
Care Provision within Families and its Socio-Economic Impact on Care Providers

Policy Briefing

Caroline Glendinning¹

Hilary Arksey¹

Frits Tjadens²

July 2009

Working Paper No.

BRF 2350

1. Social Policy Research Unit, University of York, UK

2. Health and Social Care Associates, Alphen aan den Rijn, Netherlands

© Social Policy Research Unit, University of York 2009

All rights reserved. Reproduction of this report by photocopying or electronic means for non-commercial purposes is permitted. Otherwise, no part of this report may be reproduced, adapted, stored in a retrieval system or transmitted by any means, electronic, mechanical, photocopying, or otherwise without prior written permission of the Social Policy Research Unit, University of York.

ISBN 978-1-903959-13-8

A CIP catalogue record for this report is available from the British Library.

Further copies of this report or any other Social Policy Research Unit publication can be freely obtained by visiting our website:

www.york.ac.uk/spru

Paper copies can be obtained from:

The Publications Office
Social Policy Research Unit
University of York
Heslington
York
YO10 5DD

Disclaimer

The report on which this Policy Briefing is based was commissioned by the Directorate General for Employment, Social Affairs and Equal Opportunities of the European Commission under contract VT/2008/0029. The authors are grateful for the comments of staff members on an earlier draft of the report. The views expressed in this Policy Briefing are those of the authors alone.

Care Provision Within Families and the Socio-Economic Impact on Care Providers

What is informal and family care?

Most families provide help for their relatives, close friends and neighbours when they are disabled, elderly or chronically ill. Giving help usually arises out of relationships based on love and obligation. However, for some people it can become a major responsibility, affecting their paid work, income, social activities and other family relationships.

Because care-giving takes place within ordinary relationships with family and friends, it is often a hidden process and information about care and carers is not easily accessible. Moreover, carers can be described in many different ways – according to their own characteristics (for example, their age, gender, ethnicity); according to the characteristics of the person receiving care (for example, as carers of people with mental health problems or carers of people with dementia); or according to the relationship between the carer and care receiver (for example, as spouse carers or parent carers). Some countries derive information about carers from research on the needs of disabled and elderly people; other countries use information on people receiving care benefits or allowances to estimate numbers of carers. Across EU member states, there is more information about carers of older people. Information on carers of working age adults or disabled children is fragmented, where it exists at all. There is more information about the gender of carers and their position within the labour market, but less about carers' ages. Research on carers in particular kinds of relationships tends to focus on adult children caring for elderly parents.

How many carers are there across the EU?

It is difficult to know the exact number of carers across the EU. Definitions of carers and the amount of information about them vary considerably between countries. Estimates are also affected by the recent EU enlargement process. However, member states that have few policy measures to support informal carers also generally lack information about their numbers and needs.

Using data from 2003 to 2005, the best available estimate is that there were 19 million people aged 25-plus in the EU¹ providing at least 20 hours care a week to an elderly or disabled person. Of these, around 9.6 million were estimated to provide at least 35 hours a week care and therefore to have particularly substantial

¹ It is not clear whether this estimate relates to the EU25 and/or includes additional accession countries.

responsibilities. In addition, between two and four million young people across the EU are thought to have additional care responsibilities because of a relative's illness or disability. With population ageing, the number of carers in the EU is expected to increase by 2030 by 13 per cent, to 21.5 million providing at least 20 hours a week care and 10.9 million providing at least 35 hours a week care. The numbers and proportions of older people who are themselves carers will also increase.²

Even in countries with extensive formal long-term care services, the contributions of informal carers vastly exceed those of professional services. In England, the value of the care provided by family carers is thought to exceed the budget of the National Health Service for the whole UK.³ Across the EU, there are estimated to be over one million professional nurses, in contrast to the 9.6 million family carers providing 35-plus hours a week care.⁴

Who are informal carers?

Carers are a diverse and heterogeneous population. However, care is gender-biased. In all countries, women are more likely to be carers and are also more likely to provide more physically intimate, emotionally demanding and longer-term care. The numbers of men caring are smaller; they care for fewer hours per week; and they undertake less onerous and stressful tasks (unless they are caring for partners/spouses).

Of those caring for an older person, 76 per cent are women, according to EU-wide research. Carers of older people have an average age of 55; nearly half are children of the older person; the mean number of hours per week spent caring is 45.6; and the average care episode lasts for five years.⁵ However, some older carers, particularly those looking after a spouse with dementia, may provide more than 70 hours a week care, for up to nine years.

People caring for non-elderly disabled people are likely to be aged 45 and over; again a majority are women. Most live with the person they are caring for – an indication of more intensive care-giving and a reflection of the prevalence of care for spouses and disabled children among this group. Parents caring for a disabled child have particularly substantial and long-term care responsibilities.

² Grammenos, S. (2005) *Implications of Demographic Ageing in the Enlarged EU in the Domains of Quality of Life, Health Promotion and Health Care. Studies on the policy implications of demographic changes in national and community policies*, Lot 5 Contract VC/2004/0076 no S12.396079, Brussels.

³ Bucker, L. and Yeandle, S. (2007) *Valuing Carers – Calculating the Value of Unpaid Care*, Carers UK, London.

⁴ EFN (2003) *Position Statement on Recruitment*, April (reviewed June 2007).

⁵ Triantafillou, J. and Mestheneos, E. (2006) *Summary of Main Findings from Eurofamcare*, Institute for Medical Sociology, University of Hamburg, Hamburg.

What impact does informal care have on carers' well-being and health?

Relationships between actual levels of care responsibilities and carers' subjective experiences of burden are not always straightforward. However, in general, the more intensive and demanding the care that is provided, the higher the likelihood of adverse physical and psychological effects on carers. Among carers of older people, depression and exhaustion are found to be common. Half the carers of older people across Europe report feeling 'trapped' in their care situation; other reported problems include juggling with time and attenuated social networks.⁶

Carers of non-elderly people are also likely to report negative impacts on their physical health and well-being.

The risks of adverse effects on carers' health and well-being increase with the level and intensity of care provided, and with levels of other competing responsibilities, such as paid work and childcare. Factors likely to increase the risk of adverse effects on carers' health include cognitive impairments and/or physical immobility on the part of the care recipient; caring for a spouse; and living in the same household as the care recipient. Care which is given because of a lack of any perceived alternative, rather than out of love and affection, also leads to higher levels of burden felt by carers.

The risks of poor physical and emotional health arising from care can be reduced by the provision of support and services for the care giver and/or care receiver. In some countries, for some age groups, religion may also alleviate feelings of depression.⁷

What impact does informal care have on carers' paid work and finances?

Patterns of paid work and care vary widely across the EU, depending on national and regional long-term care systems, family cultures and labour market conditions. There is nevertheless a clear relationship between reduced labour market participation and care responsibilities. Moreover, as the intensity of care-giving increases (as measured in the number of hours per week spent giving care), so the adverse effects on carers' paid work become more apparent. However, the nature of the relationship differs for men and women and also between countries with different labour markets; opportunities to combine part-time paid work with informal care responsibilities are

⁶ Lamura, G., Mnich, E., Bien, B., Krevers, B., McKee, K., Mestheneos, L. and Döhner, H. (2007) *Dimensions of Future Social Service Provision in the Ageing Societies of Europe*, VI European Congress of the International Association of Gerontology and Geriatrics, 5-8 July, St Petersburg.

⁷ TEUSURE (2006) *Services for Supporting Family Carers of Older Dependent People in Europe: Characteristics, coverage and usage. The TransEuropean Survey Report (Eurofamcare)*, February. Available at http://www.uk.de/extern/eurofamcare/documents/deliverables/teusure_web_080215.pdf.

not evenly distributed between women and men, nor across the EU. Thus working age women with heavy care responsibilities are much less likely to be in paid work in Southern European countries than in Western European and Scandinavian countries.

People with heavy care responsibilities (particularly those caring for someone in the same household) are less likely than people with light or no care responsibilities to be in full-time paid work⁸ and, if working part-time, are also likely to work fewer hours. However, it is not clear whether people with heavy care responsibilities have to give up or reduce their hours of paid work because of these commitments; or whether they have taken on substantial care responsibilities because they are already out of the labour market, for example, as housewives, unemployed or retired people. Because, in general, women are more likely to find part-time work, the adverse financial impact of caring can be more serious for men, who may have to give up paid work altogether. However, even part-time work opportunities can have adverse impacts on carers' current and future earnings and careers. Carers who are unable to combine paid work and informal care have a reduced probability of re-entering the labour market once care-giving ends. Moreover, any period of reduced labour market participation affects carers' own pensions, savings and financial independence in their own old age.

Variations in informal care between EU countries

Across the EU, social attitudes towards the roles and responsibilities of families and levels of professional long-term care services for older and disabled people vary widely. This means that the numbers of informal carers and the responsibilities they carry also differ from country to country. Where families are assumed to be primarily responsible for the care of older and disabled people, fewer resources are made available for formal services,⁹ thus placing greater burdens on informal carers and often taking their contributions for granted.¹⁰ The prevalence of informal care and the experiences of carers also reflect differences in employment patterns (particularly among women); in the prevalence of extended, multi-generation households,¹¹ and in social-cultural norms and expectations. Thus carers in Mediterranean¹² and Eastern

⁸ Schultz, E. (2004) *Use of Health and Nursing Care by the Elderly*, Enepri Research Report No. 2, July.

⁹ Lamura, G., Mnich, E., Bien, B., Krevers, B., McKee, K., Mestheneos, L. and Döhner, H. (2007) *Dimensions of Future Social Service Provision in the Ageing Societies of Europe*, VI European Congress of the International Association of Gerontology and Geriatrics, 5-8 July, St Petersburg.

¹⁰ Kröger, T. (ed.) (2003) *Families, Work and Social Care in Europe. A Qualitative Study of Care Arrangements in Finland, France, Italy, Portugal and the UK*, Work package 6, Final Report, Contract HPSE-CT-1999-00010: New Kinds of Families, New Kinds of Social Care, European Commission, 5th Framework Programme Key Action for Socio-Economic Research, Brussels.

¹¹ Mestheneos, E. and Triantafillou, J. (2005) *Supporting Family Carers of Older People in Europe – the Pan-European Background Report*. Available at www.uke.uni-hamburg.de/extern/Eurofamcare/publikationen.ph.

¹² Mestheneos, E. and Triantafillou, J. (2005) *Overview Summary of the Eurofamcare Trans-European Survey Report*, Athens/Hamburg. Available at http://www.uke.de/extern/eurofamcare/documents/overview_teusure.pdf.

European¹³ countries are likely to experience greater pressures than carers in western European and Scandinavian countries. Moreover, in countries where social protection measures are poor, carers may have to give material or financial help to the disabled or older person they care for as well.

What measures can help to support carers in providing care?

Providing support to carers is vitally important in ensuring good quality care and reducing the risks of increased ill-health among carers. There are many examples of 'good practice' services and other initiatives aimed at supporting carers, although few have been carefully evaluated, particularly for their cost-effectiveness. The limited available evidence indicates that initiatives with the potential to benefit carers are those that involve a 'package' of complementary interventions or a combination of different approaches that provide synergy (for example, day care combined with psychosocial support and practical help for carers); that tailor support to the specific needs of particular groups of carers and care recipients (for example, people with dementia and their carers); that consider the needs of both the carer and care recipient; that are embedded within existing networks and services; and that are easily accessible and low cost.

What measures can help to compensate carers for the adverse socio-economic impacts of care?

There are different ways of supporting informal carers financially. Some of these are aimed primarily at the person needing care but may also be of benefit to carers:

- In some countries (for example, Austria, Germany) the person needing care receives a care allowance or benefit; s/he may then give money to an informal carer. However the carer has no independent income of her own and may become financially dependent on the person receiving care. Moreover, if the care allowance is intended to be a substitute for professional services, carers may find it difficult to get any support themselves; they may also find it hard to undertake paid work at the same time as caring.
- In the Netherlands, disabled and older people can receive a cash Personal Budget instead of services in kind. Around one-third of recipients use this to employ an informal carer; another third buy a combination of informal and agency care. If carers work more than a minimum number of hours they must be employed under standard labour market terms and conditions.

¹³ Alber, J. and Köhler, U. (2004) *Health and Care in an Enlarged Europe*, European Foundation for the Improvement of Living and Working Conditions, Dublin.

- In other countries (for example, UK, Ireland), carers who are unable to take paid work can receive an income replacement benefit in their own right. This also recognises carers' rights to an independent income of their own; however, these benefits are usually means-tested and very low in value.
- In some Scandinavian countries carers can be employed by the municipality, to replace formal home help services.
- In the Netherlands carers can receive financial compensation simply as a token recognition of their role.

Different models of financial support have implications for carers' ability to undertake other paid work while caring and to access formal services that substitute for family care and thus provide a break from care. Indeed, some models of financial support assume informal care to be a full-time role; they therefore restrict carers' access to paid work and also inhibit the development of services to support carers and care recipients. Thus some models have the potential to increase the risks of poverty and stress among carers. Because all models provide relatively low levels of financial support, they also reinforce gender inequalities¹⁴ and do little to bridge the boundaries between informal care and paid work.

Why are informal carers important for EU and member states' policies?

In all EU countries, informal care is essential to the sustainability of long-term care systems; public funding could not cover the contributions made by informal carers. The importance of carers' contributions will increase in future, as the numbers of older and very old people increase.¹⁵

However, working age carers are also potentially part of the labour force and are therefore essential to realising the Lisbon Strategy and the EU's ambition of becoming the world's leading knowledge economy. Moreover, the European Employment Strategy encourages the extension of working life; this will need to take into account the prevalence of significant care responsibilities among people in late middle age and the growing care responsibilities of older people themselves.

At present, there is a lack of clarity in EU and member state policies as to whether to encourage people to become carers, at the expense of their potential economic contributions through employment; or encourage them to remain in or return to paid

¹⁴ Jenson, J. and Jacobzone, S. (2000) *Care Allowances for the Frail Elderly and their Impact on Women Care-Givers*, DEELSA/ELSA/WD (2000)2, Organisation for Economic Co-operation and Development, Paris.

¹⁵ *The 2009 Ageing Report: Economic and budgetary projections for the EU-27 Member States (2008-2060)*, Forthcoming EUROPEAN ECONOMY 2|2009 (Working document) Joint Report prepared by the European Commission (DG ECFIN) and the Economic Policy Committee (AWG).

work, at the expense of their care responsibilities. At the same time, EU countries are experiencing a shortfall in the paid care workforce that will increase further with demographic ageing.¹⁶

The EU and member states also have strong commitments to gender equality, and to the prevention of social exclusion. Inadequate recognition of the role of informal carers and inadequate support for their contributions leads to strong risks of social exclusion, particularly among women.

These considerations suggest the following policy priorities at EU and member state levels:

- Making visible the roles played by carers; their contributions to sustainable long-term care arrangements; and the actual and hidden costs of these contributions, both for carers themselves and for other sectors of the economy.
- Extending the focus of policies on reconciling work and family life beyond childcare to include care for older and disabled people. This means, among other measures, developing flexible labour market policies to enable carers to remain in and/or return to paid work during and after periods of caring. Furthermore, in July 2008 the European Court of Justice ruled that the laws protecting disabled people against discrimination apply not just to the person themselves but also to their carer.¹⁷ This ruling, which applied to parents of disabled children, has potential implications for how other groups of carers are treated in the workplace.
- Reviewing the eligibility criteria for, and the levels of, care-related benefits and allowances; their impact on carers' opportunities to combine paid work and care; and their impact on access to formal professional services to support carers and/or the person receiving care.
- Developing ways of linking the contributions made by informal carers to the growing demands across the EU for a sustainable paid long-term care workforce, for example by formalising the skills acquired by informal carers into employment-based competencies.
- Through the Open Method of Co-ordination, drawing the attention of member states to carers' issues, including the evaluation and sharing of examples of good, evaluated practice in supporting carers.
- Using the 2012 Year of Solidarity between the Generations as an opportunity for both the EU and member states to focus on the inter- and intra-generational provision of care.
- Using available national and international research and development programmes to generate more knowledge about the numbers, characteristics

¹⁶ Tsolova, S. and Mortensen, J. (2006) *The Cross-Atlantic Exchange to Advance Long-Term Care*. Special CEPS report. Background paper prepared for the European Commission and AARP joint conference on long-term care, 13 September, Brussels.

¹⁷ ECJ, C303/06, 17 July 2008. *S. Coleman v Attridge Law and Steve Law*.

and needs of carers. Questions included in key national surveys such as national population censuses or labour force surveys are a useful starting for estimating the numbers of carers and their demographic and socio-economic characteristics.

This Policy Briefing is based on the report:

Care Provision within Families and its Socio-Economic Impact on Care Providers 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).

Care Provision within Families and its Socio-Economic Impact on Care Providers by Caroline Glendinning, Frits Tjadens, Hilary Arksey, Marjolein Morée and Nicola Moran is available from:

www.york.ac.uk/spru

www.hasca.eu

www.vilans.nl