



Health systems and long-term care for older people in Europe  
Modelling the interfaces and links between  
prevention, rehabilitation, quality of services and informal care

## **Informal care in the long-term care system**

### **Executive Summary**

**Judy Triantafillou | Michel Naiditch | Kvetoslava Repkova  
Karin Stiehr | Stephanie Carretero | Thomas Emilsson  
Patrizia Di Santo | Rastislav Bednarik | Lydia Brichtova  
Francesca Ceruzzi | Laura Cordero | Tasos Mastroyiannakis  
Maite Ferrando | Karl Mingot | Joachim Ritter  
Diamantoula Vlantoni**

Athens | Paris | Vienna, September 2011

European Centre for Social Welfare Policy and Research (AT) • Ecole d'études sociales et pédagogiques (CH) • University of Southern Denmark (DK) • National Institute for Health and Welfare – THL (FI) • Institut de Recherche et Documentation en Economie de la Santé – IRDES (FR) • Institut für Soziale Infrastruktur (DE) • Wissenschaftszentrum Berlin für Sozialforschung – WZB (DE) • CMT Prooptiki Ltd. (EL) • University of Valencia – ERI Polibienestar (ES) • Studio Come S.r.l. (IT) • Stichting Vilans (NL) • Institute for Labour and Family Research (SK) • Institute of Public Health (SI) • Forum for Knowledge and Common Development (SE) • University of Kent – CHSS (UK) • University of Birmingham – HSMC (UK)



Funded by the European Commission  
under the Seventh Framework Programme  
Grant agreement no. 223037

## Informal care in the long-term care system – A European overview

### Executive summary

#### 1 Objectives and working methods

The main aim of this INTERLINKS report is to provide an overview of developments in *policies targeting informal carers and the extent of their implementation through a variety of supporting measures* in the participant countries. The role of informal carers is examined within LTC systems, in particular the extent to which informal care has been recognised and acknowledged as a consistent and constant linking element of the long-term care process and how this can be reflected in policies constructed to ensure the continued contribution of informal carers, together with that of formal services. Whilst recognising the limitations of the terms ‘informal’ and ‘formal’ carers, in particular with respect to the increasingly blurred boundaries between these two sectors (see 3.1), they were retained in this report to describe the necessary distinction between care provided by the informal and formal care sectors. This report therefore addresses two main questions:

- How can a ‘hand-in-hand’ approach be achieved between all care providers towards the provision of appropriate LTC for older people in all long-term care settings?
- What is the actual state of implementation of informal care support policies in the different European countries?

The report is based on the collaborative work of partners from Germany (DE), Greece (EL), Spain (ES), France (FR), Italy (IT), Slovakia (SK) and Sweden (SE) during phase 1 of INTERLINKS, which led to the production of background documents<sup>1,2</sup> the data from which were analysed and supplemented by relevant information from other sources.<sup>3</sup> Additional revisions were made following feedback from the Sounding Board Conference participants<sup>4</sup> and further information from partners, as final revisions were made after the report had been peer reviewed. The authors acknowledge all these invaluable contributions and warmly thank all who participated in the production of this report with its focus on the following features:

- The main factors that determine the way informal carers are included in systems of care provision;

---

<sup>1</sup> European Summary Overview of selected European studies related to informal care (EUROFAMCARE, HEALTH PRO ELDERLY, PROCARE, CARMEN, EUROBAROMETER LTC, DAPHNE, CAREKEYS).

<sup>2</sup> National Reports from the 7 partner countries (DE, EL, ES, FR, IT, SK, SE), based on a common template.

<sup>3</sup> In particular: Huber et al, 2009; Eurocarers, 2009; data from other European/INTERLINKS countries (e.g. UK; Netherlands; Finland; Austria) and other available sources.

<sup>4</sup> INTERLINKS 1<sup>st</sup> Sounding Board Conference, Brussels 18-19 February 2010.

- The identification of the main issues, gaps and good practices in informal carer support policies and their related programs, especially regarding how they connect with overall long-term care (LTC) policies and practices at macro (governance and finance), meso (provision and organisation) and micro (delivery) levels;
- The existing or emerging links between the informal and formal care sectors, particularly in setting the best balance for working carers in order that they can continue to work while caring.

These results were used to define the principles of a sound policy with effective measures for the support of informal carers, aimed either at facilitating or improving performance of their caring tasks. Accordingly, an analytical framework was built that allows for cross-country comparisons. Finally, 'practice examples' were described which illustrate the effectiveness and/or efficiency of some of the proposed measures.

This report is accompanied by a Case Study on 'Migrant Care Workers in Italy' which documents the country's move towards integrating these workers into the LTC workforce (Di Santo/Ceruzzi, 2010) and briefly describes the partner countries' different situations regarding the use of migrant care workers.

## 2 Structure of the report

Following the general introduction, Section 2 of the report describes the general context of informal care as part of social welfare policies and as an emerging topic in LTC policies and practices. The rationale for the need of a specific sub-policy for supporting informal carers is discussed and key features of an analytical framework for its delineation are identified. In Section 3, LTC provision in Europe is portrayed, focusing on the current contribution of informal carers to service delivery. In Section 4 an overview of the main determinants of the expected changes and their impact on the 'availability' of informal carers is analysed as well as (Section 5) the legal regulations and political decisions that have shaped the responsibilities for care between the family, the state and the market. Section 6 summarises policies for the support of informal carers in the participating countries and how they can be broadly differentiated through their respective measures and existing gaps. Section 7 highlights examples of good practice in linking informal and formal care at different levels within the LTC system. Finally, the main findings and the analytical framework are summarised in Section 8, while Section 9 consists of a list of recommendations for improving the linkage between the informal and formal care sectors, with support of informal carers being aligned with the overall LTC policy for older people. This section also contains issues for examination and validation in Phase 2 of the INTERLINKS project and suggestions for research questions, which could help to answer identified dilemmas.

## 3 Main findings, conclusions and recommendations

### 3.1 Key issues and gaps

(1) There is evidence that in all European countries examined (with the exception of Sweden), informal carers, mainly women, still provide most of the care, including hands-on care delivered to older people with LTC needs (Section 3). The inadequate availability of formal care services to meet these needs and/or limitations in access lead to the fact that informal carers have to fill the gaps (Section 6.5) either through the provision of essential care or by paying for private care services. Informal carers' indirect

financial contribution through care provision has been estimated to range from 40% to 90% of the overall costs of LTC, thus surpassing public expenditures for formal care providers. So informal carers are fundamental co-providers of care and constitute the backbone of the LTC system; and as the sustainability of public LTC budgets is at stake, their physical and financial contributions will continue to be needed in the future in all countries.

(2) There is strong evidence that the inter-country variability of the contribution of informal carers in the type and volume of services they deliver relates to both the legal framework as well as to the traditional division of responsibilities for the care of older people between the family, the state and the market (Section 5). This factor constitutes a crucial element in the formation and differentiation of both general LTC policies embedded in the respective welfare regime – with seemingly path-dependent patterns of how specific policies for informal carers are conceived.

(3) Demographic scenarios have pointed out that, in the future, the number of informal carers may decrease (Section 4). However, current developments show that informal carers will be of higher age, with increasing risks of poverty, social exclusion and negative consequences on their physical and mental health status. Together with the growing duration of time informal carers will have to provide care, appropriate support policies and measures become an urgent priority to ensure an optimum balance between the rights and needs of both cared for older people and informal carers, as well as the availability of informal carers in a long-term perspective.

(4) Working and caring: There is growing evidence that intensive caring correlates negatively with being active in the labour market and volunteering activities, or positively with part-time employment and less than average hours (Section 3.2.2). However, research papers, in particular those based on the SHARE survey, provide substantial indications that moderate levels of informal care provision (less than 10 hours/week) may be compatible with a maintained health status and a decent quality of life. This is the case in countries providing higher levels of formal services and support measures to enhance the level of employment of carers at working age, thus contributing to reaching the Lisbon targets regarding the labour market participation rates of women and older workers.

(5) The dynamics of the ‘triangle of care’ (formal carer, informal carer, older person in need of care) constitute the central unit of analysis at the (micro) level of service delivery (3.2). The presence of an informal carer frequently excludes older people from access to essential care services or decreases the level of services to which they are entitled. On the other hand, if care is shared between the formal and informal care sectors, gaps may exist in the way professional and informal carers work together and share responsibility for implementing and supervising the care process. This often results in conflicts (Section 6.5.5) and impedes care coordination, with the family carer often obliged to act as an implicit but not recognised care manager. So there is clear evidence that professionals need better preparation in how to assume responsibility for managing the care process with both stakeholders, either directly while providing care, or with the support of a case manager.

(6) At the service delivery (micro) level there is strong evidence for frequently underestimated conflicts between the older person’s and the informal carer’s needs and expectations (2.3), i.e. the older person’s choices may not always be in line with the needs or expectations of their informal carers and vice versa (6.3). Such conflicts may lead to both elder and carer abuse, but also to a sub-optimal use of respite care and other support services. This raises the issue of “whose needs are being addressed” when policies to support informal care are being formulated; the question is how to optimally link measures targeting

informal carers with those focusing on older people within overall LTC policies. The proposed framework for classifying such policies, which is outlined in the following, aims to tackle this issue.

### 3.2 Elements of a targeted policy for informal carers

Based on the above findings and as there is no commonly agreed definition of what goals<sup>5</sup> a policy targeted at carers should pursue, the report proposes the following underpinning principles:

- It should address the needs of informal carers in the short and long term and be based on all types of services addressing all issues linked to their living conditions and 'work-life balance' (including work-care, work-family, free-time for hobbies and leisure), allowing them a decent quality of life.
- It should provide informal carers, and specifically family carers, with income (cash) and social protection or practical support (in-kind services), enabling them to choose in the short and long term their caring tasks and levels of care provision, whether they are in the labour market (carers at working age) or not (pensioners).
- It should be neutral regarding informal carers' choices between caring or not caring, or caring at any level, while being compatible with the older person's needs and expectations.

### 3.3 An analytical framework for classification of informal carer support policies and associated measures

LTC policies that aim to address the needs of informal carers should consist of a mix of support measures (in-kind and in cash) that aim to respond uniquely to informal carers' specific needs (specific measures), while non-specific measures address both the needs of informal carers and the older care recipients. In both cases, measures can address their needs either directly (Table 1) or indirectly (Table 2), as follows:

- *Specific direct measures* are those that explicitly target informal carers in order to help them *in performing* their caring tasks.
- *Specific indirect measures* are those that aim to *support and facilitate the caring option* for both employed and non-employed informal carers.
- *Non-specific measures* are those targeting *both* the older person and the informal carer; they are sub-divided into *non-specific direct*, when they *primarily target informal carers* and *non-specific indirect* when they *primarily target the older person*.

---

<sup>5</sup> These goals are also examined in the Eurocarers Factsheet and Carers' charter <http://www.eurocarers.org/userfiles/file/Factsheet2009.pdf>

**Table 1** Examples of specific measures for the support of informal carers

Specific measures	Examples
Direct (hand-in-hand approach)	Information, training, education, opportunities for the exchange of experiences, peer support groups, devices, ICT solutions Training for formal carers in how to include and support informal carers in a shared provision of care
Indirect	Care leave, flexible working arrangements, care allowances, pension and accident insurances

**Table 2** Examples of non-specific measures for the support of informal carers and older people

Non-specific measures	Examples
Direct (primarily informal carers)	Respite care, support and stress relief by voluntary work initiatives
Indirect (primarily older people)	All types of home and residential care services for older people Housing accommodation and adaptation, meals on wheels, technical supplies, attendance allowance

This framework (Table 3) can help in analysing the relative importance given to informal carers' support policies within countries' overall LTC policies for older people. Whilst acknowledging that the two perspectives may not coincide, it demonstrates how the content and value of policies supporting informal carers are highly dependent on and connected with the general goals of LTC policies for older people. For example, respite care will not be used and thus will not produce the expected benefits if the existing facilities are not judged to be of adequate quality and acceptability by both informal carers and the older person in need of care.

**Table 3** Analytical framework to describe and classify informal carer's support measures

Type of support		Measures	Availability	Accessibility	
<b>Specific direct</b> <i>(help in performing caring tasks)</i>	<b>In kind</b>	Cognitive	- Information*, advice, counselling		
			- Training for informal carers*		
			- Training for formal carers in how to include and support informal carers in a shared provision of care*		
		Emotional, psychological	By professionals		
			Through peer groups*		
		Social	Recreation/happy hours/Alzheimer café		
	Health	Check up/medical visit			
	Healthy aging program*				

Type of support		Measures	Availability	Accessibility	
<b>Specific indirect</b> <i>(support and facilitate the caring option)</i>	Carer's needs recognition	Carer's needs are explicitly assessed during the assessment of the older person in need of care*			
	Legislative: Work recognition as carers	Pension Rights			
		Social security benefits (health/disability pension/sickness /unemployment/work accidents)			
	Political recognition	Advocacy groups*			
	Labour Market benefits	Work leave:	a) Paid		
			b) Unpaid		
In cash	Flexible work arrangement	a) Formal*			
		b) Informal*			
		Care allowance as:	a) Maintenance		
b) Formal recognition					
c) Substitutive for formal care					

Type of support		Measures	Availability	Accessibility
<b>Non specific direct</b> <i>(primarily informal carers)</i>	Respite	Short stay (nursing homes)*		
		Day care		
		Home custody (day/night/24h/weekend*)		

Type of support		Measures	Availability	Accessibility
<b>Non-specific indirect</b> <i>(primarily older people)</i>	In cash	Attendance allowance		
		Personal budget		
		Tax exemptions		
		Vouchers		
	In kind	All types of professional home care* and residential care services for older people*		
		Housing adaptation		
	ICT*: simple monitoring, complex monitoring			

\* Indicates potential use of ICT

## 4 Support policies for informal carers: Overall results

Key results for support policies are summarised in the following by using the above framework as a guiding tool.

In most countries examined in the report there is a lack in defining the principles of a comprehensive informal carer support policy, which goes together with a limited number of measures for supporting informal carers within the LTC systems (Section 6). Countries with more generous LTC systems usually are also supporting informal carers indirectly by providing an easy access to adequate formal long-term care services. However, measures that have been implemented in many countries have not yet achieved their goals because of poor design and/or lack of comprehensive planning – this concerns both benefits in cash and benefits in kind.

### 4.1 Cash benefits

In many countries the financial sustainability of the LTC system has been perceived as critical due to the threat of a decreasing number of informal carers and the growing needs of an ageing population. Many governments (with the exception of Denmark) have thus introduced a mixture of cash-for-care benefits linked to social security benefits. These were considered an innovative way of financing the LTC system by reducing the growth of expenditures for formal services as different types of cash benefits were seen as an incentive for informal carers to provide care:

- Care allowances are financial benefits paid directly to the informal carer in recognition of their contribution to care and to secure their mid- or long-term availability as carers; they are also considered as “routed wages” to help them in caring when employed.
- Attendance allowances are financial benefits paid to the person in need of care to allow for more choice and autonomy in choosing flexible care arrangements. Instead of choosing services in kind, the older person can hire and pay a “personal assistant”, who may be a relative, or in the regular market or in the grey or black market – and in that case, most often a migrant care worker.

In most countries, limited evidence was found regarding the ability of these cash benefits to meet informal carers’ needs and to offer them more choices, but also some drawbacks:

- As the level of cash benefits is low, they only marginally contribute to avoid poverty issues of older carers (pensioners); as their level does not equate with regular wages, they are unable to compensate for income lost due to the reduction of employed work or even the complete withdrawal from the labour market. Thus they do not fulfil their goal of an optimal care/life and/or care/work balance or at least of avoiding poverty. Also social benefits linked to cash benefits are usually lower than those applying in the regular labour market. Finally, controls in the way cash benefits are used regarding the quality of the provided services are usually weak. Only in the Scandinavian countries (and to a much lesser extent in UK, France and Germany) are quality controls equivalent to those of services delivered by formal carers.
- Cash benefits having a clear “cost containment” motivation (i.e. as a cheaper solution for the public purse) are a more expensive solution from a societal perspective, as they reduce labour market participation and act as a disincentive to gainful employment.



- Cash benefits have contributed to a blurring of boundaries between informal and formal carers. The increasing use of both cash benefits and migrant care workers has created a mixed care workforce (informal family carers, migrant workers, personal assistants, formal professional care staff) operating with varying intensity in the planning, organisation and delivery of LTC service provision (Section 3.1.4) entailing and highlighting new problems and gaps in long-term care provision.

## 4.2 Remaining gaps in policies and LTC provision

- *Difficulties in sustaining the future formal care workforce:* Although rarely explicitly acknowledged, recognising informal carers as a 'paid worker' also has negative implications in the recruitment and retention of the formal workforce. It contributes to the 'de-professionalisation' of this already poorly acknowledged worker group in the field of LTC, with low pay, low status and poor working conditions. These factors contribute to difficulties in the retention and maintenance of the long-term care workforce (Section 8.1). This has strong implications for the efforts needed in order to guarantee the adequacy of the future LTC workforce, by providing better training and qualifications defined at EU level, adequate payment, social security and working conditions. These measures are essential to improve their status and professional recognition (Section 7.3, Good Practices 6 and 7).
- *Gaps in a shared care approach:* In addition to technical training, few countries are engaged in efforts to train staff in how to assess the needs of and provide support to informal carers and to bridge the existing gaps between them and the informal carers. Also there is a lack of (possibly joint) training of informal carers in caring techniques and in how to look after their own physical and mental health (see good practice examples).
- *Difficulties in accessing respite care:* Respite care services are still underdeveloped in many countries – and even if they exist, they often fail to deliver the expected benefits for reasons outlined above.
- *Caring and Working:* Some countries have put in place efficient measures in order to tackle this issue, with Scandinavian countries being largely ahead in this regard. This came not only by providing non-specific indirect support such as adequate professional care services, but also by developing specific indirect measures addressing employment, labour and transportation issues at macro and micro levels. This illustrates an extended vision for such policies, going beyond the social and the health care sectors.

## 5 Examples of good practice

Notwithstanding the many gaps and shortcomings in policies and measures to support informal carers, a number of good practice examples can be retrieved across Europe. Some of these have been identified in the report (see Section 7, p. 48) and, during the second phase of INTERLINKS, have been analysed and peer-reviewed and are used as illustrations for key-issues in the INTERLINKS Framework for Long-Term Care (see <http://interlinks.euro.centre.org>).

Table 4 below uses the analytical framework to classify selected INTERLINKS examples, which illustrate some of the different types of support measures for informal carers and the older people they care for.

**Table 4 Analytical framework to describe and classify informal carer's support measures: using selected INTERLINKS examples (see <http://interlinks.euro.centre.org>)**

Type of support		Measures	INTERLINKS Example	INTERLINKS Code	
<b>Specific direct</b> <i>(help in performing caring tasks)</i>	<b>In kind</b>	Cognitive	- Information*, advice, counselling	Network careCompany	DE_4.5c
			- Training for informal carers*	Elderly Care Vocational skill building and certification (ECVC)	EL_4.2def
			- Training for formal carers in how to include and support informal carers in a shared provision of care*		
		Emotional, psychological	By professionals	Athens Association of Alzheimer Disease and Related Disorders (AAADR)	EL_5.6abcd
			Through peer groups*		
		Social	Recreation/happy hours/Alzheimer café	Alzheimer Cafes	NL_5.6cd
		Health	Check up/medical visit		
Healthy aging program*					

Type of support		Measures	INTERLINKS Example	INTERLINKS Code
<b>Specific indirect</b> <i>(support and facilitate the caring option)</i>	Carer's needs recognition	Carer's needs are explicitly assessed during the assessment of the older person in need of care*	Municipal obligations to support informal carers	SE_2.2a
			Integrated access point for older people	IT_3.1bc
	Legislative: Work recognition as carers	Pension Rights	Special collective agreement for informal caregivers of dependent people	ES_6.3a
			Social security benefits (health/disability pension/sickness /unemployment/work accidents)	SK_1.1c
	Political recognition	Advocacy groups*	"We Care"	DE_2.4b
	Labour Market benefits	Work leave:	a) Paid	
			b) Unpaid	Care Leave Act
		Flexible work arrangement	a) Formal*	
			b) Informal*	Dementia Guidelines and informal carers
	<b>In cash</b>	Care allowance as:	a) Maintenance	
b) Formal recognition			Municipal obligations to support informal carers	SE_2.2.a
c) Substitutive for formal care			Direct payments for carers	UK_6.3ac

Type of support		Measures	INTERLINKS Example	INTERLINKS Code
Non specific direct (primarily informal carers)	Respite	Short stay (nursing homes) *	Protected hospital discharge and palliative care teams	IT_5.2g
		Day care	Meeting Centres for people with dementia and their caregiver(s)	NL_5.6abcd
		Home custody (day/night/24h/weekend*)	Respite care platform: Organising a diversity of respite services in the community	FR_5.5e

Type of support		Measures	INTERLINKS Example	INTERLINKS Code
Non-specific indirect (primarily older people)	In cash	Attendance allowance	Special collective agreement for informal caregivers of dependent people	ES_6.3a
		Personal budget	Care at home by integrating formal and informal care	IT_6.3b
		Tax exemptions		
		Vouchers		
	In kind	All types of professional home care* and residential care services for older people*	Help-at-Home	EL_5.5cdeg
			Concept of Social Services Development - Implementation of social services development policy within the region Trenčín	SK_2.1.f
		Housing adaptation	E-Health Unit of Sotiria Hospital	EL_6.6abc
	ICT*: simple monitoring, complex monitoring	Equinoxe – a home alarm system linked to volunteering	FR_6.6e	

\* Indicates potential use of ICT

## 6 Conclusions

The sustainability and expansion of the currently mixed care workforce, consisting of informal family carers, migrant workers, personal assistants, volunteers and formal professional care staff, calls for comprehensive LTC policies. These should better address all aspects of LTC provision and in particular informal carers' support principles and measures.

As informal carers will continue to play a major role in the provision of 'hands-on' care, strong and concerted efforts are still necessary to ensure their availability in the future. The mix of supporting measures found in most of the studied countries is far from sufficient to meet both older people's and informal carers' basic needs and to allow them real choices in how optimum care can be provided.