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Mapping support policies for informal carers across the European Union

Emilie Courtin, Nadia Jemiai, Elias Mossialos

Abstract:

Background: At a time when health and social care services in European countries are under pressure to contain or cut costs, informal carers are relied upon as the main providers of long-term care. However, still little is known about the availability of direct and indirect support for informal carers across the European Union.

Methods: Primary data collection in all EU member states was supplemented with an extensive review of the available literature.

Results: Various forms and levels of support have been implemented across Europe to facilitate the role of informal caregivers. Financial support is the most common type of support provided, followed by respite care and training. Most countries do not have a process in place to systematically identify informal carers and to assess their needs. Policies are often at an early stage of development and the breadth and depth of support varies significantly across the EU.

Conclusions: Policy developments are uneven across the member states, with some countries having mechanisms in place to assess the needs and support informal carers while others are only starting to take an interest in developing support services. Given the unprecedented challenges posed by population ageing, further research and better data are needed to capture and monitor information on informal carers, to help design adequate support policies and eventually to evaluate their impact across the EU.

Key words: informal care; informal caregivers; Europe; long-term care; insurance benefits; social support.

1. Introduction

European Long-Term Care (LTC) systems rely heavily on provision of care by informal carers. Recent estimates show that informal carers contribute over three-quarters of all LTC provided [1, 2], and the size of the informal care “workforce” is evaluated to be at least double that of the formal long-term care workforce [3]. However, future supply is uncertain for a number of reasons, including the decline of intergenerational co-residency, higher employment rates of women, and rising old age dependency ratios [4]. Projections to 2060 show that the supply of informal care is unlikely to keep pace with the increasing demand in Europe [5]. Estimating the number of informal carers across the European Union is a difficult task, given differing definitions of caregiving [6], and the fact that the actual number of informal carers is usually higher than the number of carers receiving support under LTC programmes [2]. The latest data available show that about 6% of the population aged 50 or over provides care to an older relative in Europe [7]. Considerable cross-national variations are found, with the highest proportions of carers in Mediterranean countries and the lowest in Sweden, Switzerland and the Netherlands [7]. Informal carers are most likely to be female (spouses or adult daughters), except in the over-75 age group where there is an equal or higher percentage of male carers in most European countries [6, 8].

The European Union has acknowledged that population ageing presents unprecedented challenges to national health and social care systems and intergenerational solidarity [9]. Recent initiatives have targeted the employment opportunities and working conditions of older Europeans as well as their active

participation in society beyond employment and healthy ageing [10, 11]. Thus far, informal care provision and its challenges have not been a key component of the EU's response to population ageing. Despite their relevance to the future of LTC services in Europe, support services for informal carers remain largely under-researched.

At national level, concerns about how best to support informal caregivers have featured on the political agenda of a number of European countries in recent years. Often considered as “by-products” of the LTC system [12], informal carers and their needs had long been ignored by policy-makers [13]. European states have gradually implemented policies to compensate for income lost due to caring, but also to facilitate caring activities [2].

However, when it comes to services designed to support informal caregivers, only limited evidence is available. Previous studies investigating support services have mostly been country-specific [e.g. 14, 15, 16]. Existing comparative research has been restricted to a small number of countries [e.g. 2, 13] or has not focused specifically on support offered to informal carers [6]. The possibility for policy-makers to learn from other countries' experiences is therefore limited. Supporting carers is a concern among EU citizens. A recent Eurobarometer survey reported preferences regarding government contributions to helping carers. Financial remuneration for caregiving was considered to be the most important support for informal carers, followed by flexible working arrangements and pension protection [17]. Against this background, we investigate the actual provision of support across the European Union. As a first step, this article aims to provide a comprehensive

picture of the support available directly or indirectly for informal carers across member states. A detailed analysis of the depth of support services offered in each member states is beyond the scope of this paper but the mapping exercise will provide an overview of the arrangements in place in a rapidly changing policy area. The first section provides an overview of the framework and methods used to collect national information. The main results of the mapping exercise, in terms of direct and indirect support available, national policies and legal entitlements, are then set out. The discussion section highlights challenges associated with providing support services for informal carers and future directions for policy and research.

2. Materials and methods

Comparative research in the area of informal care is limited by the lack of data available, and the differing definitions, institutional arrangements and cultural expectations (e.g. whether the obligation for relatives to provide care is enshrined in national law) [13, 18, 19]. The definition of “informal care” used for the purpose of this article is broad, to capture all the dimensions of caring activities [20]. It covers any help provided to older family members with functional limitations (which includes activities of daily living as well as instrumental activities of daily living). What counts as services for informal carers is also complex to define. Carers are often not the direct focus of a service, but feature in the service system *via* their relationship with the cared-for person [21]. To determine which services to include in the mapping, we used the framework designed by Twigg and Atkin [21]. The aim of the framework is to cover all services potentially provided for informal carers,

but also the broader policy environment within which these services are provided. It distinguishes between three levels of support for informal carers (see Figure 1). The first level includes services provided in order to support directly informal carers, such as counselling, respite care or training services. The services included at the second level come to the caregiver as a “by-product of the services aimed at the cared-for person” [21]. The focus on the service or scheme is on the cared-for person but the ripple effect on the carer can be considerable, *e.g.* when a cash allowance can be used to pay an informal carer. The third and last dimension covers national services and practices as well as the assumptions made by service providers about carers (including their availability, involvement and duties). This last level does not cover support services for informal carers as such but rather the potential impact the system has as a whole on the ability of carers to provide care, *e.g.* measures in place to combine care and employment. In addition, these three levels are organised along two main dimensions. The first dimension – “degree of incorporation” - is the extent to which support is designed with the carer in mind. It ranges from services and schemes targeting informal carers directly, to national policies and legal entitlements, through help received indirectly via the cared-for person. The second dimension is the scope of support, which covers support provided at local level by voluntary organisations, to mainstream LTC services and to the national context as a whole. This second dimension is useful to account for the complex and often fragmented offer of support services for informal carers across the three levels described above. However, this article focuses mainly on the first dimension. The main advantage of this framework is that it reflects the breadth of

and variations in the types of support provided across the EU. For example, previous research on support services has distinguished between direct measures targeting informal carers and indirect measures targeting the cared-for person which can also be used to support the caregiver (e.g. care attendance allowance, which can be used to pay the informal carer) [13, 15, 22]. Both types of measure are included in the mapping.

[Figure 1 about here]

The information presented is drawn from a detailed questionnaire based on this framework and sent to 27 national experts.¹ Experts were identified through pre-existing research and policy networks. The topics included in the questionnaire are described in Table 1. National experts were asked about key elements of their national context in relation to informal care, the type of support available and legal entitlements.

¹ Austria: Birgit Trukeschitz, Vienna University of Economics and Business; Belgium: Maria Isabel Farfan-Portet, Catholic University of Louvain; Bulgaria: Ludmila Mincheva, Galina Kanazireva and Svetla Tzolova, Index Foundation; Cyprus: George Samoutis, St George's University of London Medical Programme at University of Nicosia; Czech Republic: Tomas Roubal, Ministry of Health; Denmark: Karsten Vrangbæk, Danish Institute of Governmental Research; England: Vanessa Saliba, London School of Hygiene and Tropical Medicine; Estonia: Triin Habicht, Estonian Health Insurance Fund; Finland: Jan Klavus, National Institute for Health and Welfare (up to 31.12.2011); France: Sandra Mounier-Jack, London School of Hygiene and Tropical Medicine; Germany: Marcial Velasco, Technical University of Berlin; Greece: Daphne Kaitelidou, University of Athens; Hungary: Barbara Koncz, National Institute for Health Development; Ireland: Suzanne Cahill, Trinity College Dublin; Italy: Margherita Giannoni, University of Perugia; Latvia: Lolita Vilka, Riga Stradiņš University; Lithuania: Jurate Macijauskiene, Kaunas University of Medicine; Luxembourg: Dieter Ferring, University of Luxembourg; Malta: Maria Cassar, University of Malta; Netherlands: Ronald Batenburg, Institute for Health Services Research; Poland: Adam Koziarkiewicz, Jagiellonian University Medical College; Portugal: Silvina Santana, University of Aveiro; Romania: Victor Olsavszky, World Health Organisation country office; Slovakia: Lucia Daubnerova, CEEN Economic Project & Policy Consulting GmbH; Slovenia: Anja Milenković-Kramer, University of Ljubljana; Spain: Alexandrina Stoyanova, University of Barcelona; Sweden: Anna Melke, University of Goteborg. Croatia was not a member state at the time of the data collection and is therefore not included in this mapping.

[Table 1 about here]

Data collection took place between January and October 2012. The remainder of the article draws on the 27 national experts' responses to this survey. A summary profile was produced for each participating country and sent back to the country experts to resolve inconsistencies in the data collected. We also conducted a tightly-focused scoping of the available literature to supplement our data collection. We searched SCOPUS, CINAHL, Francis, Google Scholar, Opengrey and SSRN. We limited the search to papers published after 2010 which either compared informal care provision and support across European countries, or which map out different forms of support available to carers in European countries.

The provision of support services is constantly evolving and this article only presents a picture of the situation in 2012.

3. Results

Measures have been taken to support and recognise the contribution of informal carers in many member states, but our results for the three dimensions of the framework also show that support provision is still very patchy and even non-existent in a number of countries.

3.1. Specific carer support

Adequate services are crucial to enhance carers' wellbeing and most European countries have made progress in providing specific carer support. However, their availability still varies greatly across Europe. Table 2 details the types of direct support provided in each EU member state.

[Table 2 about here]

The widest mix of support services was found in Austria, Denmark, England, Finland, Ireland, Latvia, Luxembourg, the Netherlands and Spain. At the opposite end of the spectrum, four countries were reported by the national experts as not providing any kind of services for informal carers (Cyprus, Estonia, Poland and Slovenia). Respite care services are the most common type of services and are provided in 21 European countries. Training and information are provided in 17 countries across Europe and counselling in 12 countries. The provision of support services is often complex, and happens at different levels of the national health and social care system. In Austria, for example, certain services and support can be found at the state level while others are provided at the provincial level. These include: at national level, information services, provision for informal carers under social insurance law, family hospice leave system (since 2002) and respite care (since 2004); and at provincial level, heterogeneous and more fragmented support, such as care-related advice and counselling by qualified staff, information events, regular meetings of informal carers and respite care. In Belgium, services are

relatively extensive despite the lack of national policy. This includes the extended availability of respite care in new plans for alternative forms of home care which are being drawn up nationally. In addition, many support services are funded and/or managed by non-governmental organisations at national level (see box 1). In some cases NGOs represent the only source of support, as for example in Greece for the three types of support services provided in that country (counselling, information and respite care). Although the evidence we collected on service use is very limited, access to respite care has been reported as difficult in Ireland, France and Portugal. The evidence collected via the national surveys does not point towards a specialisation by type of disability.

Box 1. “Caring for carers” in Ireland

The “Caring for carers” network in Ireland is a voluntary organisation which comprises 109 groups of carers and 160,000 informal carers across the country. They offer support services to carers including for instance:

- A network of “carers’ clinics” dedicated to the physical and mental health of informal carers. Qualified nurses offer information and advice free of charge.
- A “Caring in the home” programme, accredited by the Irish body for further education and training. It consists of a 13 week programme, including modules in nutrition, exercise, medication management, prevention of elder abuse, etc. 3,400 informal carers have been accredited between 2009 and 2011.

Out of the 23 countries which offer any type of financial support, only nine offer direct support in the form of a carer allowance (see Table 3). The provision of direct financial support is associated with a number of conditions related to available income, relationship between the carer and cared-for person, level of disability of the recipient of care and the intensity of informal care. Information on the amount of direct financial support is difficult to obtain and to compare across countries. The amount varies considerably across countries but is generally low. In Ireland for

instance, the maximum weekly rate of the care allowance varies between €204 and €358.50 for full-time carers depending on their age and number of care recipients, below the national minimum wage for experienced adult employees. Denmark appears to have the most generous scheme in place, but for a limited period of time.

3.2. “By-product” support

[Table 3 about here]

Financial support is the most common type of support provided across the member states. It can be either directed at the informal carer or that the cared-for person, who can in turn use it to remunerate their family caregiver. As shown in Table 3, the vast majority provides indirect financial support (i.e. attendance allowance to the recipient of care) while England, the Netherlands, Slovakia and Sweden offer both direct and indirect support. Data on uptake of indirect financial support are limited. In France for instance, it is estimated that the “Allocation Personnalisée d’Autonomie” has had a rather low rate of uptake (about 9% of family carers as of 2009).

3.3. National policies and legal entitlements

Our framework also includes information on a third dimension, at system level. A first finding at this level is that the identification of informal carers is a weak point in most countries, despite being an essential precursor to the development of

evidence-based policies. A system to locate informal carers in the national health and social care system has been developed in England, France, Hungary, Luxembourg, Malta, the Netherlands, and Sweden. In the remaining countries, informal carers are identified *via* the cared-for person, e.g. when their care is discussed with their general practitioner or with local social services. Similarly, the principle of assessing the needs of informal carers separately from those of the care recipient is not common across European member states. Although it has been recognised since 1995 in England, only Malta and Sweden have a similar process in place. In the remaining 24 countries, the needs of carers are not assessed *per se* but included as part of the evaluation of the needs of the cared-for person.

This lack of adequate identification and needs assessment processes can be partly explained by whether or not a national policy targeting informal carers is in place. Two groups of countries have emerged in that respect. A first group (England, the Netherlands and Sweden) comprises countries where a national policy targeted at informal carers is in place. In England, for instance, the first national strategy for carers was launched in 1999. It was enhanced in 2008 by the national plan “Carers at the heart of 21st century families and communities” and then replaced in 2010 by a new carers’ strategy titled “Recognised, Valued and Supported: Next Steps for the Carers Strategy”[23], which aims to raise the profile of carers and improve their support services (see Box 2).

Box 2. Legal recognition of carers – The example of England

England has developed specific informal care legislation, which recognises the contribution of informal carers to the LTC system. “Recognised, Valued and Supported: Next Steps for the Carers Strategy” was published in 2010 and outlines the following priorities:

- Early identification of informal carers and promotion of their involvement in designing local care provision and in planning individual care packages;

Enabling those with caring responsibilities to fulfil their educational

The remaining countries do not have a national policy in place specifically targeting informal carers. The absence of a national policy does not automatically imply that informal caregivers are not supported at local or national level, but initiatives vary greatly in scope and coverage, as reported for instance in Austria and Belgium regarding the availability of direct support services.

Another development at this third level is the provision of legal entitlements for informal carers. As European governments have begun to recognise the role of carers in the provision of care, the social protection rights of informal carers in terms of needs assessment, pension credits, conciliation of employment and caring have been incorporated into national legislation in many European countries (see Table 4).

[Table 4 about here]

Pension credits have been established in many European countries as part of their pension reforms, as a way to recognise caregivers' caring work. They usually take

the form of an amount of time credited to the carer's working record, and they have been applied to a much larger extent to childcare than to care of the elderly. Fifteen European countries do not offer any type of pension credits to informal carers of older relatives. The remaining countries offer some form of protection, often dependent on the intensity of caregiving or on the severity of the disability of the care receiver. An important caveat in this picture is that there is often no information on how much protection is given to pensions, and it is difficult to assess whether it is enough to sustain basic standards of living.

Finally, many governments have put in place measures to combine employment and caring. Indeed, one of the main costs of caring is the reduced labour market participation of informal carers and its associated long term consequences for pensions. Helping carers to combine care with paid work can take the form of leave from work or flexible working arrangements. In that respect, a first group of countries (e.g. Belgium and France) has no specific measure for informal caring but allows for some time off work as paid leave (see box 3).

Box 3. The Belgian model of “time-credits”

The right of employees to take a career break, known as “time-credits”, was introduced in Belgium in 2002 and reformed in 2011. Belgium provides the longest paid leave in Europe and its main characteristics are:

- *Flexibility* - The leave is limited to a minimum of three months and a maximum of one year for full-time workers, two years for part-timers, or five years for applicants working under one fifth of the working week. It can take the form of a break or of a reduction in working hours.
- *Justification* – Contrary to most other leave schemes, there is no need to provide a specific reason when applying. However, the time-credit with justification (to care for a young child or sick family member) can be used for longer periods of time (for a maximum of 36 months during a career, whether working full- or part-time).
- *Minimal work requirements* – An applicant must have already worked for more than five years in total and at least two years in his/her current company.
- *Benefit and pension* – The level of benefit varies depending on the age, employment history, family situation and type of break chosen by the applicant. The time credits are included as working for the calculation of pensions, but for a maximum of one year only.
- *Age and time of service* – The system differentiates between employees aged 55 and older and their younger counterparts. Older employees (who have worked for at least 25 years) receive more favourable conditions under this scheme.
- *Job protection regulations* – Employees are protected from dismissal when they apply and until three months after termination of the break or reduction in working hours.

A second group of countries has put in place specific paid or unpaid care leave and flexible working arrangements for the care of an older relative (Austria, Cyprus, Denmark, England, Finland, Germany, Greece, Hungary, Ireland, Italy, Lithuania, Malta, the Netherlands, Slovakia and Sweden). The final group of countries is composed of countries which have no measure in place for the conciliation of caring and employment.

4. Discussion

This article has sought to map out the support available across the European Union to enable informal carers to continue to provide care despite the heavy burden this carries. Our results show that many member states have further recognised the role of informal carers, with developments at all three levels of our framework. Consideration is increasingly given to the well-being of informal carers in many countries and targeted support services are being developed. Indirect or direct financial support has been developed as a way to compensate carers. The reduced labour market participation associated with informal caring has also been recognised, as well as its associated long-term consequences for pensions [6, 24-27]. In practice, the availability of services and entitlements varies considerably across Europe and a number are designed for and used by carers of children and not by carers of older people [10, 28].

All European member states are facing the challenge of creating the right conditions for informal care to be provided in the future, in times of economic downturn. Adequate support services are part of the solution. Three areas are crucial for future developments, at each level of the framework: (a) the emerging debate regarding the quality of informal care provision; (b) the changing role of informal carers and the trade-offs associated with providing support; and (c) the identification of informal carers in the national health and social care systems.

First, as direct support services are developed across Europe, the issue of improving and monitoring the quality of care provided by informal carers is coming to the forefront. Indeed, although direct support services are increasingly available, none of the countries considered in this article have a robust monitoring or evaluation system in place to measure quality of informal care. It should be noted that, in 2001, Austria introduced a federal home visit and counselling programme, but it is targeted at a very limited number of carers [29]. Quality of care in this area is a delicate issue for policymakers to tackle, as it would not seem sensitive or feasible to systematically inspect and assess the care provided by informal carers. Yet the challenge exists. A recent European report highlighted a growing number of older people experiencing mental and physical abuse in the region [30]. The heavy burden and strain associated with caregiving has consistently been shown to be a predictor of abuse. Cooper and colleagues looked at potential explanations of carers' abusive behaviours and stressed that more anxious and depressed carers reported more incidents of abuse [31]. Maltreatment was predicted by spending more hours caring, experiencing more abusive behaviour from care recipients and co-residing with the cared-for person. Informal carers who report a negative reason for undertaking informal care tend to be more anxious and to report more abusive behaviour, and the care recipient is more likely to be admitted to residential care in the following year [32]. Maltreatment could therefore be prevented partly by the timely identification of carers burdened by high stress, anxiety, depression or other such risk factors that could lead to abuse of the care-receiver; by giving the carer the choice of taking up a relevant support service such as respite care, training or

psychological and educational programmes; and by giving the carer a choice about whether to provide care at all. This issue is linked to the availability (or lack thereof) of alternative formal care services for older dependents. The available research has documented the association between the provision of care services for older people such as home care and the well-being of informal carers [33, 34]. The absence of a specific needs-assessment system for informal caregivers in most EU member states (with the exception of England, Malta and Sweden) is also particularly problematic. Policymakers should consider that this issue of quality further reinforces the importance of having identification and needs assessment systems in place to target informal carers with appropriate information and support.

At the second level of the framework, we find that direct and indirect financial support are the most common type of support provided. However, European countries vary considerably in their implementation of these schemes. The gradual introduction of financial support as part of the personalisation agenda in LTC services has had a complex impact on informal care and has ignited debates about the evolving status of informal carers [35, 36]. As noted by Ungerson, the impact of financial support schemes largely depends on whether the scheme regulates the type of worker who can be employed by care-recipients, whether it enforces social care for these care workers and whether or not the payment of relatives (and especially spouses) is allowed [37]. For instance, the introduction of a regulated cash-for-care scheme in 1997 in France has resulted in the externalisation of the time-consuming tasks – mostly those related to personal care – to professional

carers, while informal carers take on the role of care-coordinator [38, 39]. On the other hand, in Italy, a less regulated attendance allowance has fostered the development of a broad unregulated care sector, employing between 650,000 and 800,000 immigrant care workers [40-42]. It should also be noted that direct and indirect financial support for informal carers constitute important cost-containment measures within the broader LTC financing system[43]. Not matter the level of the allowance, it is always considerably lower than the costs of institutional and home care services [22].

Finally, at the third and broader level of national policies, our results have shown that the identification of caregivers is a weak point in most countries. Adequate identification is crucial in terms of both enabling data collection and appropriately targeting carers in order to give them the opportunity to participate in an intervention or to take up available support. Promoting awareness of the role of carers is key. Many carers do not formally consider themselves as caregivers [44]. Therefore, although it is encouraging to find that a variety of services are in place, it is important that these are utilised by caregivers who understand that they are in fact considered informal carers and that there is support available to them if they need it. Conflicts of interest between informal carers and care recipients are likely to constrain the take-up of support services. For example, it may be difficult for informal carers to access respite care because the cared-for person may consider it to be a first step towards institutional care [45]. Informal carers may also be reluctant to access support services due to feelings of obligation: this is especially

true of spouse carers [21, 44-46]. Research also shows that informal carers often have limited information regarding the available support services and rely on relatives to choose [21, 47]. General practitioners, being the first point of contact for patients in many countries, may be best placed to identify informal carers, assess their needs and provide them with the relevant information on the support available [44, 48]. National governments are aware of the challenges of identifying informal carers in the care system. For instance, in February 2012, a working group was set up by the Finish Ministry of Social Affairs to prepare a new bill on informal care, with the aim to raise the status of informal carers and improve their visibility in the health and social system .

Further research will be needed to make sense of the important cross-national differences found in the provision of support for informal carers. Glendinning and colleagues draw attention to how definitional differences and complex causal relationships make classifications and generalisations about international experience difficult if not impossible in that area [19]. Existing classifications have focused either on the link between the provision of informal care and the broader LTC system [e.g. 4, 49]; or on the differences in the provision of childcare and eldercare [28]. International variations are however likely to be linked to the role attributed to informal carers in their respective countries. In that respect, the classification of models of informal care developed by Twigg [12] would be a useful starting point to account systematically for the variability in the provision and support for informal carers. Twigg distinguishes between four models that

represent ideal-types of relation between informal carers and the broader health and social care system: (a) carers as resources, where the cared-for person is at the centre of the system and carers are mainly considered as resources to be drawn on to provide care; (b) carers as co-workers, where carers are seen as working alongside formal carers; (c) carers as co-clients, where carers are seen as co-clients of the LTC system and their needs are considered *per se*; (d) superseded carers, where the objective is not to support or to relieve the carer but to free him/her from the dependent relationship by offering comprehensive alternative formal care. Each model corresponds to different levels of reliance of informal carers, provision of alternative formal services and support services aimed at carers. These categories are only schematic and not mutually exclusive, as different models of carers can co-exist within countries or regional groups of countries. For example, Pickard notes that the approach adopted in England is not unambiguously a “co-client” one (England has a specific needs assessment system in place) as the 2008 Carers Strategy promotes an instrumental “co-worker” approach by describing carers as care partners, alongside formal services [16]. The classification is still useful as our results show that there is no single and straightforward definition or conceptualisation of informal care across Europe. In most countries considered, the position of informal carers remains ambiguous, at the margins of the health and social care systems. The four categories cited above should help to understand where each European country stands, based on how it provides support for carers and accounts for their needs.

This article has a number of limitations. The availability and quality of the national data on informal carers in general and support services in particular vary considerably. Only three countries (England, Luxembourg and Ireland) have up-to-date national statistical sources designed specifically to describe the provision of informal care. In most other countries, the data is at best patchy and often difficult to interpret. Second, the findings only reflect the responses from country experts and do not always pick up on regional differences within countries (e.g. services provided locally by NGOs), nor on the potential gap between published policy documents and their implementation. In order to minimise potential biases, all information was cross-checked by means of triangulation with other sources (published and grey literature). Finally, the evidence collected in some Eastern European countries was difficult to interpret. The divide between formal and informal care is often blurred and it potentially implies more support services than are actually provided for the narrower category of informal carers. Due to the sparse data currently available, the paper does not cover the level of service use or the carers' experiences of using these services. The debate on the effectiveness and cost-effectiveness of different support services is also outside the scope of this study.

5. Conclusion

This mapping exercise provides a descriptive overview of support services offered to informal carers across 27 European member states. Our findings show that the breadth and depth of support policies for informal carers vary considerably across the EU. Although we were able to collect information on all member states, this was at the expense of the analysis of national particularities.

This article should be considered as a starting point for further research. First, progress needs to be made at the evidence-base level – especially in Eastern European countries - to capture and monitor better information on informal carers, and eventually to help shape policies in all member states. Second, at the macro-level of support policies, more emphasis should also be put in future research on in-depth analysis of national specificities to understand better the magnitude and impact of the policies mapped out in this paper. As more policies and measures are being developed to support informal carers, many lessons could also be drawn from comparative analysis. In a constantly evolving policy area, a comparison of the different national informal care models will help researchers understand where each European country stands, based on how it provides support for carers and accounts for their needs.

The lack of identification and needs assessment systems in most countries are two pressing issues for policy makers. The potentially negative impact of caregiving on the physical and mental health of caregivers also needs to be considered. At-risk carers, *i.e.* caregivers who provide intensive care and who co-reside with the cared-for person, should be the primary target of these policies.

As European countries and international agencies continue promoting the active and healthy ageing agenda, investing alongside this in supporting informal carers is just as crucial to prepare for the ageing of populations in Europe.

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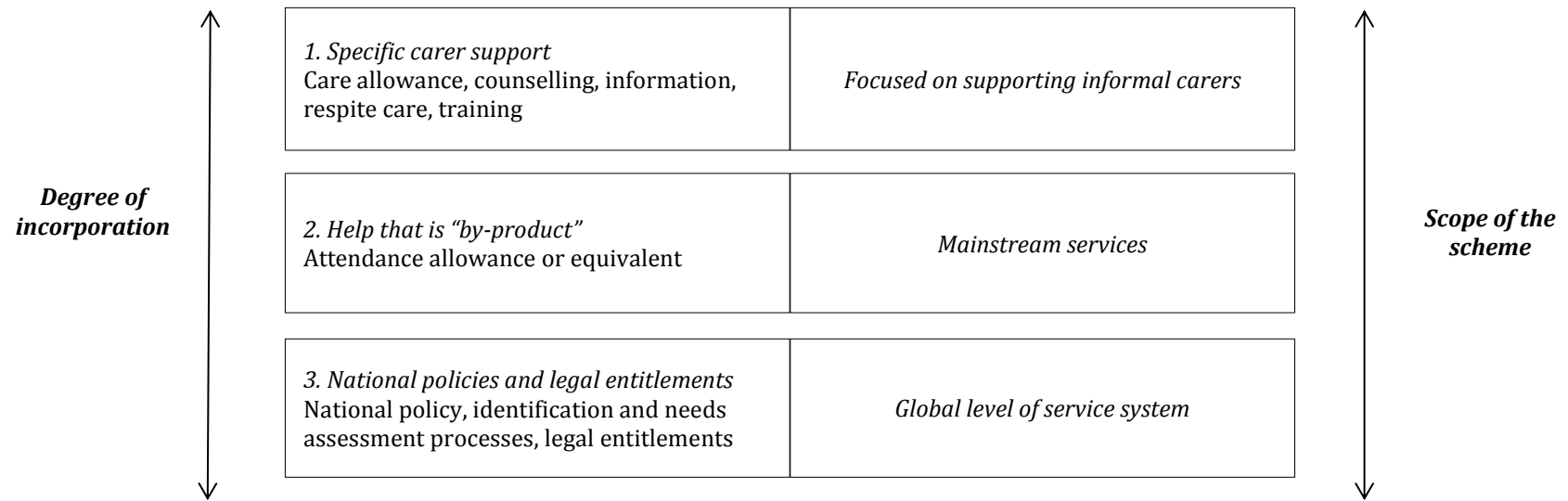
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Figure 1. Theoretical framework



Source: Adapted from Twigg and Atkin, 1994.

Table 1. Topics included in the 27 national questionnaires

National context	Type of support available	
	Support schemes	Legal entitlements
<p>(1) Data availability</p> <ul style="list-style-type: none"> - Existence of updated data at national level on the number of informal carers; - Existence of updated data at national level on the socio-economic characteristics of informal carers; - Existence of updated data at national level on support services used. 	<p>(1) Financial support</p> <ul style="list-style-type: none"> - Attendance allowance, targeted at the cared-for person; - Care allowance, targeted at the caregiver; - Evidence of support use. 	<p>(1) Pension credits²</p> <ul style="list-style-type: none"> - Availability of pension credits for informal carers; - Evidence on pension credits use.
<p>(2) Identification process</p> <ul style="list-style-type: none"> - Existence of a formal identification process; - At what point on the healthcare of social care pathway are informal carers identified? 	<p>(2) Counselling</p> <p><i>e.g. Psychological counselling to reduce carers' stress</i></p> <ul style="list-style-type: none"> - Existence of this type of support service; - Evidence of service use. 	<p>(2) Conciliation of caring and employment</p> <ul style="list-style-type: none"> - Existence of specific measures targeting informal carers such as paid or unpaid leave³; - Existence of other measures in the legislation that can be used by informal carers; - Evidence on take up of measures.
<p>(3) National policy towards informal carers</p> <ul style="list-style-type: none"> - Existence (and history) of national policy targeting informal carers. 	<p>(3) Information</p> <p><i>e.g. information from health professionals or on services available</i></p> <ul style="list-style-type: none"> - Existence of this type of support service; - Evidence of service use. 	<p>(3) Needs assessment</p> <ul style="list-style-type: none"> - Existence of a specific needs assessment process for informal carers; - Needs assessment is part of the needs assessment of cared-for person; - Evidence on take up of needs assessment process.
<p>(4) National strategy in place to support informal carers</p> <ul style="list-style-type: none"> - As part of or alongside the national policy, existence of a national strategy specifically addressing support services for informal carers. 	<p>(4) Respite care¹</p> <ul style="list-style-type: none"> - Existence of this type of support service; - Evidence of service use. 	
	<p>(5) Training</p> <p><i>e.g. Training by care professionals in nutrition, aiding transfers, mobility, and activities of daily living</i></p> <ul style="list-style-type: none"> - Existence of this type of support service; - Evidence of service use. 	

¹Respite care is defined as the temporary provision of care for a dependent older person at home or in an institution by people other than the primary caregiver.

²Pension credits were introduced in a number of countries to account for gaps in informal carers' pension records from having to undertake caring responsibilities.

³Leave from work as well as flexible working arrangements are included.

Table 2. Overview of the types of support available for informal carers across EU27

Country	Counselling	Information	Respite care	Training
Austria	Yes	Yes	Yes	Yes
Belgium	No	No	Yes	Yes
Bulgaria	No	Yes	Yes	Yes
Czech Republic	No	Yes	Yes	No
Denmark	Yes	Yes	Yes	Yes
England	Yes	Yes	Yes	Yes
Finland	Yes	Yes	Yes	Yes
France	Yes	No	Yes ¹	Yes
Germany	No	Yes	Yes	Yes
Greece	Yes	Yes	Yes	No
Hungary	No	Yes	Yes	No
Ireland	Yes	Yes	Yes ¹	Yes
Italy	No	No	Yes	Yes
Latvia	Yes	Yes	Yes	Yes
Lithuania	No	Yes	No	Yes
Luxembourg	Yes	Yes	Yes	Yes
Malta	No	Yes	Yes	No
Netherlands	Yes	Yes	Yes	Yes
Portugal	No	Yes	Yes ¹	Yes
Romania	No	No	No	Yes
Slovakia	No	No	Yes	No
Spain	Yes	Yes	Yes	Yes
Sweden	Yes	Yes	Yes	No

Source: National expert surveys.

¹ Available evidence shows that services are under-used.

Note: No support services were reported by national experts in Cyprus, Estonia, Poland and Slovenia. The definition of informal carers as well as the divide between formal and informal care is unclear in Bulgaria, Latvia, and Romania. The information provided for these countries should consequently be interpreted cautiously.

Table 3. Direct and indirect financial support offered to informal carers

Countries	Availability of financial support		Conditions
	Care allowance (direct)	Attendance allowance (indirect)	
Austria	No	Yes	Need-tested but not means-tested*
Belgium	No	Yes	Means-tested
Bulgaria	No	Yes	Means-tested
Czech Republic	No	Yes	Dependent on the level of disability of the cared-for person.
Denmark	Yes	No	For a maximum of 6 months.
England	Yes	Yes	Care allowance: To qualify carers must be 16 years old or over and look after someone who receives a qualifying disability benefit, for at least 35 hours a week. If they work, they must not have net earnings above £100 a week. Care allowance is means-tested but attendance allowance is not.
Finland	Yes	No	Not means-tested
France	No	Yes	Depends on income and severity of the disability of the cared-for person
Germany	Yes	No	Depends on the level of needs of the cared-for person. At least 14 hours of care have to be provided
Greece	No	Yes	Financial support is provided by social security organisations and professional funds. Depends on the severity of the disability and is not means-tested.
Hungary	Yes	No	Dependent on severity of the disability of the cared-for person*
Ireland	Yes	No	Carer's Allowance: Not in employment, self-employment, training or education courses outside the home for more than 15 hours a week. Only for carers who are caring on a full-time basis for someone who requires full-time care and attention and will require it for at least 12 months. Means tested.
Italy	No	Yes	Dependent on the needs of the care-for person and is means-tested.
Lithuania	No	Yes	Regulations vary per municipalities and the benefit depends on the needs of the cared-for person.
Luxembourg	No	Yes	Duration of care (maximum of 10.5h per week)
Malta	No	Yes	Dependent on the level of disability of the care receiver and is means-tested.
Netherlands	Yes	Yes	Conditional on qualifying for Exceptional Medical Expenses Act and duration of care needed.
Poland	No	Yes	Only for unemployed carers
Portugal	No	Yes	Not means-tested, depends on the severity of the disability of the cared-for person.
Romania	No	Yes	Means-tested
Slovakia	Yes	Yes	Care allowance is means-tested and dependent on the severity of the cared-for person*
Spain	No	Yes	Dependent on the level of disability of the cared-for person and is means-tested

Sweden	Yes	Yes	Care allowance: an employment contract needs to be signed with the local authorities and depends on the care needs of the cared-for person. Attendance allowance: needs-tested but not means-tested and a minimum of care hours of care per week (17) is required.
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Sources: National expert surveys.

*The evidence comes from Colombo et al., 2011 and provides information for 2009-2010.

Notes: There is no financial support available for informal carers in Cyprus, Estonia, Latvia and Slovenia.

The means which are tested in the schemes are those of the informal carer in the case of the care allowance and those of the care recipient in the case of the attendance allowance.

Table 4. Legal entitlements: pension credits and care leave

Countries	Pension credits	Conditions	Care leave	Additional information
Austria	Yes	Care recipient has to receive LTC allowance of level 3 or higher	Yes, paid and unpaid leave	Paid leave for up to one week per year; unpaid leave for up to six months.
Belgium	No	-	Yes, paid and unpaid leave	Paid leave for up to two months full-time or part-time; unpaid leave for up to two months. Entitlements depend on the employer (public or private), the age and duration of employment of the employee (see box 3 for further details)
Bulgaria	No	-	Yes, unpaid leave	Reported as under-used. In 2011, a revision of the labour code introduced flexible working for informal carers.
Cyprus	No	-	Yes, paid leave	Means tested
Czech Republic	Yes	Only for carers of severely disabled dependents, at state pension level	No	Individual agreements with specific employers exist.
Denmark	Yes	State pension is guaranteed, private pensions depend on specific agreements with the employer. Limited to 6 months of caring	Yes, paid leave	No time limit for the duration of the leave, and no requirement regarding the relationship with the cared-for person.
England	Yes	At basic state pension level	Yes, paid leave	Support depends on employment contract and can be refused for business reasons.
Finland	Yes	Pension rights are maintained, based on a formal agreement with the municipality	Yes, paid leave	No legislation targeting informal carers specifically, leave depends on specific arrangements with the employer.
France	No	-	Yes, paid leave	Carers are usually required to have a minimum number of years of experience in general and with their employer.
Germany	Yes	For informal carers providing at least 14 hours of unpaid care per week and who are also working up to 30 hours per week.	Yes, unpaid or paid leave*	Leave of absence for family support (up to 3 months, can be renewed once); for family solidarity (two years of service with the company and cared-for person must be at least 80% disabled)
Greece	No	-	Yes, unpaid leave	Up to six months, may or may not be paid depending on the employer.
Hungary	No	-	Yes, unpaid leave	Informal carers are entitled to 6 days per year of unpaid leave for family care responsibilities.
Ireland	Yes	A person cannot be awarded credits if s/he has a gap of more than two consecutive tax years in his/her insurance record (that is, s/he has no paid or credited contributions).	Yes, unpaid leave	Up to two years
Italy	Yes	Only in certain regions of Italy, no overarching national policy.	Yes, paid and unpaid leave	From 13 to 104 weeks, only for employees who have been working in the firm for at least a year continuously.
Lithuania	Yes	For carer of working age, not currently employed	Yes, unpaid leave	Mostly limited to public sector workers (up to 25 days per year of care leave; 3 days per year of supported leave for family responsibility; up to two years of continuous or split unpaid leave).

Luxembourg	Yes	or already receiving a pension. The contribution to their pension fund is on the basis of a monthly social minimum wage fixed for a non-qualified worker-	Yes, paid and unpaid leave	Paid leave: five working days granted per year for the care of a terminally ill family member. Unpaid leave: depends on specific agreements, usually for a maximum of six months at a time.
Malta	Yes	-	Yes, unpaid leave	The legislation includes: leave for a special reason (unpaid for up to 30 days per year), responsibility leave (up to one year of unpaid leave for employees in the public sector only) and urgent family leave (16 hours from their holidays entitlement in cases of sickness or accident which require the immediate presence of the employee)
Netherlands	No	-	Yes, paid and unpaid leave*	Short term leave: Employees are entitled to an annual maximum of 10 days care leave with payment for at least 70% of the salary. Long term leave: Each year a maximum of six times the work week can be included for (long term) care to support a partner, child or parent. This can be in a continuous period or spread over a longer period. The employee will then work part-time. The employee receives income only for the hours worked.
Slovenia	Yes	Informal carers who are employed as home care assistants are entitled to a pension.	No	-
Spain	No	-	Yes, paid and unpaid leave	The legislation distinguishes between: 2 to 5 days paid leave for extraordinary family contingences; partial reduction in working time (with the corresponding salary reduction); and unpaid leave for carers for a period of up to 2 years with the right for reincorporation on the same work place (in the public sector). In the private sector, unpaid leave is not a statutory right for workers and may be refused by employers.
Sweden	No	-	Yes, paid leave	Only for a relative in terminal care, leave is authorized for up to 100 days and on average 80% of the salary is paid.

Sources: National expert surveys.

*Information from Colombo and colleagues, 2011.

Note : Pensions credits and care leave are not available in Estonia, Latvia, Poland, Portugal, Romania and Slovakia. The information presented here only covers entitlements for carers of older relatives.

