



Informal Carers: Who Takes Care of Them?*

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Policy Briefs are a publication series providing a synthesis of topics of research and policy advice on which European Centre researchers have been working recently.

Until recently, unpaid care provided by relatives, neighbours and friends – informal care – had been overlooked or taken for granted by policy-makers in the context of long-term care provided to dependent older people. A certain amount of informal care is nevertheless essential in filling the gaps of formal care services, supplementing them or assuring that care is provided in certain critical transition phases (e.g. after discharge from hospital). Care provided by relatives and friends is often the only fallback option when care services are not available.

Driven by concerns over the fiscal sustainability of long-term care services and by more self-conscious and demanding carers' movements¹ in many countries (e.g. UK), informal care has been brought into the limelight. Still, despite this newfound interest, information available on informal carers is still relatively scarce. This is in part due to the nature of the subject itself as informal care is often provided by relatives and thus falls within the sphere of private family life. In addition, methodological issues make it difficult for informal care to be properly addressed in general population or household surveys.

In view of this, what do we know about who provides informal care and who benefits from it? What differences (if any) are found among countries? And what policies are set in place to support informal carers?

The aim of this Policy Brief is to contribute to answering some of these questions. It does so by using available data from national and international sources, as well as qualitative information gathered in our recent publication *Facts and Figures on Long-term Care – Europe and North America*.

One of our principle sources for gaining knowledge about family carers across Europe is EUROFAMCARE, Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage, which was an international research project funded within the 5th Framework Programme of the European Community, Key Action 6: The Ageing Population and Disabilities, 6.5: Health and Social Care Services to Older People: www.ukc.de/extern/eurofamcare.

The Brief seeks to increase knowledge on informal carers and the challenges they face, as well as to discuss some of the implications surrounding social policies that impact informal care-giving. The analysis is very much policy-oriented and takes on a comparative view, focusing mostly on countries of the European Union.

This Policy Brief is organised as follows: it begins by providing a concise portrait of informal² care-giving, highlighting common characteristics and differences across countries; it then moves to discuss why the current portrait of informal care-giving may come under pressure in the near future; and finally, it addresses some of the policies that are likely to impact informal carers.

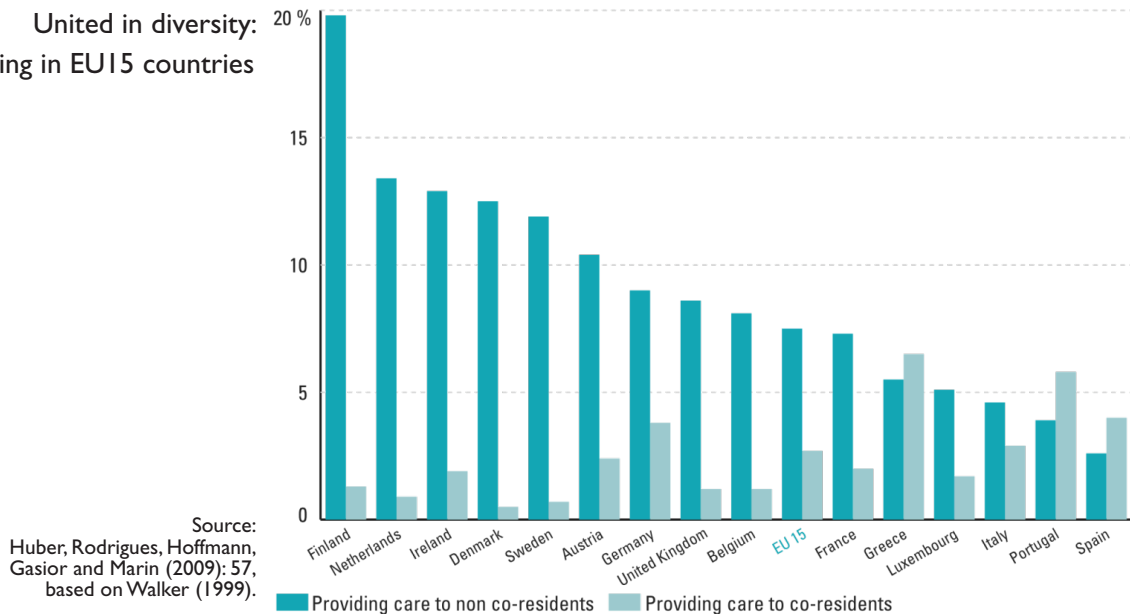
1) A portrait of informal carers across Europe: Avoiding clichés

North-South Divide: myth or reality?

The results depicted in the *Facts and Figures on Long-term Care* publication show that caring for an elderly parent is more frequent in Northern Europe than in Southern Europe, but the care provided is far more intensive in Southern Europe. These results point to the influence of living arrangements, as extended families are still more common in the South, but also to the (un)availability of care services at home. Although data is not directly comparable, the 2nd wave of SHARE presents similar findings (Attias-Donfut, Ogg and Wolff, 2005). Indeed, although one third of overall SHARE respondents living alone received help with personal care or practical tasks during the past 12 months, these rates were significantly lower in Spain, Italy and Switzerland. “It would seem that the strong dimension of family support that is manifest in Spain and Italy is weakened when older people are living alone and that these two countries may not have the infrastructure in place that facilitates solo living in old age” (Attias-Donfut, Ogg and Wolff, 2005: 174).

Caring for an elderly parent is more frequent in Northern Europe than in Southern Europe but care provided is far more intensive in Southern Europe.

Figure 1: Percentage of the population aged 15+ providing informal care to a relative aged 60+, 1999
 United in diversity: care-giving in EU15 countries



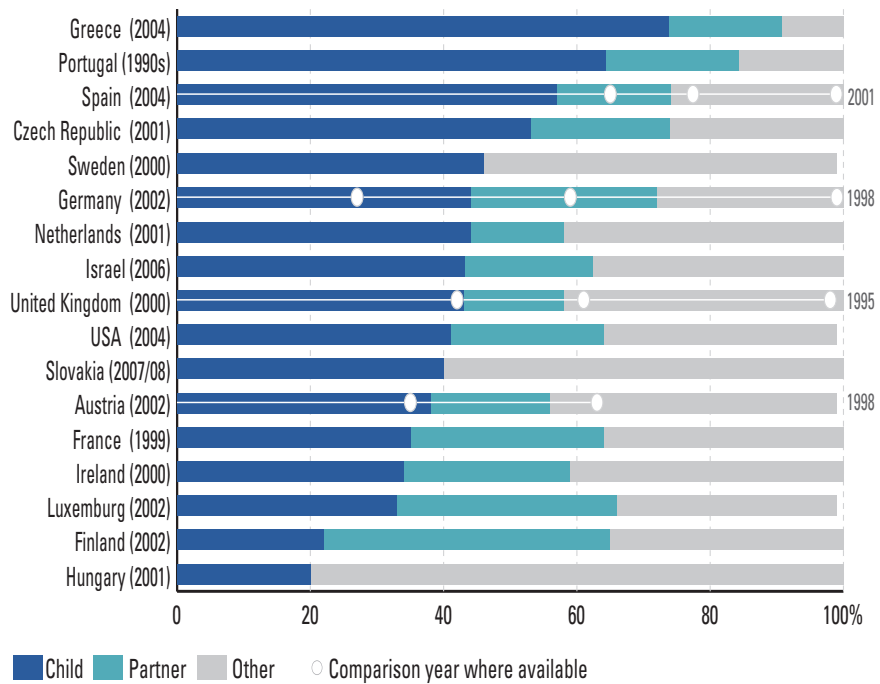
Family carers across the EU provide over 80% of all care, with women providing approximately two thirds of care mainly as daughters (in law) and wives/partners. Generalisations with regard to the North/South divide of care intensity in Europe should be avoided as they oversimplify a very complex picture. Indeed Italy has seen the number of domestic carers quadruple in the last 15 years while the proportion of foreign carers has risen from around 15% in 1990 to approximately 85% in 2005 (Lamura, Mnich and Döhner, 2006). This phenomenon has occurred mainly as a result of the lack of available professional long-term care services which have forced families to seek affordable alternatives to care for their dependent relatives (including migrant carers). Thus Italy (as well as Spain) have shifted over the last decade from the extended family-based type of care towards a model that still relies heavily on informal care, but less so on family care-givers.

Figure 2: Relationship between the carer and the care recipient in percentage

Family affair: who cares?

Source: EUROFAMCARE National Background Reports and National Survey Reports: www.ukc.de/extern/eurofamcare; OECD (2005); national sources; and Huber, Rodrigues, Hoffmann, Gasior and Marin (2009).

Definitions of carers and care recipients may differ between countries. The number of informal carers is usually higher than the number of carers receiving support under public long-term care programmes (e.g. as cash allowances). For Portugal the child refers to daughter and daughter-in-law only; for Spain (2001) grandchildren are also included; for Austria the figure for children carers represents only those taking care of their parents; however, if one also includes parents-in-law this would bring up the figure to approximately 50%; for the Slovak Republic the gender breakdown figures represent only caregivers aged 65+. It includes all care recipients; however, a large majority is likely to be the partners of those aged 65+; for Hungary data were only available for children providing care to their parents; for Greece the data for children also includes grandchildren (4.4%) and daughter/son-in-law (13.9%).



Men also care

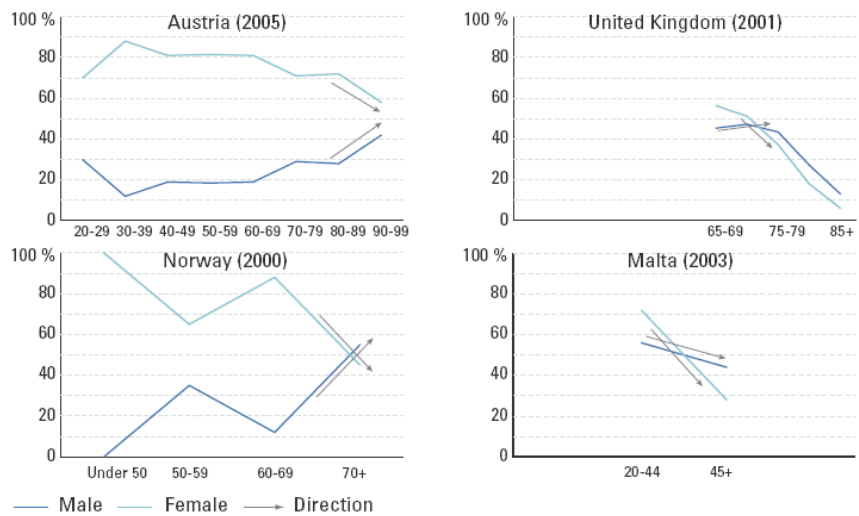
Aside from sons and daughters as primary care-givers, spouses/partners also provide a critical safety net for the dependent elderly, allowing them to delay entry into institutional care. As regards the type of care, women provide a substantial amount of personal care to their elderly relatives, namely assisting with bathing, washing, feeding etc., while men are more active providing help with Instrumental Activities of Daily Living (IADL)³, particularly during their working life. One exception is care provided to

one's partner/spouse which is more at a gender balance as both men (usually once they are retired) and women provide labour-intensive care. As male life expectancy increases this could translate into an increased availability of informal care since presently men provide as much informal care in older age groups as their female counterparts as they tend to provide care to their elderly spouse. However this hypothesis rests on men and women living together in old age.

Men tend to provide care in their later years and mainly provide care to their spouse including assistance with ADL.

Figure 3: Women provide more care to older people but men catch up in later years

Sharing the burden:
men's late catching-up



Source:
EUROFAMCARE National
Background Reports (NABAREs)
for Malta and Norway (2004);
national sources for Austria and the UK;
and Huber, Rodrigues, Hoffmann,
Gasior and Marin (2009).

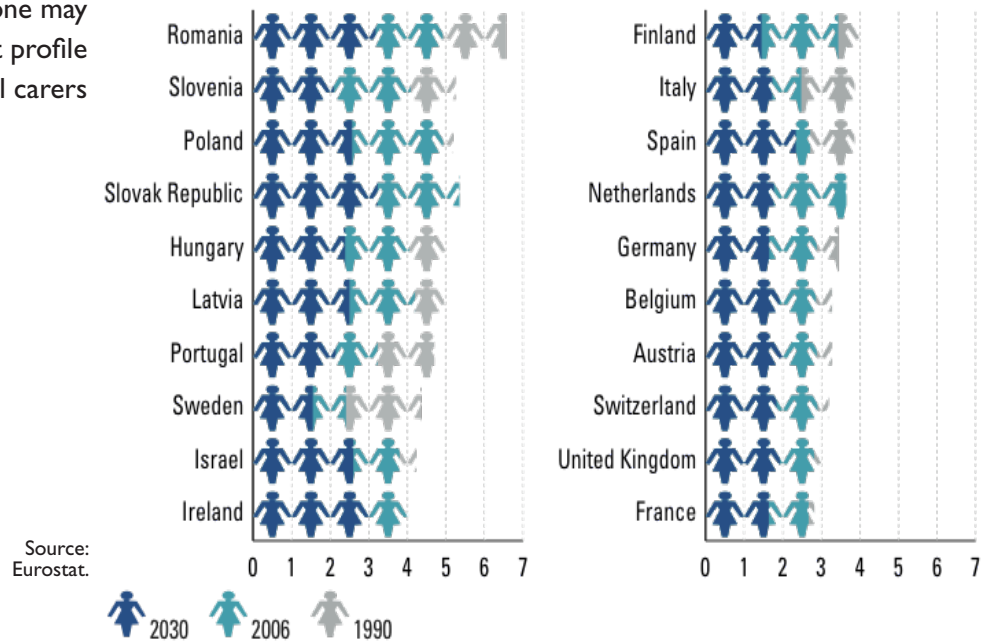
2) Is informal care in its present form sustainable?

Recent demographic, social and policy developments have raised the question of whether “care gaps” are increasingly likely to occur as informal care may become less available, which in turn could lead to an increase in demand for formal long-term care.

Currently informal carers are most likely to be women of working age. However, with population ageing, this portrait is likely to change as depicted in Figure 4. The projected “support ratio”, i.e. the ratio of women aged 45-64 (those more likely to provide informal care) for each person aged 80 and older (those more likely to be in need of care), has already diminished in the past 15 years for many of the Western European countries. This trend is likely to continue in the future and to extend to Eastern European countries.

Figure 4: “Support ratio”: number of women aged 45-64 for each 80 year-old (2005/2006)

Demographics alone may change the current profile of informal carers

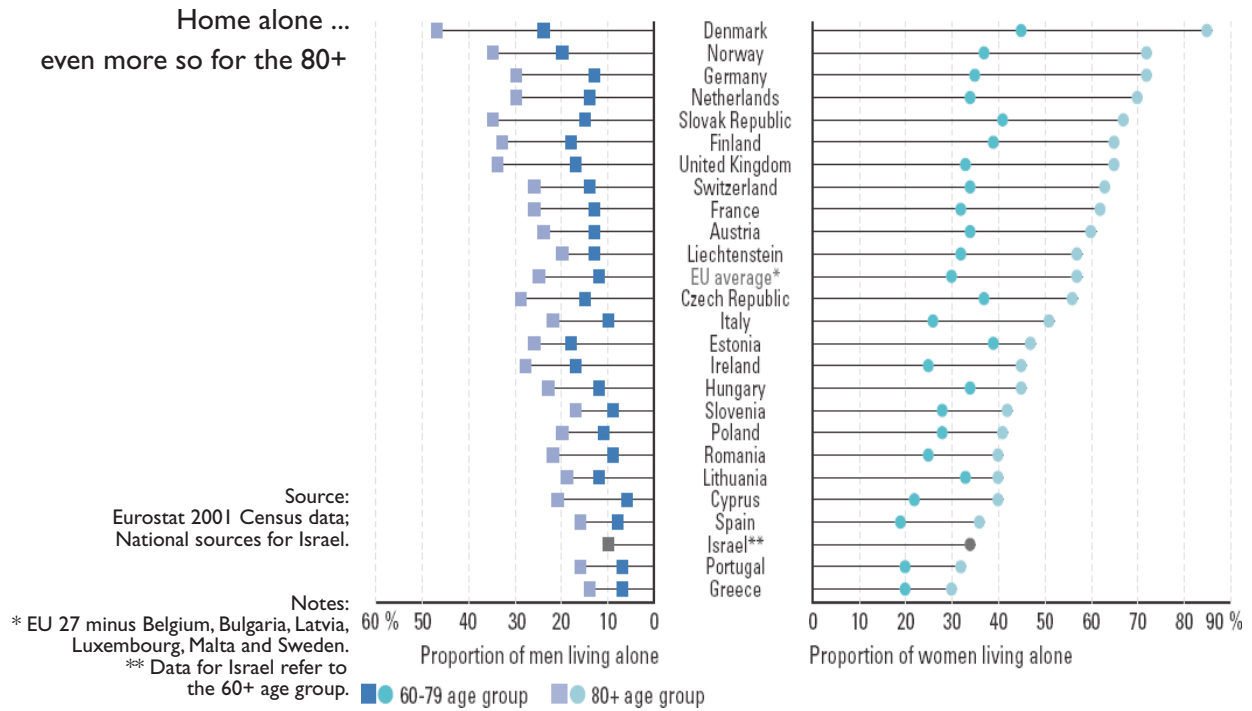


An increasing trend of older people living alone could suggest a rise in the demand for formal care services in the future.

Given the prospect of a potentially reduced number of informal carers of working age, spouses may find themselves as the main carers in the future. This depends, however, on the future living arrangements of older people, as well as on their health status. The most recent round of Census data shows an increasing trend of older people living alone, particularly women once they reach the age of 80. Although partners can potentially take over some of the care tasks from their children, elderly women living alone seem more likely to have to rely on professional care services if they live far from their children, or the latter are unwilling to leave gainful employment for care-giving purposes.

Although living with a child is still extremely common in many regions of the world, it is the couple-only arrangement which is the most common for older people in Europe and North America. Therefore children who are not living in the vicinity of their elderly parents may not be available to provide informal care even if they are in principle willing to do so. Furthermore, as fertility rates decline, the number of available children able to share care duties among them will be smaller in the future. In light of these trends, non-family members are increasingly taking on a caring role albeit more for assisting with IADL. Nonetheless involvement in the organisation and coordination of care as well as in the care itself remains very much a family business so care gaps in this sense are unlikely to occur.

Figure 5: Living alone for people aged 60-79 and those aged 80+, Eurostat 2001 Census data



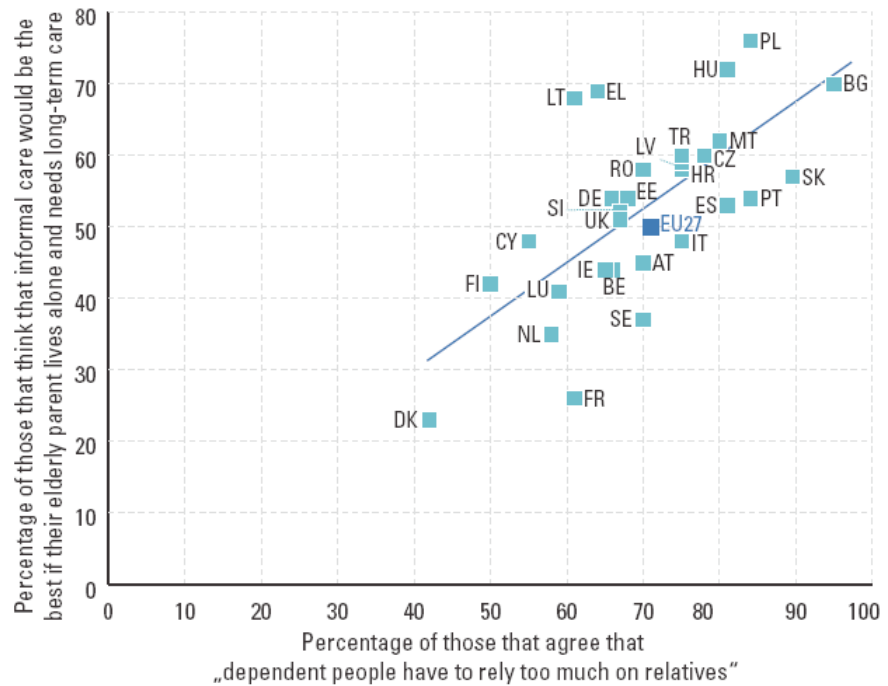
The goals of the Lisbon Agenda could challenge the availability of informal carers, particularly women.

Approximately 40% of informal carers are in gainful employment across Europe, and this number is likely to rise in the future as more women across the UN-European Region are entering the labour force. This leads to the key policy question as to whether informal care in its present form (i.e. with a large share of women out of the labour force providing care between 45 and 64 years of age) is likely to hold in the future. On a macro-level, combining the goals of the so-called “Lisbon Agenda” (i.e. increasing employment rates for women and older workers, postponing retirement) while trying to avoid a “drying out” of the family care pool is a key policy challenge.

Finally, many relatives still prefer informal carers to take care of their elderly family members, but there is a growing sense of conflicting expectations that elderly people are too dependent on their family carers (see Figure 6). Moreover a preference for family care may also partly be due to the lack of suitable alternatives in the formal sector. As employment and education rates of women have dramatically risen in recent decades, carers may be more reluctant to give up on employment opportunities for a caring role. This feeling of over-reliance is particularly felt in countries which also favour more family care (mainly transition countries and Southern Europe) which could suggest a change in the identity of women concerning their role in society.

Figure 6: Answers to Eurobarometer survey regarding health and long-term care in the EU, 2007

What appears to be the best option for dependent parents may not necessarily be the best option for their daughter/son



Source: Eurobarometer (2007), question: 7a and 29.1.

3) Policies in place: how far do they go to meet the challenge?

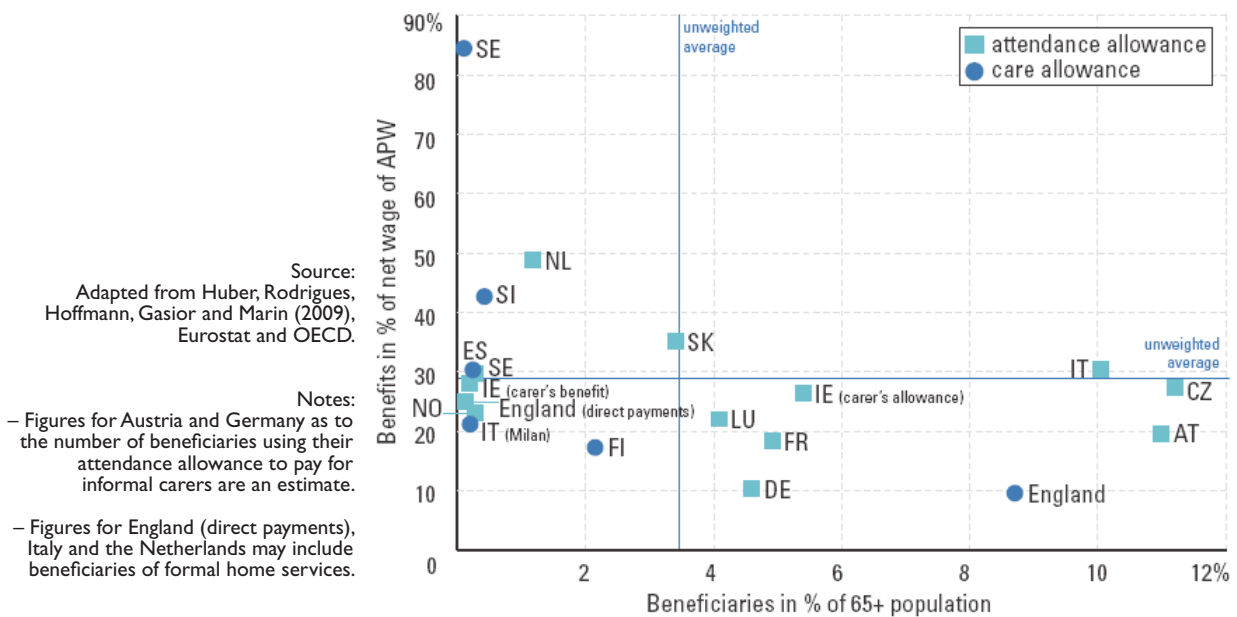
Recognising the importance of informal care and the present and future challenges that it faces, some countries have sought to put in place policies to support carers. In fact, addressing the needs of carers and recognising them as key stakeholders has been one of the defining characteristics of recent policy developments in long-term care. These policies have been developed either by providing cash benefits to carers, thus compensating for lost income or recognising their role as carers, or by setting up services aimed at facilitating their caring tasks (e.g. counselling, respite care, etc.).

3a) Providing cash to carers

One set of policies aimed at supporting carers that has gained momentum in recent years has been cash-for-care benefits. These cash benefits are paid directly to carers (care allowances) or to those in need of care (attendance allowances), which may then be used to compensate informal carers. The increasing role played by these benefits goes hand in hand with the development of policies aimed at increasing user choice in access to long-term care, as informal care becomes one of the “options” available for those in need of care. But this development also has a clear

“cost containment” motivation, as supporting informal care may be seen as a cheaper option for the public purse, even if from a societal point of view it may be more expensive to have people out of the labour market. The amount of social benefits available to informal carers is usually small in relation to the cost of providing professional care services – as Figure 7 depicts, the average amount of these benefits in many countries is inferior to 30% of the average wage. Yet small as they may be, they might still be enough to maintain dependent people in their homes (at least up to a point) and thus avoid more expensive institutional care – an objective termed “ageing in place” (OECD, 2005). Some of the cash benefits available to those in need of care provide lower amounts if informal care is the chosen option (e.g. in the case of Germany or the Dutch Personal Budget), thus discounting for overhead costs.

Figure 7: Relative generosity of cash benefits (care allowances and attendance allowances) Providing cash to carers from which carers may benefit



However clear the trend towards providing cash for care may be, these policies come with trade-offs that policy-makers ought to bear in mind when weighing-in their options. The allure of cost-containment is a powerful one, but providing cash for care may have potential side-effects on the labour supply of carers, acting as a disincentive to gainful employment. Balancing the goals of the Lisbon Agenda on employment and supporting informal carers need not be conflicting goals of social policy, but their conciliation may prove challenging. In countries where care allowances are in place, these usually come with the condition that caring becomes a full-time activity or close to one.

The provision of cash benefits to carers comes with trade-offs, notably in terms of employment.

Table 1:
Hurdles in the conciliation
of care allowances
with employment

Country	Benefit	Means-testing	Other benefits	Limitations on paid or full-time employment
Ireland	Carer's allowance	Yes		Full-time care required (cannot be accumulated with more than 10 hours employment/training per week).
Ireland	Carer's benefit	No	Supplement benefit for children.	Full-time care required (cannot be accumulated with more than 10 hours employment/training per week). Maximum duration of 65 weeks.
Finland	Care allowance or informal care allowance/ support for informal care	No	Leave and support services to relatives. Respite care (2 days per month). Pension credits (limited) and accident insurance. Quasi-contract.	May be accumulated with paid work.
Luxembourg	Carer's allowance	No	Pension credits (based on minimum wage). Paid social contributions. Respite care.	Minimum of 50 hours per month of care is needed. No cash benefit.
Norway	Care wage (<i>Omsorgs-lønn</i>)	No	Below average pension credits. Post-care-giving pension. Contract.	Usually limited to 3-10 hours weekly. Exceptional use (burdensome care).
Slovenia	Home care assistance or family attendant	No	Pension credits. Unemployment benefit. Parental insurance. Paid social contributions	Carer must be unemployed or working part-time.
Slovak Republic	Care allowance	Yes		May be accumulated with paid work up to 2 times the national subsistence minimum.
Sweden	Carer's salary (<i>Anställda anhörige</i>)	No	Full social protection. Contract.	Exceptional use.
UK	Carer's allowance	Yes	Pension credits. Supplement benefit for children. Increased social benefits.	Minimum threshold of care given is 35 hours weekly. Carer cannot be in full-time education (more than 21 hours weekly of education).

Source:
Adapted from Huber, Rodrigues,
Hoffmann, Gasior, Marin (2009): 83.

Providing relatively unregulated cash benefits (i.e. where little proof is required on how the money is spent) may be seen as an empowerment tool for users and have administrative advantages, saving on paperwork and inspections. However, it can also lead to the creation of informal markets for the provision of care. This seems to have been the case in Italy, Austria and to a certain extent Germany which rely to a great degree on undocumented migrant carers. Even though the benefits may be small in value in their national context, existing wage gaps may make them attractive to migrant carers. On the other hand, introducing too many constraints on who may receive the benefit may result in a reduced benefit take-up as preferred care options such as care provided by the spouse or close relatives are excluded (this might be the reason for the low take-up of Direct Payments by older people in England).

Cash benefits may also risk trapping informal carers, most notably women, in a socially precarious and many times unwanted care role. Critics of the implementation of cash for care argue against these policies as a move towards a “refamiliarisation” of care (see Kröger and Silipa, 2005), i.e. a move towards a retrenchment of the role of the State in disfavour

of families and in particular women. It is however a difficult issue, since cash for care benefits also represent the recognition of the role and importance of informal carers and may contribute to the improvement of their social status and well-being, as some of these benefits also entitle informal carers to pension credits or sickness insurance. However, given the strong gender dimension attached to the issue of cash for care, gender mainstreaming concerns seem to be conspicuously absent from the design of these benefits.

Another point against the provision of cash benefits to family carers relies on a much more near-sighted argument: that of (supposed) economic efficiency. Under this reasoning, close relatives should be precluded from receiving cash benefits since this would mean paying for services that they would likely do anyway. This policy stance, however, risks overburdening carers even more and may lead to reduced availability of carers in the future.

3b) The importance of providing services to carers

Carers often enjoy little leisure time due to the intensity of their caring duties, which require a large amount of time to be spent in the home of the care recipient. Family carers are as a result likely to experience to some degree feelings of isolation, psychological distress including anxiety (which incidentally can also affect their “presenteeism” for those who work), depression and loss of self-esteem. They may also be more prone to risky behaviour (e.g. smoking), or to neglect their own health. Taking up preventive health measures is even more important as informal carers are themselves ageing: e.g. according to a study carried out in the UK (Doran, Drever and Whitehead, 2003), a substantial number of carers were aged 85 or older; more than half of these were providing at least 50 hours of care a week; and one third of these heavily burdened carers rated their health as “not good”. Middle-aged carers on the other hand might simultaneously be shouldering the responsibility to care for their own (grand)-children – the so-called “pivot generation”.

While cash benefits may go some way to support the informal carers financially, it still requires the latter to be heavily involved in care duties.

Consequently, important as cash benefits may be for informal carers, this is not the only way to support informal care-giving and it may even be argued that it is not the best way to alleviate their burden. Care services aimed at informal carers themselves are equally important if many times overlooked.

Respite care allows informal carers to take a break from their care duties and may prove fundamental for their psychological well-being by pre-

venting burnout. However, available places in respite care remain scarce across Europe, even in countries with a relatively wide coverage of care services (e.g. Denmark) – see Table 2. Providing respite care, or short-term stays in institutional settings or at home, may pose some delivery constraints and require greater flexibility in the provision of care (e.g. if respite is provided at home by service providers). Take-up services are fairly low for a variety of reasons, one being that family members find that it disrupts the care recipient too much to be placed in a short-term institution with new carers, particularly those with dementia. Another obstacle is the cost of respite care, especially for those carers who have had to give up gainful employment.

Table 2:
Limited availability of
respite care across Europe

Country	Year	Available beds or beneficiaries in percentage of the 65+ population
Denmark ^(a)	2007	0,3%
Germany ^(b)	2007	0,1%
Ireland ^{(a), (b)}	2004	0,2%
Netherlands	2003	1,4%
Norway ^(c)	2006	0,1%
Spain ^{(a), (b), (d)}	2006	0,1%
Sweden	2006	0,6%
Switzerland ^(b)	2006	1,4%
UK	2005/2006	0,6%

Source:
Statistics Denmark (StatBank), Statistics Norway (StatBank), IMSERSO, CBS (Statline), Federal Ministry of Health (Germany), The Information Centre (Social Care Statistics), Department for Health and Children (Ireland), Swiss Federal Statistical Office and the National Board of Health and Welfare (Sweden).

Notes:
(a) Number of places.
(b) Beneficiaries younger than 65 may be included.
(c) Age group is 67 and older.
(d) Underestimation, as data is not available for all regions.

Availability of respite services is improving but more systematic support to informal carers is needed.

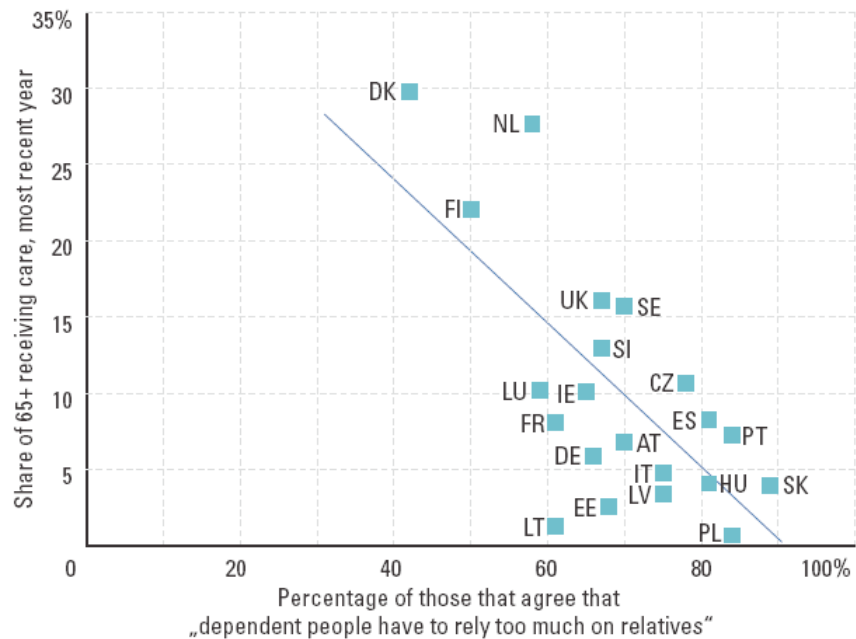
Even when it is available, take-up of respite or other services available to carers may be low as they might not be aware that such services exist. Certain countries have sought to improve the information available for people with care needs and their families, an issue that has been well-documented as one of the major problems for family carers. In Austria as recently as 2006, applicants for the LTC allowance have been provided with so-called “counselling vouchers”, which enable them to receive a visit by a nurse to get information, advice and practical hints about the formal care system and benefits available (Leichsenring, Ruppe, Rodrigues and Huber, 2009). In other countries, carers’ associations have themselves established websites and hotlines that help carers navigate through the complexity of care systems.

Respite care is not the only service likely to impact positively on informal carers. Day-care centres may also ease the burden of care on family

members and so can other home care services. Although the jury is still out on the exact relationship between supply of informal care and existing formal care services, the most recent empirical evidence suggest that availability of home care services may reshape the type of informal care provided towards less burdensome domestic help (Bonsang, 2009). In Northern European countries, where provision of home care services is higher, more persons seem to be able to provide informal care by limiting it to less demanding tasks (household chores) and thus limiting the feeling of overdependence of older relatives on their family for care – Figure 8.

Figure 8:
Over-reliance on relatives ...
does it signal overburdening
of carers?

Source:
Huber, Rodrigues, Hoffmann,
Gasior and Marin (2009)
and Eurobarometer (2007).
Notes:
Figures for the share of 65+ receiving
formal care only for Austria
and Germany are an estimate.



There is a strong case for conciliating support for informal carers while investing in formal care services, for “if anything the evidence points to family carers providing rather more hours of care when formal services are provided as well” (OECD, 2005: 45). However, recent policy developments show contradicting signs on this matter. In the Netherlands, the concept of “usual care” has been introduced in the assessment of eligibility for home care services, which effectively implies that those closest to the person affected – most likely the partner and/or children of the dependent – are expected to provide the necessary care. The policy trend observed in some countries towards targeting services to those more in need of care (e.g. in England and Sweden) may also leave some tasks to be carried out by informal carers alone.

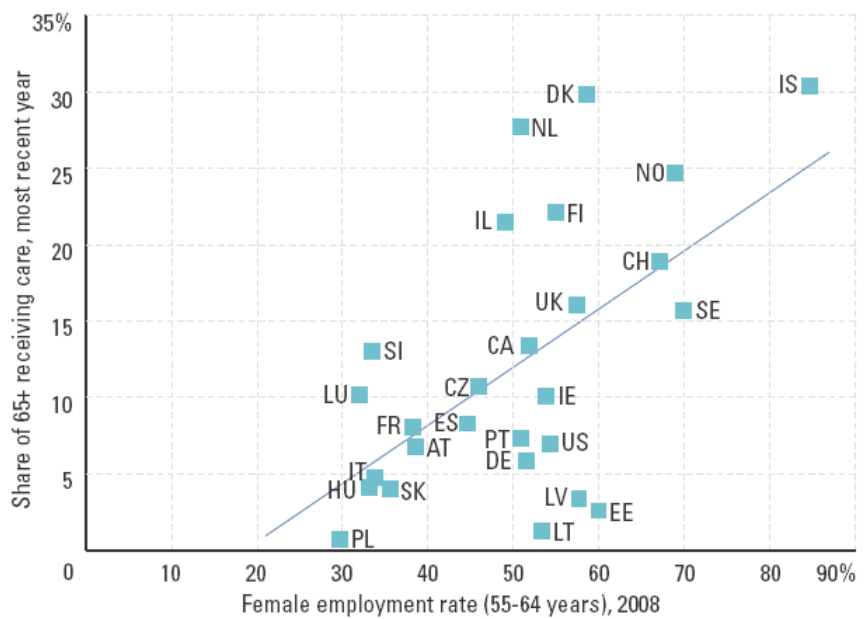
Less burdensome care could also help mitigate the possible trade-off between care and employment faced by informal carers. Supplementing

Combining informal with formal care at home could provide a better framework to allow women in particular not to leave the workforce early which could put them at risk of financial hardship.

informal care with formal care services at home could thus prove to be the best way of striking a balance between fulfilling the employment goals of the Lisbon Agenda, while ensuring that informal care remains available. The data presented in Figure 9 suggest that formal care services may contribute to improve the labour market situation of older women of working age. While juggling employment with caring responsibilities can be daunting, remaining in paid work can also have a positive impact on carers as it provides income and pension rights, helps to maintain social networks, offers a temporary relief from their caring role, enhances self-esteem and offers the opportunity to share concerns with colleagues in a similar situation.

Figure 9: Availability of formal care services and female employment rate (55-64 years)

Care services may improve the conciliation of employment and care duties



Source: Huber, Rodrigues, Hoffmann, Gasior and Marin (2009), Eurostat and OECD.

Notes:

- Figures for the share of 65+ receiving formal care only for Austria and Germany are an estimate.
- Figures for Canada, USA and Israel refer to the employment/population ratio.
- Figures for the USA are for 2004.

4) Conclusion

Informal care-giving remains the backbone of care provision in Europe and for many dependent older people it is their preferred care option. Complete replacement of informal care by formal care services is neither financially feasible nor socially desirable. Policy-makers should therefore ensure that the carers' own needs as much as those of the care recipients are taken into consideration and met. Some countries have already taken steps in this direction, namely by providing carers with a statutory right to receive an assessment of their needs for services in addition to services for older people (as is the case of the UK).

As this Policy Brief has shown, some of the policies aimed at supporting carers come with trade-offs (balancing employment goals with financial support for carers as an example) and these should be borne in mind when setting-up those measures. This is not to say that an attitude of “laissez-faire” on the part of policy-makers is the adequate course of action as this paper has shown that too many issues remain unresolved or even unaddressed by current social policies aimed at carers.

Thus, despite the obvious gender dimension associated with informal care-giving this issue has yet to be tackled by current policies. Conciliation of care duties and work seems to take place despite and not because of current social policies, which are still a long way from fostering that conciliation as far as care for dependent elderly is concerned. Respite care is not yet widespread or made attractive to carers and those in need of care. While the advantages of conciliating home care services with informal care seem to have been proven, there are some contradictory policy developments in this respect. Finally, budgetary constraints made worse by the current economic crisis may push towards delaying or not providing support measures to carers under the erroneous argument that care will be provided by them anyway.

This Policy Brief has highlighted a series of societal, demographic and policy developments that are likely to change informal care as it is currently provided (i.e. mostly by female relatives of working age). This should not necessarily be perceived as a potentially harmful evolution as the current arrangement probably does not suit many of today’s carers who are overburdened with demanding care tasks.

The key issue that public policies should therefore address is not to try to crystallise the current informal care arrangements, but rather to adapt to the changing conditions. It is not the same if care is provided by daughters, spouses, people of working age, retired or migrant carers as each comes with different challenges, but the main point should be that conditions are created for adequate informal care to be available in the future.

While the “disappearance of informal care” may well be an exaggeration, perhaps the future carer will take on a role more focused on assisting with Instrumental Activities of Daily Living and emotional support, which is the area where elderly dependent people feel their needs are the least met. This would allow the family carer not to have to pay too high a price on his/her career and well-being by being relieved from some of the burden of heavy care.

Notes

- 1 See the European Carers Association: www.eurocarers.org
- 2 Our definition of informal care refers to help provided to old-age persons (aged 65 or older) who need permanent (for more than 6 months) assistance in carrying out Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL), by informal carers that may be partners/spouses, children or other relatives, neighbours or friends, although a pre-existing social relationship with the person cared for is not required.
- 3 Comprising tasks such as cooking, laundering, housecleaning or managing one's medications.

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