reduced labour market participation; more intensive care-giving is associated with a lower probability of labour market activity by working age women. However, the extent of the impact on labour market activity varies, depending on gender, local opportunities for part-time work, the availability of services and attitudes towards family responsibilities. In southern European countries, working age women are more likely to have reduced labour market participation than in western Europe and Scandinavia. Causal relationships are not clear; some carers may take on care responsibilities because they are already unemployed or full-time housewives.

Examples of good practice in supporting carers

Some types of financial support to help with the costs of care that are aimed at disabled or older people (for example, care allowances, personal budgets) can also benefit carers financially. However, these measures may restrict carers in undertaking paid work and/or accessing formal services. In some countries, carer benefits recognise carers' rights to an independent income and the impact of care on their earnings. Models of financial support may reinforce gender inequalities in responsibilities for care.

There are many innovative services to support carers, but few have been independently evaluated to demonstrate what works, why and for which groups of carers. Measures that appear to provide effective support for carers include packages of complementary interventions tailored to specific groups of carers and those they care for (see Box 1). Apart from short-term or unpaid leave, policy measures to help carers stay in or return to work are scarce.

Policy recommendations

Carers are central to ensuring long-term care systems are affordable; but carers are also a significant part of member states' labour supply.

- The EU should encourage member states to conduct research that makes visible the roles of carers; their contributions to sustainable long-term care systems; and the actual and hidden costs of those contributions.
- Member states should consider the potential contributions of family carers

in the context of growing EU-wide pressures on the long-term care workforce – for example, contributing skills acquired while caring towards qualifications for paid care work.

- EU-wide policy actions could be facilitated through the Open Method of Co-ordination (an EU programme to enable member states to share experiences and good practice), with future rounds focusing specifically on carers.
- 2012 will be European Year of Intergenerational Solidarity – an ideal opportunity to highlight the intergenerational transfers of care from children to elderly relatives.
- EU employment policies, including those on extending working lives, should take into account the significant care responsibilities of working age people. Closer links are also needed between policies on informal care and those on the professional care workforce, so that both are treated as part of an integrated long-term care workforce. Well-evaluated policies and practices to support carers in paid work while caring, or help them retain contact with the labour market during a period of leave, are also needed.

About the study

- The study used EU and other cross-national datasets, including the Eurofamcare study of care for older people.
- Expert informants from England, Netherlands, Flanders, Italy and Austria (where data was expected to be available), were asked to supply national data on carers of non-elderly people.
- Expert informants and members of the Eurocarers network supplied examples of 'good practice' in supporting carers and/or alleviating adverse impacts of care, giving priority to examples that had been independently evaluated.

Challenges in conducting the study

There is little EU-wide data on numbers of carers, even those with heavy responsibilities. The most extensive evidence is on family care for older people, particularly the Eurofamcare study (www.uke.de/extern/eurofamcare).

There were greater difficulties in collating information on carers of non-elderly people. Studies do not always specify the age of care recipients and different criteria are used to identify carers with heavy responsibilities. In some countries, evidence on carers is estimated from information about the care needs of disabled or older people or from data on care allowance recipients.

Identifying carers with heavy responsibilities is difficult. Subjective experiences of burden do not always correspond to objective measures (for example, hours of care per week). Subjective and objective measures are also affected by countries' beliefs about the responsibilities of families and the state and by the actual availability of services. It was rare for national surveys to identify carers providing, say, over 20 or over 35 hours per week care and focus on their circumstances; heavy care responsibilities tend to be used as a dependent rather than an independent variable.

The study identified a number of innovative service initiatives to support carers, but few had been independently evaluated to show their effectiveness and cost-effectiveness.

Further information

The study was commissioned by the Directorate General for Employment, Social Affairs and Equal Opportunities of the European Commission under contract VT/2008/0029. It was carried out by Caroline Glendinning (SPRU), Hilary Arksey (SPRU), Frits Tjadens (Health and Social Care Associates), Marjolein Morée (Vilans Centre of Expertise on Long-Term Care, Utrecht), Nicola Moran (SPRU) and Henk Nies (Vilans Centre of Expertise on Long-Term Care, Utrecht).

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The full working paper Glendinning, C., Arksey, H., Tjadens, F., Morée, M., Moran, N. and Nies, H. (2009) *Care Provision within Families and its Socio-Economic Impact on Care Providers*, can be downloaded from the SPRU website: www.york.ac.uk/spru/research/pdf/EUCarers.pdf and from: www.hasca.eu or www.vilans.nl

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