



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

European Overview Paper

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Table of contents

1	Introduction	4
1.1	Objectives of the report and working methods	4
1.2	Structure of the report	5
2	Background to the report	6
2.1	General context	6
2.2	Services in kind and benefits in cash	7
2.3	Why a policy to support informal carers is needed	7
2.4	A framework for classification of informal carer support policies	9
3	Informal and formal long-term care work	11
3.1	Definitions of informal and formal care	11
3.1.1	Informal care	11
3.1.2	Formal care	11
3.1.3	'Professionals'	11
3.1.4	A rapidly changing situation	12
3.2	Informal and formal care work	13
3.2.1	Informal carers' characteristics and their contribution to care provision	14
3.2.2	Services provided by informal carers and distribution of tasks within the family and with formal carers	14
3.3	The impact of caring, support needed and working carers	15
3.3.1	Health, quality of life, social integration and caring	15
3.3.2	Working and caring	17
4	Changing perceptions of care and the context of carers' changing roles	19
4.1	Determinants of the changing perceptions of care	19
4.1.1	Demographic changes and the need for care	19
4.1.2	Changes in social structures	21
4.1.3	User empowerment and privatisation	22
4.1.4	Economic changes	23
5	Caring as a shared responsibility: An overview of legal and political aspects	25
5.1	Responsibilities at the European level	25
5.2	Responsibilities at country level	26
5.2.1	Financial maintenance obligations	26
5.3	Sharing of responsibilities between family and state	28
5.3.1	Practical 'hands-on' care obligations	28
5.3.2	Sharing care work between informal and formal caregivers	29
5.4	Support measures for informal carers: an analytical approach	29
5.4.1	Financial support measures (cash-for-care)	30
5.4.2	In-kind services	31

6	Policy, legislation and implementation: An overview of policies and gaps in support for informal carers within long-term care	34
6.1	Elements of a targeted policy for informal carers	34
6.2	Assessing support measures for informal carers	34
6.3	The issues in shaping and implementing informal care policies	35
6.4	Policies for supporting informal carers and integrating them into the LTC system: Main country approaches	37
6.4.1	Germany	37
6.4.2	Greece	38
6.4.3	Spain	39
6.4.4	France	40
6.4.5	Italy	41
6.4.6	Slovak Republic	41
6.4.7	Sweden	42
6.5	Gaps between policy and provision of support to informal carers	43
6.5.1	Gaps in funding formal care services	43
6.5.2	Gaps in cash benefits	44
6.5.3	Gaps in the balance of responsibilities between family, market and state	44
6.5.4	Gaps in giving voice and power to informal carers	45
6.5.5	Gaps between formal and informal carers in working 'hand-in-hand'	45
6.5.6	Gaps in caregivers' social rights	46
6.5.7	Gaps in the quality of services	46
6.5.8	Gaps in fairness and equity	47
7	Examples of good practice addressing links and interfaces in long-term care	48
7.1	Linking health and social care at the systems level	48
7.2	Empowering informal carers at the organisational level	49
7.3	Training of informal and professional carers	50
7.4	Links at the interfaces between informal care and long-term care systems at the delivery level	50
8	Main findings, conclusions and recommendations	55
8.1	Main findings and issues	55
8.2	A classification of LTC policies and measures	56
8.2.1	In-kind services for older people (non-specific and indirect measures for informal carers)	57
8.2.2	Cash benefits (specific or non-specific indirect measures for informal carers)	57
8.2.3	In-kind services to support informal carers (<i>specific and non-specific, direct and indirect</i>)	58
8.3	Relevant research issues and the existing gaps at practice level	59
8.4	Caveats for designing a sound informal care policy	60
8.5	Conclusions: Linking the informal and formal care sectors in an integrated model of long-term care	61
9	References	62

1 Introduction

1.1 Objectives of the report 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 as supporting measures in the participant countries. We have focused mainly on existing or emerging links between the informal and formal care sectors, on the balance set between working and caring and on policies and ‘good practices’¹ for the effective support of informal carers in performing their caring tasks. We have also tried to identify the main gaps between these 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 role of informal carers is examined within LTC systems and the connected health and social care sectors; in particular we look at the extent to which informal care has been recognised and acknowledged as a consistent and constant linking element of the long-term care process, as reflected in policies constructed to ensure the continued contribution of informal carers together with that of formal services. The report therefore addresses the issue of how to achieve a ‘hand-in-hand’ approach between all care providers towards the provision of good LTC for older people, in all long-term care settings and whatever the present status of LTC in the different European countries. Whilst recognising the limitations of the terms ‘informal’ and ‘formal’ carers, we have retained these terms in this report as a necessary distinction between care provided by the informal and formal care sectors, despite the blurring of boundaries between the two. The definitions of these terms are examined further in Section 3.

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^{2,3} the data from which were analysed and supplemented by relevant information from other sources.⁴ Additional revisions were made following feedback from the Sounding Board Conference participants⁵ and further information from partners, and final revisions were made after the report was peer reviewed. We acknowledge all these invaluable contributions and warmly thank all who participated in the production of this report.

Finally, 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)

¹ The criteria for good practice in each area are being defined in collaboration with other WPs and specific practices will be examined in phase 2 of the INTERLINKS project.

² European Summary Overview of selected European studies related to informal care (EUROFAMCARE, HEALTH PRO ELDERLY, PROCARE, CARMEN, EUROBAROMETER LTC, DAPHNE, CAREKEYS).

³ National Reports from the 7 partner countries (DE, EL, ES, FR, IT, SK, SE), based on a common template.

⁴ In particular: Huber et al, 2009; Eurocarers, 2009; data from other European/INTERLINKS countries (e.g. UK; Netherlands; Finland; Austria) and other available sources.

⁵ INTERLINKS 1st Sounding Board Conference, Brussels 18-19 February 2010.

and briefly describes the partner countries' different situations regarding the use of migrant care workers.

1.2 Structure of the report

Section 2 gives the general context of informal care as part of social welfare policies and as an emerging topic in LTC policies and practices and discusses why a specific sub-policy for supporting informal carers is needed.

The work of long-term care, including the current contribution of informal carers to service delivery is examined in Section 3, while Section 4 gives an overview of the main drivers pushing for changing the present state.

Legal and political aspects regarding the sharing of responsibilities for care between family and state are then analysed in Section 5, while policies for the support of informal carers in the INTERLINKS countries and gaps between policies and provision of support are discussed in Section 6.

Section 7 describes examples of good practice in linking informal and formal care at the different levels within the LTC system and Section 8 summarises our main findings and conclusions and identifies some issues for examination and validation in Phase 2 of the INTERLINKS project.

2 Background to the report

In this section we aim to describe briefly the general political and economic context in which LTC policies are emerging as a specific area of social and welfare policies (2.1 and 2.2), the rationale of a policy for supporting informal caregivers (2.3) and to outline a suggested framework for the classification of informal care policies (2.4).

2.1 General context

A number of relevant policy documents backing up efforts to support informal care, informal carers and the people they care for, acknowledge and recognise that this is an issue of public interest in the area of LTC for older people:⁶

- *Regional Implementation Strategy for the Madrid International Plan of Action on Ageing 2002* (ECE/AC.23/2002/2/Rev.6; commitment No. 9 “To support families that provide care for older persons and promote intergenerational and intra-generational solidarity among their members”).
- Recommendation Rec (2006) 5 of the Committee of Ministers to Member States on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015 (Article 3.8 “Community living” calling on states to assess the needs of families as providers of informal care, to provide them with information, training and assistance, psychological support and to enable reconciliation of private and professional life and gender equality)
- *UN Convention on the Rights of Persons with Disabilities* (A/61/611 from December 6, 2006; Preamble: “Persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”)
- *Long-term care in European Union* (2008), within the Open Method of Coordination (OMC) related to the health and LTC agenda, informal care is recognised as a key factor in LTC system sustainability (Article 3.3).
- Recommendation CM/Rec (2009) 6 of the Committee of Ministers to member states on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society (Article No. 1.17 “Relatives should receive material and other assistance to enable them to support persons with disabilities at home”. Article No. 1.20 “Regular periods of respite care should be available to provide family carers with a break from responsibilities. This helps to ensure that home-based supported living can continue for as long as possible”).

Despite these commonly designed political recommendations, according to Marin et al (2009: 5), “there is arguably no major area of social policy in the European Union (EU) in which Member States differ more than in the way LTC for people who depend on ongoing social and medical help is organised and funded”. There are some, mainly northern, countries where there is a conception of LTC based on the social rights at any person’s disposal, while in other, mainly southern countries, LTC services are provid-

⁶ Long-term care is often defined as a variety of health and social services provided for an ongoing or extended period to individuals who need assistance on a continuing basis due to physical or mental disability (in Long-term care: a complex challenge. OECD Observer, 2007).

ed only in cases where social networks are absent and the financial means of the person in need are not sufficient to pay for private arrangements (Rothgang/Engelke, 2009).

These differences are rooted in a history where LTC, initially a family issue embedded in charities, voluntary organizations and “poor law” regulations in the context of local or regional social assistance legislation, has now become a social and political problem in all European countries. Starting in Scandinavian countries, this change happened over the past 40 years, during a period of modernization of social welfare policies (from “welfare to workfare”), which moved this domain into the position of an acknowledged area of general social policies.

The integration of the specific issues of family carers for older people into the EU overall political agenda is much more recent and appears as a result of the introduction of the social dimension following the Lisbon summit (European Older People’s Platform, 2004), which looked at measures to enhance the rate of employment in the labour market, especially for women and seniors (55-64), and which put in the forefront of the social and political agenda the issue of how best to balance responsibilities and roles regarding care between families, state and the market.

2.2 Services in kind and benefits in cash

Welfare policies in general are based on access to two types of services addressing social needs and termed ‘in kind’ or ‘in cash’. Services in kind were first introduced in the Scandinavian countries to support working parents of small children with specific care needs, and access to services was considered universal as a citizen’s right. At least since the 1970s, the rationale for supporting family members caring for disabled older people seemed similar. However, carers of older people most often belong to the 45/65-generation (sandwich generation) rather than to the 25/45-generation, and there is also a large group of older carers (65/80) retired from the labour market. As they face different problems, both groups need specifically designed policies and thus specific measures – cash benefits being one of them.

Still, when the introduction and/or reform of cash benefits in the area of LTC gained momentum in many European countries during the 1980s this was not only due to the needs of carers. In a political climate favouring more market-driven mechanisms to the ‘paternalistic and inefficient way’ of delivering public services, competition of providers and opportunities for choice of users should be increased (Evers et al, 1994). The market forces would thus boost efficiency and quality of delivered services – and thus also user satisfaction. In this context cash benefits were considered as a tool with a potential to enhance both choice and (purchasing-) power of the users who could thus purchase care arrangements that are best fitted to their needs and expectations. Transfers in cash were not only intended to directly benefit persons in need of care (attendance allowance), as they can also be used to compensate for their informal carers’ support. In many cases, attendance allowances are completely controlled by the family carer, as the person in need of care might not be able to administer the money. In addition, some countries also introduced so-called care allowances that are direct cash payments to the carer.

2.3 Why a policy to support informal carers is needed

A separation between countries’ LTC policies can thus be identified regarding:

- The balance set between services in-cash and in-kind,
- The way these are combined to support privately and/or publicly delivered services,
- Their degree of access and availability.

All these factors clearly have a major impact on the way care is organised and delivered and on how this is in line with the respective needs and choices of both the informal carers and the older people they care for.

A major difficulty, therefore, in isolating a sub-policy specifically designed for informal carers is its ‘invisibility’, which stems from the fact that both at the policy (macro) level and at the provision (meso) level, the needs and wishes of informal carers are often “conflated” with those of the person they are supporting (Arksey/Glending, 2007). Decision-makers often take for granted a certain harmony between these two actors, neglecting the complex and sometimes “conflicting dynamics of care-giving relationships” which become evident at the micro (delivery) level (Myers/MacDonald, 1996; Scourfield, 2005).

Whilst giving more choice to the older person may be empowering, his/her choices will always impact on the caregiver’s situation, though it may not always be in line with the latter’s needs and wishes. For example, if attendance allowances are used to pay the carer, s/he can be placed in a situation of subordination with respect to the recipient, especially in cases of economic weakness. Depending on the health status of the person in need of care, it could, however, also be the carer who has complete control of the benefit and the care arrangement. Cash benefits as such are therefore an ambivalent mechanism that calls for appropriate needs assessments procedures with the aim to align both perspectives. This is equally valid when it comes to the allocation of services in kind. Though providing services to older people may, at first sight, seem to be in the best interest of informal carers, as these services take over ‘hands-on’ care, conflict of interest may also arise in this case, as the cared for older person may not agree to the substitution of the family carer by a professional worker. However, an opposing argument from disability rights activists is that policies focusing on supporting carers would contribute to perpetuating and exacerbating the dependency of ageing people with disabilities (Morris, 2006).

The issue of whose needs are or should be addressed in LTC policies thus needs to be clearly addressed: Building a sound policy for older people does not automatically imply an appropriate policy for informal carers. This issue will be further discussed in Section 5 with respect to the reconciliation of caring and working.

A second issue lies in the fact that informal carers may be considered as both care-providers and as people in need of care (see also Section 6.1). They may act as either the sole resource of care or as co-providers of professional services with professionals, but they might also be individual clients for formal services or co-clients together with the older family member in need of care (Carretero et al, 2009; Garcés et al, 2009; 2010). This dual role becomes irrelevant only when informal carers are not delivering hands-on care, since the care needs of the older person are satisfied by formal services (the superseded carer model: Twigg/Atkin, 1994). There thus exists a gradient between two extreme models:

- a) Informal carers are considered as sole service providers (Mediterranean welfare regime) and, due to a lack of public formal services, neither they themselves nor the older person have a choice of solutions unless they can pay for private care.
- b) The superseded carer model, when the carer has the choice not to provide hands-on care due to the provision of adequate public services for older people in need of care. In this case the need for a specific informal carer policy seems to be less pressing, as long as the professional services are of a quality satisfactory to both stakeholders.

Within the continuum between these two extremes various policies can be identified, sometimes blurring the concepts of formal and informal care and with measures intended to support older people not necessarily being in line with those supporting informal carers and vice versa. Also the degree to which informal carers are recognised and treated as key (but not necessarily equal) partners in providing care and/or are given responsibilities for coordinating care, varies considerably. All these dimensions are key issues when comparing informal care policies and especially in the analysis of whether measures intended to support older users are in line with those supporting informal carers.

2.4 A framework for classification of informal carer support policies

LTC policies that aim to address the needs of informal carers are thus confronted with various contextual issues that remain difficult to disentangle. In order to get some clarification of the underpinning goals of policies and measures specifically directed toward supporting informal carers and their links with general LTC policies, we need a framework which classifies measures (both in-kind and in cash) into those that respond primarily to informal carers' specific needs and to those primarily addressing the needs of older people; in both cases, measures can address these needs either directly or indirectly. Taking these issues into consideration and for the purposes of this report, we propose the following classification:

- *Specific measures* supporting informal carers are those that uniquely target informal carers in order to help them in performing their caring tasks. These may not require the input of formal carers (*specific direct*) (Garcés et al, 2010; Carretero et al, 2009), or may entail a 'hand-in-hand' approach between formal and informal carers (*specific indirect*).

Table 2.1 Specific measures for the support of informal carers

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

- *Non-specific measures* are those targeting both the older person and the informal carer; they can be divided into *non-specific direct*, when they primarily target informal carers and *non-specific indirect* when they primarily target the older person.

Table 2.2 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)	Housing accommodation and adaptation, meals on wheels, technical supplies, attendance allowance

As this classification shows, when assessing their respective effectiveness regarding informal carers, it is important to disentangle the perspective of the informal carer from that of the user, acknowledging that

they may not coincide: for example, respite care will bring the expected relief to informal carers only if they judge that the proposed setting guarantees good quality and is appropriate to the older person's care needs, as well as being acceptable to the older person. On the other hand, it may be that housing accommodation is planned according to the user's needs, while not responding to the informal carer's situation or expectations (see also Section 5).

Therefore, since the content and value of policies supporting informal carers are highly dependent on their connection with the general goals of LTC policies for older people, in which it is deeply embedded, this framework should help specify the relative importance given to informal carers' support policy in overall LTC policies. These issues are taken forward and considered in greater detail in Section 6, also highlighting the main gaps between policy and provision of support to informal carers.

In summary

- The needs of informal carers do not always coincide with those of older people they care for. Thus LTC policies must clarify whose needs are being addressed and policies for the support of informal carers have to be assessed for such potential conflicts.
- The dual role of informal carers, both as partners in care provision with formal carers and as clients with their own needs for support, leads to further difficulties in constructing policies for their inclusion in LTC systems that are emerging at the interface between health and social care services.
- Finally, a framework for classification of measures supporting informal carers has been suggested, with the aim of specifying whose needs are being primarily addressed either directly or indirectly

3 Informal and formal long-term care work

In this section we aim to describe how the previously clear demarcations between the informal and formal care sectors are becoming more blurred (3.1) and to show how the work of care provision is shared between the two sectors (3.2). Based on these findings, in Section 3.3, we then examine the impact of care provision on informal carers' health, quality of life and working status.

3.1 Definitions of informal and formal care

Defining what is understood by the terms informal and formal care across European countries, was a crucial starting point to the work between partners. Studies such as EUROFAMCARE and PROCARE, as well as the literature review, provided various definitions, with a synopsis of common characteristics for each sector as follows:

3.1.1 Informal care

- Care mainly provided by family, close relatives, friends or neighbours
- Carers are non-professionals and not trained to provide care; but in some cases they may benefit from special training
- Carers have no contracts regarding care responsibilities
- Carers are not paid although they more and more commonly obtain financial contributions
- Carers perform a wide range of tasks (also performed by formal carers) including emotional support and assistance
- No limits to time spent on care – never/rarely officially 'off duty'
- No general entitlement to social rights

3.1.2 Formal care

- Services provided by trained, licensed and qualified professionals
- Services are controlled by the state or other types of organization
- Caregivers have contracts specifying care responsibilities
- Caregivers are paid and entitled to social rights and working regulations.
- Care tasks are specified according to professional qualification
- Care workers have a time schedule and go 'off duty'

3.1.3 'Professionals'

There is no universal definition of 'professionals' for LTC purposes. The term is usually related to the formal as opposed to the informal care sector and implies professional training and a specific role, with some discretion in decision-making. In this sense professionals can be distinguished from 'paid workers' who also operate in the formal LTC sector, but may not have specific training or a well-defined role. Volunteers, many of whom are also trained and may even receive some financial compensation for their work, constitute a separate category.

Professional care staff can thus include: GPs; medical and other specialists; nurses; home helpers; personal care assistants; care managers; civil servants of state, regional or municipal authorities; and semi-professional workers e.g. migrant-care workers, whose status is increasingly moving from the informal to a formal level.

The concept of the ‘Welfare Diamond’ (Evers et al, 1994), which classifies care provision into four sectors of public, market (private businesses), voluntary (NGOs, non-profit etc), and household (family, friends, neighbours) services, when applied to the LTC system and the orientation of the different ‘actors’ involved, is summarised in the following overview.

Table 3.1 Informal and formal care sectors and orientation within long-term care

	Political responsibility orientation	Stakeholder orientation	Employment orientation	User orientation
Formal care	Care as a responsibility of the welfare state	Services delivered by various types of organisations and considered as a source of income for professional carers	Care as an activity belonging to the labour market	Older people and IC’s thought as marketable clients
Informal care	Care as an individual or family responsibility	Services provided freely by family members or other private people	Care as an activity not entitled to working regulations	Older people considered as belonging to the private sphere.

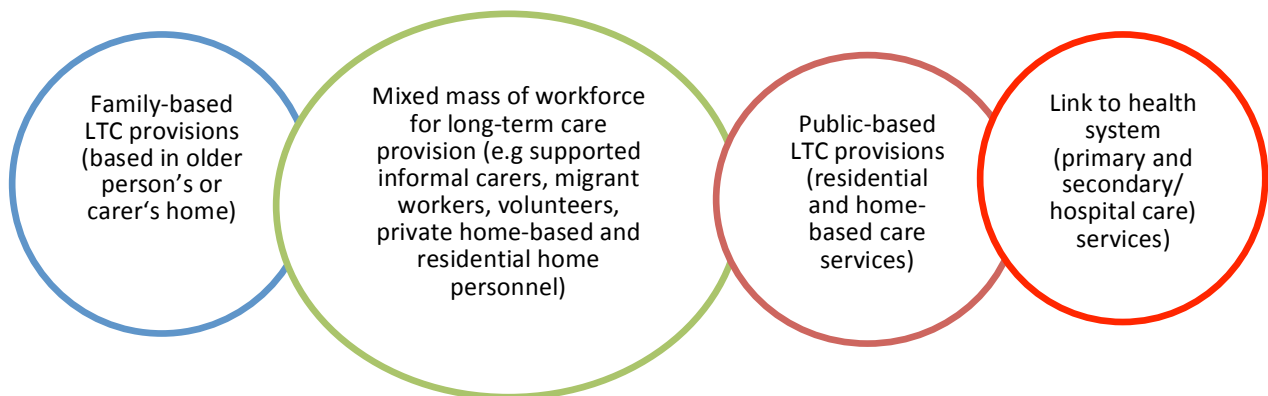
3.1.4 A rapidly changing situation

Despite the above definitions, findings from the seven INTERLINKS National Reports revealed that boundaries between the two sectors appear to be less clear-cut than these definitions suggest, with many ‘blurred’ areas common to a lot of countries. This phenomenon arises mainly from two trends:

- The extension of ‘cash for care’ measures enabling informal carers, as providers of care, to be financially compensated for the care they deliver (e.g. by care or attendance allowances), and to benefit from some training and social rights; but also from the recognition that informal carers are also clients of formal services, with needs for their own support measures (see also 6.1).
- The extensive use of live-in (and live-out) migrant care workers, whose status lies between the two distinct categories of formal and informal carers is a relatively new trend in LTC provision. These workers may be initially selected by families mainly on the basis of trustworthiness and ability to live harmoniously with the older person and within the family (relationship aspects). However, the Italian experience, examined as a Case Study for WP5 and the subject of a separate report, shows that increasing opportunities are being provided for their upgrading to the level of (semi-) professionals, through training and regularisation of their work status (Di Santo/Ceruzzi, 2010).

This blurring of the boundaries between informal and formal care provision (family-based vs. public-based) is leading step by step to the creation of a mixed workforce – informal family carers, migrant care workers, personal assistants, formal professional care staff – operating with varying intensity in the provision, the delivery and the sharing of LTC services.

Figure 3.1 Sharing long-term care obligations between family and public: a typology of care provision



3.2 Informal and formal care work

Long-term care in most European countries is only just emerging as a system and the changing situation regarding the distinction between informal and formal care is crucial for LTC policies and practice. Data show that heavy reliance is placed on informal care provision (however it is defined) for most care tasks (Mestheneos/Triantafillou, 2005; EUROFAMCARE, 2006a), but the blurring of boundaries between the informal and formal care sectors may entail major problems regarding how caregivers substitute for or complement each other and consistently coordinate and integrate their tasks. Most INTERLINKS National Reports commented on the tendency for professional carers to view informal carers as useful contributors to the care process so they can 'downsize' the volume and content of formal services, rather than set the care plan at an optimal level for both users and carers. In general, it seems that informal carers are mainly used as substitutes for formal care, rather than partners in a shared care arrangement.

Furthermore, LTC is distinct from formal health care provision in that LTC systems are based on a triangular (older person/informal carer/formal carer) rather than a dyadic relationship (patient/physician). The *interrelationship between these three stakeholders* is at the heart of this report, as it constitutes the core of two types of linked policies – those directed towards the older person and those directed to the informal carer. Thus a comprehensive LTC policy should address informal carers as both co-providers of services, acting as partners with formal professionals, but also as clients with their own needs for care and support services.

Based on the above, an informed policy regarding informal carers needs the analysis of valid comparative country data covering at least the following issues:

- What are the characteristics of informal carers? What level of care is provided?
- What are their caring tasks and how are they distributed between family members and between informal and formal carers?
- What is the differential impact of the type and level of caring tasks on informal carers' overall health, quality of life and social inclusion?
- Is there a link between caring and working and, if yes, of what type?

3.2.1 Informal carers' characteristics and their contribution to care provision

All WP5 National Reports and European data show that a high proportion of home care is provided by informal family carers and only a very brief summary of INTERLINKS country data on informal carers and care provided is given here.

- In DE approx. 4.2 million people are informal carers compared to 214,000 people working for formal care services.
- In EL family carers estimated that only from 2-14% of all care needs were supplied by formal services, the rest being provided by the main and other informal carers.
- In ES over 70 % of older people with care needs receive informal care and 80.9% of the informal caregivers who also receive formal help consider it to be insufficient.
- In FR the estimated number of informal carers is around 4 million, while only 650,000 are considered to be formal carers.
- In IT an estimated two thirds of the help needed by older people is provided by their families and even in the most difficult conditions of dependency, only 3% of older people are in residential care, only 4.9% receive integrated care at home and only 9.5% receive a dependency allowance.
- In SE, 70 % of the total volume of care to people 75+ living at home is provided by family carers, despite the explicit municipal obligation in this field.
- In SK there are no data on numbers of informal carers; special supporting measures are offered only for those of them providing a minimum of 8 hours of personal care per day (ca 52, 000 people).

These data can be complemented by those from the EUROFAMCARE study on family carers in six European countries (EUROFAMCARE, 2006a), by which the following main characteristics of family carers were surveyed:

- Carers are mainly women (76%); mean age 55 years (65 years in SE sample) with a distribution of 15-96 years; spouses (22%), children/children-in-law (60%); 41% employed; 56% live in same household (or same building) as cared-for older person.
- Intensity and duration of care: Mean hours of caring: 46hrs/week; Mean length of care (at time of interview): 60 months;

3.2.2 Services provided by informal carers and distribution of tasks within the family and with formal carers

Practical care tasks/activities provided by family carers can be divided into three main groups:

- a) Personal care or routine daily living activities (e.g. bathing, toileting, eating, dressing),
- b) Household work (e.g. cleaning, cooking, shopping, laundry),
- c) Activities that provide company and emotional support ('to listen or just to be here') and promote the social inclusion of people with care needs, or activities aimed at administrative help (e.g. paying bills, contact with authorities).

As indicated above, in the provision of LTC including health care, the EUROFAMCARE study provided information from six countries on carers' estimations of the relative proportions of care, including financial support, currently provided by the formal and informal sectors for older people living at home and

who are totally or partially in need of support and assistance by another person. They show the relatively low input by formal services to the total provision of care in all countries, even for older people living at home with the highest care needs (Lamura et al, 2007). The same study showed the low provision and use of specific support services for family carers, whilst in the countries having few such services (EL, IT, PL), carers made more use of substitute generic services e.g. GP and other medical specialists (EUROFAMCARE, 2006a).

Also, according to data from the Survey of Health, Ageing and Retirement in Europe (SHARE), in (mainly Nordic) countries with a high level of services for older people, the percentage of beneficiaries receiving help from their family members and the frequency of help provided by them is higher than in Southern countries, while these findings are reversed regarding the intensity and type of care provided (Attias-Donfut, 2009). The type of care and the relative availability of services respectively delivered informally or formally may generally complement or substitute for each other (Bonsang, 2009), for lower or higher levels of disability respectively. Additionally, the configuration of tasks within the family differs according to countries (Fontaine et al, 2009), but also according to the type (cognitive/physical) of disability (Gramain/Malavolti, 2004).

3.3 The impact of caring, support needed and working carers

3.3.1 Health, quality of life, social integration and caring

While informal care may be free of charge to the public administration, it has its own 'hidden costs', including detrimental health and psychological effects on carers, decrease in labour supply and deterioration of household finances (Jimenez-Martin/Vilaplana, 2008).

Caring may have negative effects on the carers' physical and emotional health, which are increased in those undertaking heavy and demanding care responsibilities (Glendinning/Bell, 2008), so that carers are at risk of becoming patients themselves (Reinhard et al, 2008). In the EUROFAMCARE study, carers in the UK and Sweden reported the highest quality of life (65% and 67% respectively), whilst those in Greece and Italy reported the lowest (50% and 51% respectively), a finding probably linked to the greater availability of services and policies targeted to carers in the former countries (Lamura et al, 2007). Carers experience the care of older people with dementia as a particularly burdensome task. In this context, Alzheimer NGOs throughout Europe have provided examples of good practice (EUROFAMCARE, 2006b) in supporting both older people suffering from dementia and their families through a wide spectrum of interventions (See 6.5.4: Good Practice 18).

Due to the fact that carers often do not have time for themselves, they frequently experience social isolation. Furthermore, they are at a high risk of social exclusion as they are characterised by higher levels of poverty due to lower or non-participation in the labour market and the extra expenses of care provision. This risk is aggravated by the fact that the burden of care provision frequently falls unequally on one family member, usually a woman, whose decision for becoming a carer is most likely to be dictated by circumstances, rather than representing a real choice to provide care. There are still strong normative expectations towards family care provision, and the transferral to a residential care facility or even the use of formal care services is often interpreted as an 'abandonment' of older people. In addition, families must calculate the direct and indirect costs of taking on care tasks. Whether or not a – usually female – family member can give up, reduce or interrupt her employment depends on, among other factors, the remaining income of the spouse. Thus the decision to take on family care can be considered an 'entanglement of calculus and morality': Support for an older relative results from the rela-

tions between income chances, socio-political and legal frameworks of costs and the access to alternatives for family care, the assessment of realizing one's own biographical aims, and the ethical value of caring for one's parents (Dallinger, 1997).

There is no straightforward relationship between the level of burden experienced by a given informal carer and the intensity of care delivered: some intensively caring carers may be more resilient than others in an objectively less intensive care situation. Also being in the labour market may either increase or decrease the burden of care. Still, on average a high level of caring enhances the probability of being overburdened as does a previous poor health status, a reduction in paid work (affecting more women than men) and finally the feeling of not being supported by formal services (Lamura et al, 2007; Reinhardt, 2008).

Table 3.2 gives information on the areas in which family carers reported specific needs for support. It demonstrates the variations by country: needs are much higher in countries with less access to services in kind. Increased needs for support were reported by those caring for older people with heavy care needs.

Table 3.2 For which areas of need would family carers like to have more help for the cared-for older person? (Data by country, % values)

Need		Greece	Italy	UK	Sweden	Poland	Germany	Total	
								% on all older people in need of care	% on whole sample
Emotional / psychological / social	N	896	900	847	672	876	897	= 5,088	5,923
	%	63.8	49.2	33.5	44.6	32.4	43.1	44.6	38.3
Domestic care	N	855	900	862	687	921	932	= 5,157	5,923
	%	55.7	45.1	31.4	21.3	26.2	32.3	35.7	31.1
Mobility	N	716	893	780	563	798	914	= 4,664	5,923
	%	60.1	45.9	32.1	25.2	28.9	35.7	38.4	30.2
Health care	N	892	819	636	613	721	808	= 4,489	5,923
	%	55.3	48.1	29.2	18.1	29.3	28.8	36.3	27.5
Care organisation and management	N	733	870	663	608	750	720	= 4,344	5,923
	%	62.5	39.1	29.0	12.0	22.8	31.5	33.6	24.6
Personal care	N	660	737	587	549	461	770	= 3,764	5,923
	%	55.3	44.8	35.6	20.9	26.9	31.7	36.8	23.4
Financial support	N	528	404	297	85	374	338	= 2,026	5,923
	%	74.2	64.1	40.1	17.6	61.0	44.7	57.5	19.7
Financial management	N	795	851	645	583	771	779	= 4,424	5,923
	%	36.9	24.0	18.1	3.9	13.4	9.8	18.4	13.7

Source: EUROFAMCARE, 2006a.

Despite these needs for help, only one third of this sample of carers had used a support service in the past 6 months, even if these were available. The stated main reasons for lack of service use were the complex and bureaucratic access procedures and high costs, as well as lack of information, inflexibility in

meeting their needs and services being of insufficient quality either to the family carers or their older relatives (EUROFAMCARE, 2006a).

3.3.2 Working and caring

Huber et al (2009) have collected country data on the employment status of men and women at different ages and caregiving status, demonstrating that very few countries have achieved or are in a position to reach the Lisbon employment target for older people. Progress has been so slow that mainly countries that had already reached the target by 2000 are above it, namely Scandinavian countries, Switzerland (as a non-EU member) and NL and UK (before the crisis). Germany and France are still below the target, as are Southern and Eastern countries at an even lower level. The rate of part time employment is dramatically variable across countries and by gender, with women having more part time employment than men, while it is the opposite for full time employment. The conflicts generated by attempts to juggle working and caring responsibilities are illustrated in findings from the Eurobarometer 2008 survey. Despite the fact that approximately 70 % of carers declared they were willing to increase the level of care in the next year, 15% had to reduce the amount of their working hours because of caring for older relatives, with the vast majority of the latter experiencing not only the negative impact on their income, pensions and/or social rights because of the reduction, but also various types of care burden linked to their caring tasks. With respect to this burden, their main concern regarding their dual role was experiencing pressure on their time and loyalty: how to balance job demands with care demands and the fear of negative side effects on the cared-for person because of inadequate alternative caring arrangements during their, albeit reduced, working hours. But they also experienced difficulties in their private life with their relationships and welfare of their children, family and friends (Keck/Saraceno, 2009). More generally, as Arksey et al (2009) reported, carers have less capacity to anticipate the future, as all their energy is concentrated on the present care commitment and in wrestling with financial affairs and when caring ends, they are too often left alone and poorly equipped to deal with this significant change in order to build a new life.

Regarding the link between caring and working in different groups of countries, the conflict is illustrated in Table 3.3. It shows that the rate of employment of 50-65 year old workers depends in all countries on whether they are high-intensity carers (defined as providing more than 1h/day of care), as opposed to low-intensity carers (defined as providing less than 1h/day of care), or non-carers, as follows:

- In all countries low-intensity carers are **more** likely to be in the labour market than non-carers.
- In all countries high-intensity carers are **less** likely to be in the labour market than low-intensity carers.
- In all countries high-intensity carers are **less** likely to be in the labour market than non-carers (except for men in Eastern Europe).
- For **women**, employment rates for both low and high-intensity carers are lower in Southern and Eastern Europe than in Scandinavia and Central Europe, although for men there is no clear trend by caring or country status.
- For **women** employment rates in Southern and Eastern European countries are much lower in all caring and non-caring categories than those in Scandinavian and Central European countries, whereas for men there are fewer variations in employment rate by non-caring and caring category and country group.

Table 3.3 Rate of employment and caring intensity (for men and women aged 50-65years): A comparison by groups of countries

Country group	Scandinavian countries %	Central European countries %	Southern European countries %	Eastern European countries %
Women				
Non-carers	58	45	30	31
Carers (without cleaning)	62	47	29	31
<1 hour/day	67	54	35	40
>1 hour/day	34	35	17	24
Men				
Non-carers	70	55	61	47
Carers (without cleaning)	73	63	53	73
<1 hour/day	74	68	63	78
>1 hour/day	65	52	42	65

Source: SHARE survey, second wave 2006-2007 (Fontaine, 2009). N.B.: Percentages need not sum up to 100 either in line or in column.

Data show that, in countries where access to services is easier, access to the labour market for women informal carers seems facilitated. Other studies based on SHARE provide clear indications that the substitution of informally provided ‘hands-on’ care by professionals can lead to a more equitable distribution of care tasks in a successful ‘hand-in-hand’ approach; formal carers ‘deliver’ practical care, so the family only has to ‘care for’ (Attias-Donfut, 2009), resulting in better health and quality of life for informal carers (see section 4.1.2 for a focus on gender and work).

However, these studies do not provide evidence regarding whether there is a facilitative or obstructive link between caring and working, a question that is further analysed in Sections 6, 7 and 8, which also provide examples of employment policies and practices that support working and caring.

In summary

We have shown how the blurring of boundaries between the informal and formal care sectors, mainly due to the changing role of informal carers and their specific needs for support (whether in kind or in cash), is leading to a changing relationship between caregivers in both sectors. This has implications for the creation of effective links between the two sectors, which could lead towards the production of a more unified model for LTC systems, with the common goal of providing good quality care for older people. Main issues to be resolved in linking the two sectors (see also Sections 4, 5 and 6) are:

- What specific policies and measures targeting informal carers can promote their recognition and inclusion as partners with formal care teams?
- How can formal carers be trained both to involve informal carers as partners in care, but also to support them in their caring tasks?
- What policies and measures facilitate working and caring, whilst safeguarding informal carers’ health and quality of life?

4 Changing perceptions of care and the context of carers' changing roles

The aim of this section is to demonstrate how perceptions of informal and formal care are changing and to examine some of the main contributory factors, including demographic (4.1.1) and social changes (4.1.2). We discuss why and to what extent these could lead to increased needs for LTC and in 4.1.3 describe emerging trends such as user empowerment, demands for better quality of services and privatisation. In 4.1.4 we examine changes in the economic field, including the possible effects of growing income inequalities on needs for care, as well as the issue of combining working and caring, particularly for women and older workers, within the context of LTC provision.

4.1 Determinants of the changing perceptions of care

4.1.1 Demographic changes and the need for care

Demographic data on ageing and data on needs for care and informal carers, including employment status (Huber et al, 2009; Eurostat), indicate that a number of demographic changes regarding the working age population and the elderly population could lead to a rising demand for LTC formal services, with major issues about the sustainability of the actual level of funding of LTC systems.

Birth rates, ageing and the effects in Europe

Four factors underline Europe's ageing society: high life expectancy; better health status; low fertility rates and the effect of the baby boom generation reaching old age. According to Eurostat's baseline population projection, their joint main impact, will be the following:

- European population will increase until 2035 to 521M and then decrease to 506M by 2060, due to an average birth rate of 1.5 (less than the 2.1 rate needed to maintain population level).
- The median age of the EU will increase between 2004 and 2050 from 39 to 49 years, as the number of young people (aged 0-14) in the EU will continue to decline in absolute terms from around 100 million in 1975 to some 66 million by the year 2050.
- The population of working age (15-64) will be most numerous around the year 2010 (331 million) but will subsequently decline to about 268 million by 2050.
- The proportion of population over age 65 will double in the next 40 years as a consequence of the baby boomer generation reaching retirement age.
- The proportion of very old (over 80 years) in the total population, who constitute the main consumers of health and long-term care, will rise from 4.1% in 2005 to 6.3% in 2025 and to 11.4% in 2050.

Even if these average changes are very unequally distributed among European countries mostly due to their differences in birth rate, this trend should increase LTC needs. A recent Eurobarometer survey (Eurobarometer, 2007) provides estimates of current population needs for care for the oldest age group, with the findings that of those aged 85 and over, 29% report severe limitations in carrying out daily living activities due to physical or mental conditions, whereas 24% have been in personal need of regular help and LTC over the last ten years.

In view of the increasing incidence and prevalence of Alzheimer-type dementia with increasing age, the predicted rise in the numbers and percentages of the oldest age groups has implications for the higher needs for care of older people with this disease, affecting both the informal and formal care sectors.

Old-age dependency ratio

This ratio (number of people over 65 divided by the number of people aged 15-64), which is currently 25%, will reach around 53% in 2050 for the EU-25 but with high variations across countries, with the highest rates projected for Italy and Spain (66-67%) and the lowest for Denmark, Luxembourg, Malta, the Netherlands and Sweden with around 40% (Huber et al, 2009). As the potential input of care provision from informal carers' may decrease, due to low birth rates and therefore the smaller size of younger generations, a rising demand for formal services is expected, thus raising the question of the financial sustainability of LTC budgets.

Ageing of informal carers

In this context the ageing of informal carers will be an issue as spouses and/or 'children' aged 65+ are thus likely to be one of the main future source of informal care and will therefore also need some support as carers (Mestheneos/Triantafyllou, 2005).

Additional Factors

Rather than age alone, it is the combination of population age and health status that constitutes one of the main drivers of health care spending, so the level of health and disability of the future generation of older people will influence needs for care. According to the 'compression of morbidity' scenario⁷, the greatest proportion of the expected gain in life expectancy (projected to increase by 5 years by 2050) should correspond to 'healthy life years' (Hubert et al, 2002), although current trends indicate that it is levels of severe disability that are declining in some countries, rather than mild to moderate disability. As ageing people will be in better shape they will be able to provide for themselves for a longer period, meaning that demand for services, particularly the requirements for heavy care, could be less than demographic projections suggest (OECD, 2005). Also informal carers may benefit from better health and thus need less support in caring, although the "burden of disease" caused by mental problems such as depression may offset these positive effects.

Gender differences in life expectancy

Among spouse carers women currently predominate, both for cultural reasons but also due to their greater life expectancy and to the tendency for marriages to take place between younger women and older men. However, mainly due to a reduction in mid-life mortality for men during the past 20 years, gains in life expectancy (and particularly for healthy life expectancy) for men have been greater than for women, with the result that the gender gap in life expectancy at age 65 for men and women is decreasing (Huber et al, 2009). This implies a possible future increase in the numbers of male spouse carers due to the higher availability of couples to care for each other, although this may be offset by the growing number of single-person households due to increasing levels of non-marriage, separation and divorce, as well as the unpredictable effect of patterns of re-marriage on care responsibilities.

⁷ The results of a study designed to test the compression of morbidity hypothesis, proposed that healthy lifestyles can reduce and compress disability into a shorter period toward the end of life, make a compelling argument for the reduction and postponement of disability with healthier lifestyles as proposed by the compression of morbidity hypothesis.

4.1.2 Changes in social structures

Conceptions of ageing and LTC policies

The way the process of ageing is considered in society has a strong effect in shaping the representation of older people, and thus a strong impact on the main principles of LTC policies and overall LTC system design. This is particularly the case when looking at issues such as older people's rights to participation in society, and to be in the labour market.

When ageing is viewed mainly as a negative phenomenon associated with a loss of physical and mental capacity and working potential, older people will naturally be considered to have less potential to participate in social and economic life, thus being less employable and less autonomous. This negative stereotype may also extend to use of support services and whether older people are seen as relying passively on help (whether from formal or informal sources), or able to use their own resources and exercise choice, which in turn affects the attitudes, practice and behaviour of formal carers.

In contrast, in Northern Europe, where services in the public, private and NGO sectors are better developed, older people and their families are increasingly empowered to act as consumers, benefiting from a choice of services and being able to select those most suited to their needs. Also in countries where ageing is considered primarily through its social dimension, with older people being entitled to the same rights as any citizen regarding social and economic participation (e.g. DE, GB, SE), there is a strong tendency for the rate of full-time employment of the 55/65 age group to be higher, although the relationship is also compounded by other factors such as gender (see below).

Table 4.1 Gender-specific employment rates in per cent of population in age groups (2008)

Country	Men			Women		
	15 to 24	25 to 54	55 to 64	15 to 24	25 to 54	55 to 64
Germany	49,7	87,1	61,7	44,5	74,7	46,0
France	33,4	89,1	40,5	28,0	77,3	36,0
Great Britain	57,5	87,9	67,6	55,1	75,4	49,0
Italy	29,1	86,7	45,5	19,4	60,2	24,0
Netherlands	69,6	92,0	60,2	68,7	79,5	41,1
Sweden	45,9	89,4	73,6	45,9	83,5	66,9
Spain	43,2	84,4	60,9	35,7	65,9	31,1

Source: OECD.

Informal care and gender

The importance of opportunities to reconcile work and caring is particularly relevant for women, who have traditionally been the main caregivers. As they are increasing their participation in the paid labour market, whether from economic necessity or personal desire, and as they look for better education to enhance their employment opportunities, they frequently postpone their first birth in order to give priority to their first job. For the generation of 30-50 year olds this entails the issue of caring not only for their young children but also for their ageing parents. Their changing roles give thus rise to questions as to whether they will be able to continue providing both types of caring or whether they will have to sacrifice their own education and working ambitions to remain caregivers. The question of reconciliation of work and care is central, as these women are currently both higher users of health services due to the

physical and mental burden of care, as well as being at risk of future poverty due to their potential non-participation in the paid labour force.

Caring: a family issue

Informal care at home has been identified as the preferred option of care by most EU citizens, so clearly families will continue to play a role in providing long-term, home-based care (Marin et al, 2009: 7) But changes in marriage and divorce patterns and family size, as well as internal and external migration of younger generations in search of employment, put values and norms concerning family responsibilities under pressure. Regardless of willingness, this has implications for the ability of families to provide informal care, not only in terms of personal hands-on care and other essential daily tasks, but also in the provision of social relationships and emotional and psychological support (Jegermalm, 2005). There is also the issue of the sandwich generation (see also 2.2 and 6.3), i.e. the generation of younger retired but still active older people, supporting their children by caring for grand-children, as well as caring for their own parents (Glendinning et al, 2009). Additionally, older carers are more likely to have their own needs for care and support, and these needs may differ from those of younger generation carers. That is why trying to reconcile policies for children with policies for older people has been at the heart of the reform of the welfare state in the Scandinavian countries (Esping-Andersen, 1990).

4.1.3 User empowerment and privatisation

Service 'demand' from older people and their families

Care needs of older people tend to be complex and call for co-ordinated approaches to provide a continuum of care responsiveness and flexibility in answering to their changing needs. This continuum cannot be addressed without taking into account the expectation of older people and their families regarding the way services ought to be organised. This a priori view is reinforced by the fact that as their level of education and knowledge is growing, users are becoming more aware of the quality of the services provided. Another sign of this changing perception of care is that older people demand the retention of their autonomy, not only by staying at home, but also by being more involved in the definition and planning of their own care services, a process of user empowerment which could benefit from the promotion and support by the professionals involved (see Kümpers et al, 2010). In DE for example, signs of a new culture of age and support and care services are beginning to show: for an increasing number of elderly people old age has now become an employment-free phase that enables the continuation and even diversification of existing interests (Schneekloth/Wahl, 2005). These older people possess high levels of self-confidence and a distinct sensitivity to age discrimination. They are particularly interested in the prevention of chronic illnesses and view themselves increasingly as customers in the provision of preventative or supportive services. There are promising beginnings to the complementary development of a new culture in professional help, which views older people increasingly as customers with a demand for quality and informal carers as partners in a joint caring team.

Quality of formal services

As competition is considered a powerful tool to enhance quality of care through choice among various types of providers, privatisation of the LTC sector has been considered a main driver of changes in the way citizens, acting as *consumers*, could be empowered. In this regard, various types of cash benefits have been designed in order to facilitate a greater choice by each recipient of services better suited to their specific needs. Other means of empowerment have been put in place in some countries e.g. the Carmen project (Nies/Berman, 2004) found an increasing trend for user empowerment through:

- Information campaigns, forums, user panels, consultations and user groups, as different strategies to empower and involve older people and also their carers in the integration and planning of the services needed.
- Re-orientation to user-led services as a way to meet the users and carers needs and preferences, through the set up of their own services, normally non-profit driven.

As many studies based on SHARE data have shown (Attias-Donfut, 2008), substituting formal for informal care when needs are growing, does not entail less intervention from informal carers (in terms of frequency) than previously, contradicting the 'moral argument' that providing more public services would render carers less responsive to their older people's needs and 'squeeze out' informal support. Also, according to Bonsang (2009) and others, formal services substitute for informal care as the disability level of the older person increases. As concern for the cared-for person is the main motivation for providing informal care, both non-working and working carers will not willingly accept their care to be substituted by formal services if they judge them to be inferior or not responding to the older person's needs. So for informal carers also, the quality of the alternative formal services is a central issue, whose weight is enhanced by changes in the economy (Bolin et al, 2008). Nevertheless, it remains to be assessed to what extent users' choices lead to decisions that are in line with carers' expectations.

4.1.4 Economic changes

Growing income inequalities and consequences for care needs

Rising income inequalities in many EU countries (Wilkinson/Pickett, 2009) is likely to have a significant effect on increasing poverty levels amongst older people, which in turn could contribute to rising care needs. Social inequality is linked to both health and functioning, with those on lower incomes experiencing reduced autonomy and capacity for self-care, as well as in the use of health and care systems. Additionally, informal carers already have higher levels of poverty than non-carers, so that they are likely to be disproportionately affected by growing income inequalities, unless specific measures are taken to counteract these negative effects, e.g. income support and social security contributions, improved access to the labour market, regional equalisation of service funding (see 7.1, Good Practice 2).

The question of employment in the labour market

Since the 1990s, in attempts to confront globalisation and enhanced competition, governments of advanced European welfare states are engaged in a more active approach of welfare policies with a focus on moving people into work, or closer to employability. High on the agenda is the issue of how to increase labour market participation of women and older workers, whilst at the same time making more demands on people to care for disabled and chronically ill and frail older relatives (Arksey/Moree, 2008). Supporting carers in combining care with paid work in the labour market is thus a part of the wider family/work reconciliation policy framework.

Following the extension of the dual breadwinner model, current policies are strongly focussed on trying to increase the rate of participation in the labour market, especially for the 55-64 year-old cohort, by provision of financial support enabling them to both work and continue to fulfil their caring tasks at the same intensity. It remains to be seen if the level of this financial support has been set high enough to counter the effect of the declining numbers of potential carers, as well as the negative long-term effects of their 'hidden' care work (see 3.2).

An alternative or complementary policy to enable carers to enter the labour market is by providing and paying for more services, a cost that would fall on the taxpayer, except in countries with a social insur-

ance system (e.g. AT, DE). In this case, however, raising the employment rate would also increase fiscal resources potentially available for LTC funding, thus allowing for the provision of more formal public services. For instance, it has been shown that an increase in government expenditure for formal care had a positive impact on the employment level of women aged 45-49 across Europe (Viitaanen, 2007).

In summary

- We have shown how perceptions of informal and formal care provision are changing, in line with demographic, social and economic changes in the INTERLINKS countries. These changes are also leading to increasing needs for care, particularly the high-dependency care that will be needed for the growing number of Alzheimer sufferers. The question of how these needs can be met, whilst concurrently addressing the goals of the Lisbon agenda for increasing participation of women and older workers in the labour force, raises the issue of combining working with caring and how to support and protect the health of working carers.
- Emerging trends such as user empowerment and demands for better quality of services more responsive to the real needs of older people and their families are leading to increasing use of private services by those able to pay, whereas growing income inequalities in some countries may restrict the degree of choice in the future.

5 Caring as a shared responsibility: An overview of legal and political aspects

In this section we focus on how responsibilities in caring are shared between family and state and how the balance has been set, legally or implicitly, between these two main stakeholders, notwithstanding the role played by the market and the non-profit sector.

The aims of this section are:

- To identify the main ‘actors’ at European level as well as in INTERLINKS WP5 countries, having legal commitments related to the financial and practical help for older people with LTC needs (5.1, 5.2);
- To describe approaches to sharing both financial and practical care responsibilities between the informal (mainly family) and public (state) sectors (5.3);
- To give a description of the main measures (financial and in-kind services) aiming at supporting informal carers (5.4), based on the framework for classification of informal carer support policies (2.4).

For the purpose of this report, the term “*legal aspects of care*” is used to refer to all relevant issues in the care sector agenda, including informal care, being recognised as matters of public interest. Within this categorisation, the support of caregivers, including informal carers, and meeting their social needs through public support, takes a position of equivalent value to that of the support of people in need of care, i.e. care recipients,⁸ notwithstanding that their respective expectations and needs may not conflate.

5.1 Responsibilities at the European level

Despite the diversity of LTC policies, it appears that some common characteristics can be observed throughout Europe in this regard, namely, the highlighting of the position of family and informal networks within the LTC system and efforts to encourage their legally recognised status within the care sector. According to Huber (2007: 24), ‘the availability of informal care by family, friends, and the voluntary sector’ belongs to ‘drivers of LTC spending growth in the future’ and the support of informal care and informal carers being recognised as a public interest, belongs definitely to the “youngest” branches of social policy in European and national settings.

Regarding legal aspects and responsibilities for the care of older people and the position of those providing them with care services (especially on an informal basis), other common tendencies can be observed:

- There are highly persisting social expectations that family members, mainly women, will continue to provide massive amounts of care for their older family members, in direct opposition to the Lisbon goals of increasing the general employment rate in the European Union up to 2010.

⁸ The European Project EUROFAMCARE attempted to balance the rights for support of care recipients and care providers through defining formal care as (1) formal services for older people, (2) formal care services provided to support informal carers and to include practical and financial support measures.

- The legal status and extent of social protection of those providing care for older people is in most countries not equally recognised in relation to the status of those providing care for small children with care needs.⁹
- In some countries, support of informal carers continues to be mainly organised through social assistance programmes as against other areas with mandatory schemes, such as obligatory disability insurance schemes (Lloyd/Wait, 2005).
- In a majority of countries a supportive policy for informal carers as a part of an overall LTC policy does not exist, although some countries now have specific support policies for informal carers (see 6.4.1). Supporting measures targeted at informal carers still mainly aim at improving the financial situation of the family (e.g. by providing a care allowance as a substitution for income loss due to being out of the regular labour market because of the need to provide care). Measures to improve the working conditions for informal carers, similar to people in regular employment, are scarce. This situation only perpetuates the informal status of informal carers without offering real opportunities for alternative solutions (access to the labour market).

5.2 Responsibilities at country level

5.2.1 Financial maintenance obligations

The financial maintenance obligations of the family to its non-self-sufficient members are specified in the legal systems of all countries participating in the project. Differences between countries can be found at different levels:

- The range of close relatives having this type of duty/obligation (e.g. spouse, children, siblings, daughter-in-law or son-in-law)
- The extent and form of such obligations
- The conditions under which the obligation arises
- The legal area in which the obligation is specified (Civil Code, Family Law, Marriage Act, Constitution)

The INTERLINKS National Reports on informal care (DE, EL, ES, FR, IT, SK, SE) indicated that amongst the countries' legal provisions concerning main responsibilities for the support of older people with care needs, *three main approaches* can be identified:¹⁰

- In the majority of participating countries (FR, EL, IT, ES, SK), primary responsibility for the financial and practical support of dependants devolves on the immediate *family* (mainly spouses and children), with the state commitment taking a supplementary role, either when the family is unable to provide support or, more recently, in policies for the provision of direct financial or practical support to informal family carers (except EL) (see Table 5.1).
- The second type of arrangement is found in Sweden where responsibility for social services for inhabitants is explicitly designated to the *state* or any local political levels (counties, municipalities); thus practical or financial participation in care is not expected from family members. Nevertheless,

⁹ Article No 33 'Family and professional life' of the Charter of Fundamental Rights (2000) stipulates a commitment for the reconciliation of family and professional life for people having a child, but not for other (older) family members in need of care.

¹⁰ Although Lamura et al (2007) classify FR and IT into a separate category of "Standard Care Mix".

in order to respond to the negative impact of cuts in formal services which took place at the beginning of the nineties, informal care has been given a more prominent roll and municipalities have been given legal responsibility to develop programmes to support family carers of older people living in isolated areas (7.2, Good Practice 4).

- Finally, a third and different approach can be identified in Germany where responsibility for care is given to the *person in need of LTC* through the statutory LTC insurance, which, as a part of the social insurance system, represents a 'deposit' to cover possible expenses for future care. However, although this insurance covers 99.7% of the German population, it was not designed to cover the full costs of care, i.e. informal carers are still implicitly and explicitly expected to fill the gaps.

All of these factors may entail differences in the stringency of the obligation, for example:

- If the family can, but is not willing, to pay, the amount of payment/co-payment can be decided in some countries by the court (FR, DE) or by the municipality (SK).
- If the family is not able to fulfil its maintenance obligation, especially for economic reasons, many countries define a de jure assumption of the responsibility to the state instead of the family (FR, DE, SK).

Table 5.1 Financial maintenance obligations in participating countries

Country	Financial maintenance obligations
SE	According to the Social Services Act, the municipal authorities are ultimately responsible for ensuring that the residents of a municipality receive the support and assistance they need. ¹¹
SK	All the family members shall help each other and, depending on their abilities and possibilities, contribute towards improving the material and cultural level of their family.
FR and DE	Economic support is to be supplied by the state when the relatives cannot financially meet situations of need.
IT	Legal obligations on the family to pay alimony are either in the form of economic support to meet the situation of need, or a request to go and live together with a member of their household.
ES	The System for the Autonomy and Attendance to Dependence recently developed in Spain recognises the role of the informal carer and establishes a monthly economic provision for them. This aid has been developed in order to maintain the older person with care needs in her/his own home, attended by informal carers. The system also establishes the creation of a special Social Security for informal carers, which guarantees them access to the health/sanitary system and also counts towards their future retirement pension.
EL	The family is responsible for the care of its members of all ages. Only if the family cannot provide such care, social welfare schemes will step in. Legal responsibility of the family is specified in the Constitution of 1975, amended in 1986 and 2001.

¹¹ While in some areas there are different regulations concerning the responsibilities within the family, e.g. through the Marriage Act, responsibility for providing informal care within families is ruled out, and the obligation by law to provide informal care was excluded from the Social Services Act in 1956.

5.3 Sharing of responsibilities between family and state

5.3.1 Practical 'hands-on' care obligations

Whether the provision of practical and personal care, on a short or long-term basis, is implicitly included as part of the maintenance obligation (e.g. DE, EL, IT), or is explicitly excluded from this legal framework (e.g. SE), or is left to the informal carers' personal responsibilities, is far from being clear. For example in some countries (e.g. EL, SK), despite the fact that the maintenance obligation is stated in national legislation, it is not possible to clarify if practical care is included within the maintenance obligation scheme, as was found also in the EUROFAMCARE project (EUROFAMCARE, 2006a).

This blurring of responsibilities partly explains why informal carers in many countries are still obliged to provide most of the practical 'hands-on' care required by their relatives.

The issue of informal carers of older people acting as providers of care services depends strongly on the role and responsibility of the state in service provision. Hence the range of care services and the relationship between the informal care sector on one side and the state, the market and voluntary organisations on the other, vary between different kinds of welfare states (Jegermalm, 2005). Interest in informal care increases when welfare states are under pressure and obliged to discuss potential prioritising and rationing of the welfare services. So in countries with a background of less involvement of the state and/or few formal services, there is the high risk that policy makers will continue to view informal care as a relatively free and accessible resource – as long as it is not publicly acknowledged – that will ultimately fill the gaps and substitute for the deficiencies of publicly provided service delivery.

As illustrated by the responses of a large sample of European carers almost 61% of carers were willing to continue caring unconditionally, even if this meant having to provide more care (EUROFAMCARE, 2006a). Still, as a consequence of increasing care needs of older people, combined with a lack of public care services and less women available to provide informal care, in some countries families have started to find alternative 'self-constructed' arrangements. In particular in Southern Europe, but also in countries situated close to Central and Eastern European countries (e.g. Austria or Germany) the employment of private migrant care workers has become a common solution. They provide, ideally, individual, one-to-one, person centred care more or less around the clock for a relatively affordable price (Di Santo/Ceruzzi, 2010; see also Section 7.2, Good Practice 5). Even for the relatively wealthy Scandinavian countries, which rely heavily on public care services, it is becoming more and more difficult to maintain the relatively high level of formal LTC. In Sweden (but also in Finland and Norway), the need to contain increasing costs, in combination with the stated preferences of older people themselves to remain in their home environment for as long as possible, has led to what has been described as a "rediscovery of family care" (Johansson, 2004). But this goes with the obligation (6.4.7) to promote and support the increased participation of the informal care sector through various measures promoted by both the public sector and NGOs (Mestheneos/Triantafillou, 2005).

Even if there is some evidence of convergence towards an increasing recognition of the role of informal care in the provision of long-term care, there are still wide variations between countries in the organisation of care and the way in which practical care responsibilities are shared between family and state.

5.3.2 Sharing care work between informal and formal caregivers

The general finding of most WP5 Interlinks countries is that relationships between informal carers and professionals operating in the LTC field are more often substitutive rather than complementary and cooperative based. There are two fundamental reasons for insufficient level of cooperation (PROCARE, IT, FR, EL, DE):

- *Unequal sharing of care duties between informal carers and professionals:* Professionals are mainly responsible for physical and medical care and the family caregivers 'do the rest', professional staff expecting them to provide a high rate of personal care and prime responsibility for domestic help. Even the implementation of financial schemes aiming to promote a higher rate of professional involvement in the provision of LTC services e.g. Personal Autonomy Allowance in FR, has not reduced the amount of work undertaken by informal carers.
- *Unequal caring status of informal carers and professionals:* Professional care providers do not always acknowledge the contribution of informal carers and they are only seldom regarded as partners in the system (discussed further in 6.6.5).

Despite the above issues, this research study identified a wide range of methods to promote better cooperation between informal carers and professionals, with positive outcomes regarding the use of services and satisfaction of informal carers related to:

- *Information and education of cared-for and caring people (e.g. ES).* Families having information or advice from doctors, nurses or therapists about available services they are eligible to apply for, use the recommended formal/professional services at a considerably higher rate.
- *Use of home care services (e.g. DE).* Home care services have a coordinating role between informal carers and professional health care services. Their coordination work is promoted especially by the social services of the hospitals and rehabilitation facilities, as well as by the LTC support centres. When home care services are being used, the satisfaction of informal carers is generally high (BMFSF, 2002: 204)

Other links promoting cooperation between informal and formal carers are: the active involvement of older people and their families in care assessment, care planning and hospital discharge processes; case managers acting as care coordinators between formal services, users and families members; NGO and advocacy groups providing information and practical services for older people and informal carers. These and other examples of good practice in linking the informal and formal LTC sectors are described further in Section 7.

Nevertheless, it should be emphasized that all these examples take their added value only when addressed in specific policy focusing on informal carers, which is embedded within broader LTC policies.

5.4 Support measures for informal carers: an analytical approach

During the two last decades, there has been a trend amongst the EU member states to shift their LTC policies from providing care in institutions to delivering care at home or equivalent settings. In this context it has become a common goal to try to better integrate informal carers in the overall formal provision of home care services resulting from an acknowledgment of their major contribution to overall care (from 50% to 95% according to most countries).

For working age carers and especially women, this involves a more active approach of the state (from 'welfare to workfare') aimed at increasing labour market participation and the creation of a positive 'working environment', through access to cash benefits and specific in-kind services and support measures to better reconcile work and care and thus becoming part of LTC policy (see 6.4.1). For pensioners and others not participating in the labour market, support measures involve the provision of income protection (cash benefits) and practical services in-kind, designed to relieve them of some of the burden of care and to enable them to continue to provide care. Using the classification of services presented in Section 2, we provide an overall description of these services (see also Section 6) based on a preliminary WP5 INTERLINKS database, which will be used in Phase 2 to construct a matrix of services by country.

5.4.1 Financial support measures (cash-for-care)

The different types of cash payments for informal carers and their forms of implementation reflect institutional and cultural traditions in the individual societies and of their respective welfare regimes. The country specific goals in implementing them are thus shaped by wider institutional and cultural traditions, particularly with respect to beliefs about the relationship between the family's responsibilities and collectively funded state provision. It is the latter which determine both the extent and amount of these benefits, which are driven by three main factors explaining why the number of beneficiaries and levels of benefit are highly variable between countries:

- The level of social protection and linked taxation, which operates on the status of the informal carer and on the 'reservation wage' (or opportunity costs i.e. the level of revenue which makes worthwhile the effort of entering the labour market).
- Rules for accessing benefits, such as means testing (whether family and/or family carer) and/or needs assessment levels, all of which can act as a barrier for potential beneficiaries
- The financial level of benefits, which facilitates (or not) the supplementation of the usual working wage, or enables the replacement of full-time by part-time employment, or is adequate as sole revenue.

Specific, direct: Care allowances

By this first type of care allowances, mostly in Eastern European countries and the UK, funds are allocated directly to the informal carer in order to compensate for loss of employment and income due to care giving. In some cases, such allowances are also used to maintain or procure an income for people out of the labour market who are not eligible for other social benefits, in exchange for providing informal care.

Usually the income level set for care allowances is low and has not expanded widely for three reasons: firstly, due to the limited budget devoted to LTC in most countries, payment to carers is restricted to those providing only the highest levels of care or to the most economically deprived: for carers in the labour market a 'market level' of such payments could be counterproductive for employment levels; and finally, as some of the beneficiaries are either retirees or have a low probability of entering the labour market, their allowance could be set at a lower level than their market cost - and most of these care allowances come with a lower level of social protection.

Care allowances take a completely different form in Nordic countries (SE, FI, NO) where they come with a quasi-employment contract with the municipalities, thus corresponding to an amount closer to market levels and embedded in a generous benefit package regarding direct support services in kind. However, entitlements are restricted to a small number of informal carers: mainly those caring for the population of frail and lonely older persons in isolated areas, where the organisation of formal services is not feasi-

ble or too costly. Public support of families who are employing migrant carers in Italy relates to a certain extent to this type of care allowance (see Di Santo/Ceruzzi, 2010). An additional form of financial support is the entitlement to some form of social security rights for paid carers and, in Spain, for non-paid carers.

Non-specific and indirect: Attendance allowances (AA)

These are benefits allocated to the person in need of care according to various criteria that can be used in a more or less stringent manner including paying informal carers. They can be divided into two types.

- *Cash payments* that are transferred to those entitled who may then decide how to use the money to compensate for their care needs (AT, DE, IT). In France, this type of entitlement (APA) only applies to people above the age of 60.
- *'Vouchers'* to which people in need of care are entitled after an assessment of individual needs. They may then purchase services, usually from accredited service providers (some regions in IT), but also directly (FR). A sub-type of this category is the *personal budget* for consumer-directed employment of personal assistants: People in need of care may, directly or through a third party agency (case manager), use the cash in order to recruit and pay an informal carer (or a personal assistant) (DE as a pilot project, NL, AT, SE, UK) with some (SK) or no restrictions for using it for family carers.
- The third type corresponds to *'routed wages'* for family carers, who are considered as "co-workers" (IT, UK, NL, ES, SE) as they supplement or replace *in kind services*.

Other types of indirect financial supporting measures have been put in place for older people, such as tax exemptions or reductions on social security contributions to favour direct hiring and payment of a care worker (which can include a family carer) or personal assistant (FR, DE; see also 6.4 for further discussion).

5.4.2 In-kind services

Non-specific and indirect

- **Home based professional formal services:** Bringing professional services into the home of the older person has been considered for more than three decades (especially in Scandinavian countries) as the best means to support 'potential' informal carers. Because professionals are providing services, families are placed in the position of either only having to provide emotional support to their beloved person, being relieved from the main caring tasks and able to choose to give some forms of help. But in the case of family members choosing to provide 'hands on' care, one of the most important professional caregivers' roles should be to support carers in their caring tasks by empowering them in order that they act more effectively. So supplying professional services should also be considered as 'direct supporting measures', even if they are professionally mediated. However, this type of support entails putting a specific policy in place regarding the education of professional caregivers, in line with changing perceptions on the respective roles and responsibilities of formal and informal carers and the new links which have to be built between them in order to make them more aware of informal carers' needs for care. Surveys show that this type of policy has mainly developed in Scandinavian countries and in the NL while a lot of work remains to be done in order to transform the relationship between formal and informal carers into a mutual and equal partnership in the provision of care.
- **Home support devices and home adaptations:** The most frequent tools to be included in LTC packages and at least partially reimbursed (DE, FR, SK and others).

- **Monitoring technologies:** currently their main use of proven value is in hospital at home-based programs for home monitoring of LTC patients with complex health histories, as well as for tele-medicine support for health and care services in remote areas. Although strongly promoted by the technology industry and considered as a powerful tool to support informal carers in their caring tasks, they have not yet delivered on their promises in this area and are not widespread, either due to their high costs, technical difficulties in using them, but also the fact that they do not always correspond to the real needs of users (older people and their families).

Non-specific and direct

- **All types of respite care** (day care; temporary stay; 24 hours home custody etc.): Their goal is to give informal carers the opportunity of a break from caring in order to temporarily reduce their caring burden and enable them to continue to provide care over a longer time period. But as surveys show (EUROFAMCARE, 2006a), carers will use them only if they are convinced that provided services are suited to the older person's needs and are well-managed and staffed with licensed professionals. In the absence of such conditions guaranteeing their quality, they are not prone to use them (FR, SK).

In-kind specific support

They consist of a series of tools the goals of which are to enable informal carers either *to choose* the solutions best fitted to their situations or help them to better perform their caring tasks.

- **Information** (on services availability and accessibility): Though considered in all studies as the major demand of informal carers, there is a lack of information in many countries, with the marked exception of Sweden.
- **Advice/counselling:** In order to help carers choose the best available options as well as supporting them psychologically in caring, counselling and advice centres can be an important support.
- **Training/education:** In many countries courses for carers are offered by public or private non-profit organisations, often in an experimental form and they are usually specifically developed for Alzheimer carers (7.2, Good Practices 6 and 7).
- **Self-help and peer support groups:** If functioning well, peer support is of great benefit to some carers, even if there is only limited evaluation concerning their effectiveness.
- **Advocacy groups and informal carers' associations:** They play an important role at two levels: at the European level Eurocarers are lobbying the European Commission and assembly, while at national level advocacy groups provide feedback on the accuracy of reports on the national action plans against social exclusion and intervene in the decision making process in order to shape policies regarding informal carers. They are strong in some countries (UK; NL) and numerous but weak, because of their fragmentation, in others (FR). In Scandinavian countries, where the elected municipal councils are responsible for informal care policies, advocacy groups and patient organisations are quite powerful and are part of the decision making process when new legislation is created. Several municipalities have regular meetings with the different groups to discuss issues of care and/or they also regularly participate in projects as reference groups etc.
- **Employment support:** Care leave and flexible working arrangements have both proved to exert a positive effect on informal carers, only if there exists both a strong involvement of the employers and of the state (leading to arrangements which correlate practically with the caring situation), and also if carers are sufficiently financially compensated and without loss of social rights (Repkova, 2009).

In summary

Three main approaches have been identified in the division and sharing of responsibilities for the care of older people between family and state in the participating INTERLINKS countries.

- **The family** has first responsibility for financial support (EL, ES, FR, IT, SK), although obligations for the provision of practical care are frequently unclear.
- **The state/municipalities** are explicitly responsible for care at full cost (SE).
- **Older people with LTC needs** have responsibility for and rights to care via the compulsory LTC insurance (DE), although full costs of care are not provided and informal carers fill the gaps.

It is this primacy of responsibility that largely determines the wide country variations in formal care provision for older people with LTC needs, although recent legislation in most countries to support informal carers and the corresponding development of support measures, indicate an increasing recognition of the role and value of informal carers in the provision of long-term care. Finally, a classified description of support measures for informal carers is provided for use in Phase 2.

6 Policy, legislation and implementation: An overview of policies and gaps in support for informal carers within long-term care

In this section we outline the proposed contents of a specific policy for informal carers (6.1) and describe how resulting support measures can be assessed (6.2). The main issues in implementing such a policy are identified in 6.3 and 6.4 describes the main policies and their implementation in the INTERLINKS countries, within the context of their specific LTC policies; finally, 6.5 addresses the main gaps between policy and provision of support to informal carers.

6.1 Elements of a targeted policy for informal carers

As there is no commonly agreed definition of a policy targeted at carers and describing measures and linked services that could constitute its core, we suggest the following elements that, following the results of our study, should be considered in constructing a policy targeting informal carers:

- 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 (Kovacheva et al, 2008).
- It should be neutral regarding their choices between caring or not caring, or caring at any level while remaining in the labour market, and it should be compatible with the older person’s needs and expectations.
- 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 (younger generation carers) or not (retirees).

As a corollary, and in line with the classification of support measures presented in Section 2.4, policies for informal carers should consist of a mix of support measures (in-kind and in cash) that aim to respond primarily to informal carers’ specific needs (specific measures), while simultaneously addressing the needs of the cared-for older people (non-specific measures). This last constraint should be kept in mind constantly when assessing any policy with a potential impact on carers.

6.2 Assessing support measures for informal carers

Support measures for informal carers, together with their links to the health and LTC systems as well as the gaps between policy and provision of support, can be analysed with respect to the following criteria covering the macro, meso and micro levels:

- Their specific contribution to the financial sustainability of the LTC system, particularly regarding their connection with the issue of funding formal services at acceptable levels;
- The balance they set between individual, family, market and state responsibilities encompassing a gender dimension (degree of de-familialisation);
- Their contribution to achieving a better balance between caring and working as regards ‘economic well being’, citizenship, social inclusion and social rights (degree of care ‘commodification’);

- Their contribution to fairness and equity in access;
- Their contribution in giving voice and power to Informal carers at all levels;
- Their contribution to a better integration of formal and informal care;
- Their contribution to the quality of care;
- Their ability to reconcile both the users' and the families' expectations regarding care and quality of life;

In-kind services: While in-kind services directly supporting informal carers are indispensable, it is important to note that professional services delivered to the older person by trained and qualified social and health professional workers (services in-kind), even if their main aim is to respond to the needs of the older person, can also be considered as a support to informal carers. Adequate services for older people relieve informal carers (totally or partially) from care work, thus reducing their risk of care burden and social exclusion, while increasing their quality of life (Carretero et al, 2007; Garcés et al, 2010). Also for carers in the labour market, the availability of adequate formal services can contribute to remaining in employment and limiting their poverty risk.

Entitlement rules and the comprehensiveness of accessible services are thus crucial components in the assessment of the benefits of in-kind support measures, as they are key elements for a real and effective choice for both informal carers and older people.

In-cash support: Different types of cash benefit are supposed to financially compensate informal carers for their caring tasks. Care allowances, even if directly targeted at the informal carer, may not be an efficient solution to the informal carer's financial needs, if the entitlement does not allow her/him to combine care and employment, if the amounts granted are too low, and if it does not increase choices. Access conditions and the level of funding are thus key to their effectiveness. Also, attendance allowances used by the older person to 'hire' a family or other informal carer may address the financial needs of the informal carer, but, similar to all forms of untrained care provision, unless combined with training for the practical skills needed for caring tasks, it could potentially be harmful regarding the quality of the services provided.

6.3 The issues in shaping and implementing informal care policies

Despite the progress achieved in informal care recognition and support provision for informal carers, the WP5 National Reports highlighted some open LTC-related issues regarding informal care policy. As all public policies, policies for informal care face political, financial and economic challenges, but they also raise specific questions concerning the future role of informal care within the LTC system, which relate to conceptual issues.

The first dimension is political with respect to the issue of how much public money should be used to secure an adequate level of formal service provision to respond to both older people and informal carers' needs. Whatever the potential contribution of informal carers to care provision, formal services will always be necessary and probably at an increasing level of provision, to cover the needs for care of non self-sufficient older people without family support, as well as those whose families are unable or choose not to provide care. Political choices will influence the balance set between public expenses, private insurance and direct contributions from the older person or family carers (7.1, Good Practices 1 and 3) and will have a direct impact on entitlement schemes (universal/means-tested/ assessed needs) and the type and amount of funding provided to the LTC system and its services. In this regard, and as shown in Section 3, it is clear that, with the exception of Scandinavian countries, formal services' contribution to

the total provision of care is still lower than services provided by informal carers in the family and other informal care settings. The latter are still considered as a cheap and relatively accessible care source that will ultimately fill the gaps and substitute for the deficiencies of publicly provided services. Here the financial sustainability of LTC is evoked, even if evidence shows that the main drivers of cost are the higher use of intensive medical technology and the inefficiency between the health and social care sectors, rather than the direct cost of social services specifically linked to disability.

The second dimension relates to implementation in relation to the classical 'governance conflict' regarding legislation/policy effort vs. practice/implementation: On the one hand there exist 'evidence based' efforts made by legislators and national authorities to bring in some new forms of informal care support (e.g. the Law of Promotion of Personal Autonomy and Care to People in Dependency Situations in ES; the Act on social services in SK, the development of APA and specific programs designed by CNSA in France). On the other hand, the real effects of such legislations are impeded, both by the long time range needed for full implementation (e.g. SK, ES, FR), but also by the wide discretionary power regarding their urgency and their place on the political agenda. Also, because of traditional social and moral obligations, as well as some constitutional specifications on families to provide care (e.g. in EL), there may also be no easy legal recourse, either by individuals or advocacy groups, by which the legislator can be forced to act (6.4.2) The situation is the reverse in Sweden where, in terms of legal regulation, the caring obligation falls primarily on the state's shoulders (6.4.7).

The third dimension concerns the economic question how to reconcile working and caring in order to build a stronger economy. On the one hand, the efforts of family caregivers, primarily women, to increase their own employment and economic independence, are counteracted by the above-mentioned high expectations in relation to their obligations in family care. On the other hand, supporting informal carers to enable them to continue to fulfil their caring tasks at the same or even higher level of intensity, may prove unsustainable because of the long term negative effects of their 'hidden' work. Thus, keeping the 'sandwich generation' (45/54) and the 55/65 cohort in the labour market is at stake. Research studies found that family carers had less than average disposable income as a result of caring, due to high out of pocket payments and co-payments for services (e.g. in DE and EL) and/or due to a reduction of working-time or withdrawal from the labour market (high in EL, DE and UK). It was also demonstrated that there are large cross-national inequalities in financial support for family carers and older people in need of care (EUROFAMCARE, 2006a).

In some Mediterranean countries (EL, ES, IT) the low employment rate of carers and women is, among other variables, a consequence of insufficient national budgets for welfare state programmes: The intensity of social expectations for providing care by the family, primarily by women, leads to low female employment, which in turn prevents high taxation because of families' lower disposable incomes. This in turn limits the achievable national revenues, thus preventing the establishment of a financially sustainable welfare state, able to respond to users' and carers' real needs. It has been estimated (Esping-Andersen, 2003) that raising the employment rate of 45/55-year-old women from 35% to 55% would impact positively on the LTC budget and on the quality of care. This gives one of the clues to the economic rationale of the Scandinavian model, but it involves strong and specific decisions regarding both labour market policies and pension schemes, which are also determinants of any LTC policy.

Last but not least the conceptual issue, which consists of the widespread and misleading tendency to conflate the needs and the opinions of the informal carer in a single unit with those of the person they are supporting, has to be underlined once more (see Section 2). Decision-makers both at the policy (macro) level and at the practice (meso) level must not overlook the complex and sometimes 'conflicting

dynamics of care giving relationships' at the micro level. It is this misconception that has clouded the issue of whose needs are or should be addressed in LTC policies (Myers/MacDonald, 1996; Scourfield, 2005). In this regard, it is the triangular relationship between formal services, older people with care needs and their families which is at stake: the issue is how to overcome the isolation of recipients and family carers by better cooperation and improved relationships with formal services.

6.4 Policies for supporting informal carers and integrating them into the LTC system: Main country approaches

As exemplified in the INTERLINKS National Reports, policies for the support of informal carers reflect a variety of European approaches in several policy areas (social, labour, education, health), which may or may not be formally linked with general LTC policies. The main approaches to the support of informal carers, both in policies and their practical implementation through in-cash and in-kind services, together with their links to the LTC system, are summarised below by country (based on WP5 National Reports).

6.4.1 Germany

The principles of the German care policy are: 1. People in need of care should, as far as is reasonable and feasible, be given care at home. 2. Home care should be given by informal carers or at least supported by them. 3. Rehabilitation should be put into practice rather than LTC provision. When informal care is given at home, the LTC insurance pays an attendance allowance to the person in need of care, which he or she can forward to the informal carer. As an alternative, the beneficiary is entitled to benefits in kind or can combine the care attendance allowance with in-kind services. Policies to support informal carers are thus designed as a combination of direct and indirect specific and non-specific measures.

- 1) The *Social Security Code XI, Social Care Insurance (Sozialgesetzbuch XI, Soziale Pflegeversicherung)* covers the following measures:
 - People in need of care, entitled to receive nursing allowance, have a legal right to up to four weeks of respite care (§39 SGB XI) and up to four weeks of short-term care in an institutional facility (§42 SGB XI) per year and if necessary to supplementary day/night care (§41 SGB XI).
 - Furthermore, the LTC insurance funds are legally bound to provide information and counselling services (among others §§7,7a SGB XI), especially obligatory counselling sessions with the person in need of care in his or her home (§37 Section 3 SGB XI) and care giving courses for informal carers whose attendance is voluntary (§45 SGB XI).
 - More recently the LTC insurance funds and the health insurance funds have started setting up LTC support centres (§92c SGB XI) for local counselling close to home, for the provision and care of people in need of care and for their informal carers.
 - Informal carers are covered by the statutory occupational accident insurance and, when providing more than 14 hours of care per week, the beneficiary of nursing allowance can also apply for them to be covered by the statutory pension insurance. (§44 SGB XI). In addition to this, informal carers who were employed in the period before taking on care, can pay unemployment insurance contributions on a voluntary basis.
- 2) In 2008, the '*Act on care leave*' (*Pflegezeitgesetz*) for gainfully employed people with a relative in need of care came into force. In the case of a sudden crisis situation with acute care needs they are entitled to – usually unpaid – leave from work for up to ten days or to be granted full or partial

leave from work for a one to six month ‘care period’. During this time they cannot be dismissed and, despite losing their salary, their social insurance is maintained through the LTC insurance funds.

- 3) An inheritance law reform benefits informal caring children and grandchildren in the event of their succession.

6.4.2 Greece

Greece has no clearly formulated LTC policy and no policies for the support of informal carers. Policies for older people are based mainly on the KAPI¹² principles of maintaining older people as active and participative citizens in their home environments for as long as possible. Residential care (mainly private) is used by only an estimated 1.5 to 2% of citizens over 65 years (data are available for licensed residential care units only, whilst many operate unofficially as ‘hotels’). Public home care services for older people in need of care were originally developed, in line with the Lisbon agenda, with the aim of releasing women from caring duties and enable them to enter the labour market, as well as of creating new jobs in the care sector. In practice they have to focus primarily on isolated and poor older people with low or moderate care needs and restricted financial resources to pay for care. Furthermore, the insecure funding of the home-care programme, with staff being unpaid for long periods, is a major barrier both to their continuity as well as to their expansion to meet existing needs. Findings from the EUROFAMCARE National Survey showed clearly that family carers are viewed primarily as a resource and not considered to have their own needs for support. Although supporting an older relative can be claimed for income tax relief, there are almost no benefits such as cash, pension credits/rights or allowances for the carers, whilst financial support for disabled people and older people with care needs themselves is minimal, with just 2.1% of family carers reporting receiving any such financial help for care provision (Triantafillou et al, 2006). Currently, the only supporting services for carers, mainly in Athens or other big cities, are NGO based self-help, support and training groups designed for family carers of Alzheimer disease patients. Despite this absence of public support for family carers, the Greek National Strategy Report on Social Protection and Social Inclusion 2008-2010 reported the “implementation” of a series of measures to safeguard integrated access to healthcare and long-term care, including “support to families providing such care services informally” (Ministry of Health and Social Solidarity, 2007: 103). The lack of comprehensive, affordable and qualitatively acceptable services for older people and the lack of support for informal carers have forced families to find their own solutions to care, namely through the employment of migrant care workers (the majority of whom have no work permits). In contrast to the Italian situation, the Greek government is still hesitant to take action in relation to the regulation of migrant care workers.

Thus the main issue in LTC confronting the new government is the formulation and implementation of policy that enables older people and their families to have real choices in care provision through securely funded public services, as well as supporting integration and regulation of all services in the care sector, including informal care. However, an even more important question is what incentives could persuade a government under great financial pressure, to invest in development of a LTC system that sup-

¹² KAPI = Open Protection Community Centres for older people, consisting of approximately 1,000 centres throughout Greece, providing social, preventive health and recreational activities and serving mainly the less dependent older local population (see also Kümpers et al, 2010).

ports both family carers and the older people they care for, when they are used to relying almost entirely on family solidarity to provide and pay for all forms of care for older people?

6.4.3 Spain

- 1) *Regulation of social security for informal carers* - Royal Decree 615/2007. The inclusion of non-professional carers into the Social Security system is possible through a regulation that provides the requirements and procedures for affiliation, registration and contribution. The intention is to overcome the isolation faced by many carers and to increase their autonomy by means of a public LTC system. It also provides an acknowledgement of the work done by carers and family members and contributes to ensure their future retirement pension.
- 2) *Flexible working time for informal carers*. The Spanish Law 39/1999 of 5 November, to promote reconciliation of work and family life of working people, expands the right to shorter working hours and unpaid leave to workers who have to care for elderly and ill relatives. The law also provides the possibility of the reduction of working hours or unpaid leave for care of family members on grounds of age, accident or illness that cannot either care for themselves or perform paid work. This right is set as an individual right of the worker. Article 2 provides that 'legal guardians' caring for a physically, mentally or sensory disabled person who does not perform a gainful activity, shall be entitled to reduced working hours, with a proportional reduction in wages between at least one third and up to half the duration thereof. The same right applies to people who have to take care of a relative to the second degree of consanguinity or affinity, who because of age, accident or illness cannot look after themselves and do not perform paid work.
- 3) *Training of professional and informal carers*. The Spanish Dependency Law establishes the need of training of professionals and informal carers. In the framework of this regulation, an agreement including the common criteria for accreditation in training and information for informal carers has been concluded. This agreement also establishes the aims and contents of training for informal carers. Apart from technical knowledge, their role as caregivers, the prevention of risks and damage, hygienic guidelines, as well as the psychological aspects of caring. Also the creation of self-help groups, emotional and psychological support, spare and free time for the caregiver, relationships between the person in need of care and the caregiver, etc. have to be addressed.
- 4) *Agreement for the improvement of the quality of services provided within the family environment*. The resolution of 4th of February 2010 establishes a set of rules to be accomplished in order to be entitled to financial support in the family environment. The objective of these rules is to ensure the quality of care if the person in need of care and/or his/her family choose benefits in cash.

A new Act 39/2006 Coll. "Promoting Personal Autonomy and Attention to People in Situations of Dependency" is being introduced. This Law stipulates assistance in case of care needs and it aims to promote personal autonomy and to improve the quality of life of people with care needs. Assistance can be offered by means of services in cash or in kind, the former having priority. The regulation specifies the provision of services according to a three-grade classification of care needs: grade I-Moderate care needs; grade II-Severe care needs; grade III-High care needs. Each grade has two levels depending on the assessed autonomy and on the intensity of care required.

The 'Dependency Act' defines a list of services to promote personal autonomy and attendance. These are prevention services, tele-care (including personal alert system), home help (including housekeeping and personal care), night and day care facilities (including day centres for older people, day centres for

people under the age of 65 years, day centres with specialized care and night centres) and residential care according to the various types of disability. Benefits can take on three different forms: subsidies for services in kind, an attendance allowance to compensate for care within the family and direct payments to afford personal assistance (only for High Dependency). The provision of services in cash or in kind is defined through a personal plan of intervention (PIA) which is based on a preliminary assessment of the individual needs by a social worker and a negotiation with the family and the entitled person.

In practice, several issues are emerging affecting the use of formal care and its integration with informal care. Inter alia, there are regional differences in supply and use of informal care, e.g. higher levels of informal care can be observed in smaller townships. Jimenez-Martin and Vilaplana (2008) pointed out that formal care is used only when the needs of the older person are rising beyond informal carers' capacities. Further studies, analysing the situation of informal carers in the Valencia Region (Carretero et al, 2006; 2007, Garcés et al, 2010), showed that the informal caregivers are usually the spouse or the daughters/sons of the person in need of care. Though providing daily care on average for more than 28 hours a week, informal carers can cover the needs of the older person only partially. As the study states, 80.9% of the informal caregivers consider support structures as insufficient. This situation should be slightly improved through the implementation of the 'Dependency Law' which, however, is still ongoing. In particular, training and support services for carers are still not implemented at all.

6.4.4 France

During the past decade there has been a considerable increase of public expenditures for LTC in France. These resources certainly served to enhance the modernisation of care homes and the professionalisation of home care and social workers, but the main focus of LTC policies has been to increase the rate of employment as LTC, in particular home care, has been considered as the most promising sector in terms of its potential for further growth. This strategy has been linked to the introduction of market-mechanisms with the aim to enhance quality by competition and choices for users and their families. Indeed, the number of providers, in particular the share of private for-profit organisations, has increased considerably.

In this regard, cash mechanisms such as vouchers and care allowances have been introduced and are more and more used by older people to hire and pay home helpers for domestic work and personal assistants, creating new job opportunities and partly legalising the hitherto grey market of domestic work. This benefit may also be used to employ all types of family members (with the exception of spouses). However, these benefits were undoubtedly not construed as a mechanism to reconcile caring with working in the labour market. Informal care is still considered as a source of services and (even unpaid) care leave has not been introduced, as employers are not eager to respond positively to working carers' needs by enabling flexible working arrangements. The gender balance in caring thus remains unchanged, neither has the employment rate of women aged 50/65 increased. In this regard, it should also be acknowledged that, within the 'family policy' frame, policy for informal carers of older people is clearly in a disadvantaged position regarding competition for funding with that addressing child care for the 30/50 cohort.

Information and counselling are beginning to be systematically carried out in single access-points that are run on behalf of the General Councils of the Départements (MDH). Training, education and psychosocial support are still either not legally defined and/or poorly reimbursed, even if there exist some interesting experiments regarding Alzheimer carers. Housing accommodation and technical devices are legally defined and partly reimbursed. Respite and day care are other promoted types of support, but they are still insufficient (less than 1% places compared to classical settings) or underused, because of a

lack of knowledge, due to fears of informal carers regarding their quality and/or a refusal by the person being cared for.

6.4.5 Italy

In Italy public services only provide a small part of the services for older people in need of care and their families. Estimates suggest that two thirds of the families provide care themselves, even in the most difficult conditions of care needs: only 3% of older people are in residential care, only 4.9% receive formal care services at home, and 9.5% receive a flat-rate attendance allowance.

The majority of the supporting measures for informal carers are not national but subject to the administration of every region. In general, they promote training and supporting groups for relatives, economic contributions aimed at the payment of fees in residential homes, social and healthcare vouchers and other initiatives. Italy is characterised by a high reliance on migrant care workers for the provision of practical care for older people at home (substitution of family care by 'paid' informal carers), but at the same time is planning and implementing structural reforms in the LTC system, including the regularisation of migrant care workers and their evaluation in terms of user satisfaction, improved care provision and cost benefit, as well as the possible negative aspects.

The better allocation of resources is a crucial point in the agreement between Government, Regions and Local Authorities in planning and implementing structural reforms (see Di Santo/Ceruzzi, 2010).

6.4.6 Slovak Republic

There is no unified definition or system of LTC in Slovakia. In the document 'National Report on Strategies of Social Protection and Social Inclusion', LTC is defined instrumentally as 'social services, care allowance and direct payment for personal assistance'. From this operationalisation, it is evident that: (1) LTC is not a holistic system with a unified structure, governance and financing, but rather a set of instruments being provided by different responsible authorities under different sectors and financial mechanisms, and (2) instruments utilised within home care settings are focused on both cared-for and caring people, sometimes with blurred effects on these target groups, and (3) strong attention has been paid to informal (primarily family-based) care which takes over the bulk of care commitments. For this reason, improving the financial situation of informal carers arose as a commitment of the Slovak government, declared in the Programme Declaration of the Government of the Slovak Republic for 2006-2010.

During the last decade some political decisions have been taken to intensify support for informal carers, in particular by the introduction of a care allowance as a contribution to a basic income. Furthermore, entitled carers will have their social and health insurance contributions paid by the state and possibilities for respite care have been extended. Also the reconciliation of work and care was addressed by regulating flexible working regimes in line with the Labour Code. Finally, social counselling provided by the state administration, municipalities or civic organisations has been enhanced and public support of NGOs organising social rehabilitation programmes (including information exchange and care-management experiences) have been extended.

Measures with 'blurred' effects regarding the target group consist of various forms of cash benefits for people with a severe disability, e.g. attendance allowances, funding for architectural adaptations, care devices or for increased costs due to a severe disability). These benefits are certainly contributing to make intensive family care easier and more convenient in the home setting. There are also some legally

stipulated possibilities to combine informal care with formal care services, aimed at providing family carers with real choices concerning care commitments and to reconcile caring, working and personal life.

However, due to strong family traditions and other contextual factors, employment of family carers, flexible working regimes, respite care programmes and the combination of formal care (day care centres, nursing care) and informal care have been utilised up to now only to a minimal extent (Repkova 2008; 2009). Informal care has been taken as a substitution for, rather than as a complementary part of a holistic, coordinated LTC sector for older people with care needs. These problems, including a very low level of protection standards for informal carers, have led to efforts to prepare a draft on a Long-term Care Act, based on a decision of the Governmental Council of the Slovak Republic for Seniors (2009). The implementation of this legislative framework will depend on the new government elected in summer 2010.

6.4.7 Sweden

1) The Assistance Benefit Act: This initiative provides the possibility for people with extensive needs for assistance to employ personal assistants, including family members that can get full payment for any help they provide as assistants. Anyone who needs more than 20 hours assistance per week for their basic needs are entitled to assistance allowance under this regulation. However, this Act refers mainly to people under 65 and only applies to over 65 year olds who have already been granted assistance before their 65th birthday and the number of assistance hours may not be extended after this date (Assistance Benefit Act SFS 2005: 332).

2) Recent legislation (2009) specifies the support of family carers as an obligation of municipalities.

Care for older people in Sweden is based on the philosophy of providing older people with support to live a high quality, independent life for as long as possible. The management and planning of care for older people is split between three authorities – the central government, the county councils, and the local authorities. In 1992 the Ädel reform changed the central administrative role of the government, restricting it to a legislating, facilitating and controlling body, while all detailed planning, funding, and allocation of resources henceforth became the responsibility of the municipalities together with the county councils.

All permanent residents in Sweden with impediments are eligible for care solely determined by assessment of needs. The maximum monthly fee for LTC is set by the central government with further reservations depending on the financial situation of the individual, thus guaranteeing that all older people in need of care are able to receive necessary care and treatment in Sweden. As of 1 January 2010, the local authorities are required to draw up an individual plan for each care receiver that clearly states each step of the required treatments and services. The plan must also disclose the name of the person that is officially in charge of the case and clearly specify which authority is responsible for each component of service and care offered.

Since the establishment of the welfare system in the 1930s, Swedes have become used to rely on the state for the care of older people. However, in recent decades informal care in Sweden has gone through a transition: from not being fully recognized to becoming a considerable part of the LTC system. The rapidly ageing population has turned the policy-makers' attention to care provided by relatives or friends which has increasingly been recognized as a partial solution to these challenges in Sweden. The main strategy has so far been to strengthen the support of informal carers, mainly through programmes

managed by The National Board of Health and Welfare, aimed at developing informal care and addressing issues regarding both direct and indirect carer support and quality in care for older people, the emphasis being on sustainability, duration, infrastructure and quality.

The municipalities are now required by law (the Social Services Act) to support informal caregivers, with the objectives of helping to reduce the workload, preventing illness, and providing informal carers with the knowledge and the information they need to continue caring (see 5.4.2 and Section 7.2: Good Practice 4). Virtually all municipalities now have a variety of different forms of respite care and other forms of support for informal carers (personal support; support calls contacts and family groups etc.) and the incentive funds have also enabled a wide variety of so-called feel-good activities, provided by municipalities, although almost all the municipalities express the continuing need for further development (Kommunernas anhängstöd slutrapport, 2009: 7). However, the results of this change in policy and of the new incentives for informal carers have not yet been extensively evaluated: Did the measures really improve support to spouse carers of older people living in isolated areas? Did the number of younger informal carers increase? Did budget constraints reduce costs and increase efficiency without decreasing overall quality and accessibility to LTC?

6.5 Gaps between policy and provision of support to informal carers

6.5.1 Gaps in funding formal care services

Insufficient financial resources for in-kind services, whether specific or unspecific, seem to be one of the main gaps between policies (declared requirements) and practices. Despite some examples of good practice in a context of limited budgets (see Section 7) and with the exception of Scandinavian countries, the implicit assumption that unpaid work of informal carers to 'fill the gaps' is still prevailing in most European countries.

Providing easy access for older people with care needs to professional services is probably the easiest way to support informal carers. However, informal carers also need supportive measures addressing their specific needs (respite care, housing accommodation etc.) that are linked with those of the person being cared for. Individual countries' capacities to publicly fund such services are an important issue when it comes to discussing the financial sustainability of emerging LTC systems.

Economic and budgetary projections for the EU-27 Member States (European Commission, 2009) illustrate that an ageing population would increase the pressure for more public spending in health care. Also other studies have shown that, in relation to health care, it is the intensity of services and the use of new technologies, rather than age and health, which are the main drivers of health expenditures (e.g. OECD, 2005). According to the 'compression of morbidity scenario', as medical expenses are more and more concentrated on the last years of life, it will be the LTC system which will predominantly cover an increasingly extensive period to support (older) people with disabilities that are not necessarily linked to chronic diseases. Financial sustainability is thus an issue for both health and LTC, but it seems to be a major concern in the medical care sector, which appears to be more costly than social care based services and makes up already currently about 10% of the GDP in the wealthiest European countries (OECD Health Data, 2009), while LTC specific expenditures vary between below 0.5% (ES) and around 3.5% (NL, SE) of the GDP (Huber et al, 2009).

Still, financial sustainability of LTC will depend on a more efficient use of health *and* social care budgets, through better coordination and integration of social and health care services and by targeted innova-

tions at the interface between formal and informal care. The most interesting debate will thus remain, whether the strong and established health sector will shift costs to the emerging LTC sector (and thus most probably to families and informal carers) or whether synergies and a fair distribution of responsibilities and resources will be found by involving the interests of all stakeholders. The mere attempt to limit access to publicly funded formal LTC services will certainly not be an acceptable solution for carers and their family members in need of care.

6.5.2 Gaps in cash benefits

In order to control for an expected rising demand, the amount of cash benefits has usually been set at a relatively low level. Attendance and care allowances are far from compensating for the volume of services delivered by informal carers and often represent only a symbolic recognition of caregiving. Only for a very small portion of carers who are still in the labour market, these benefits may represent an incentive to give up or partially reduce a paid job. In Central and Eastern European countries (e.g. SK), people (primarily women) who are receiving care allowances are in the majority of cases not employed, with health and social insurance contributions at minimal levels (Repkova, 2008; 2009).

There is little evidence that cash benefits have been able to achieve a higher rate of employment. In more wealthy countries, cash benefits have allowed part time employed carers (mostly women) to continue to care without losing too much in terms of revenue (NL). However, this has seldom been the case in France, where the rates of employment and part-time work are lower, and even less in Germany, where cash benefits have been designed as an incentive for women providing care, while being financially 'compensated'. The situation is different in the UK, as the care allowance takes a specific form linked to an activating welfare policy focusing on 'single women': it appears that, in spite of the low level of payment, a rather significant proportion of the targeted women have accepted to undertake caring activities, but at the price of difficult working and living conditions (Glendinning et al, 2009).

6.5.3 Gaps in the balance of responsibilities between family, market and state

The rise of cash benefits has resulted in a commodification of care, with formerly unpaid family carers or volunteers now receiving cash benefits. The boundaries between unpaid and paid informal care are thus becoming increasingly blurred. It is widely discussed whether people in need of care are really able to choose the best way to use cash benefits, not only for themselves but also according to the needs of their carers. In order to better control the use of such benefits, voucher systems are considered to be more appropriately targeted, even if they often cover a lower amount of care. For instance in the German LTC Insurance, entitled persons may choose between a benefit in cash and a benefit in kind, e.g. if assessed in level 3 (heavy care needs), a person in need of care would be given the choice between a cash benefit of €685 or in-kind services at a value of €1,510. This regulation was supposed to be a strong incentive for households to choose benefits in kind, but a vast majority of beneficiaries have opted for cash benefits, choosing to cover the 'care gap' between the approximately 2 hours of formal care services per day and the usually much more intensive real care needs of the beneficiary by themselves.

Cash benefits carry the risk of modifying the 'gift based relationship' between the family carer and the cared for person, even if surveys have extensively shown that the number of hours provided by informal carers largely supersede their paid amount. However, the availability of informal carers provides a strong incentive for regulators to perpetuate a situation in which informal carers run the risk of being trapped and lose a certain amount of freedom; for example, in the case of attendance allowances, informal carers depend on the goodwill of the beneficiary regarding the level of payment. This is less the case for care allowances as payment goes directly to informal carers, thus allowing them more freedom,

but mainly in situations where the beneficiary is the sole carer. Nevertheless informal carers, albeit with cash support, are frequently left alone to search for individual solutions to their caring burden, either by involving other family members, or by employing personal assistants who may be migrant care workers (see Di Santo/Ceruzzi, 2010), or in the search for affordable and acceptable formal services.

Finally, it appears that most of these cash benefits are more to be considered as part of a non-explicit strategy aiming to maintain the level of informal care provision. Apart from some rare cases where informal carers may enter the labour market as qualified workers through vocational experience and training (good practice: France), cash benefit mechanisms have in general not been successful, either in allowing informal carers to enter the labour market with a dual activity (with the exception of NL), or to give them decent caring conditions.

6.5.4 Gaps in giving voice and power to informal carers

The need for information on the existence and availability of services and all forms of support, together with information on the health condition of the older person in order to provide the best care, was identified as the most important type of support for carers in the EUROFAMCARE study. The provision of such information to families, as well as universal access to and active involvement in the needs assessment process and individual care planning, considering also the informal carer's needs (e.g. as in IT and SK), would constitute a significant link between formal and informal care provision, resulting in improved care for older people in need of care.

6.5.5 Gaps between formal and informal carers in working 'hand-in-hand'

Problems appear at service delivery level with regard to the distribution of roles between formal and informal carers. One main barrier to cooperation seems to be the integration of professionals' skills with the practical skills of the informal carers. For example, in Italy (but also in other countries) professionals consider their supervisory function in regard to informal carers as natural, as the latter act just on 'lay knowledge' based on personal experience, rather than on professional knowledge (WP5 - Italian National Report: 7). Thus, the informal carer may de facto be excluded from the professional network established in support of the older person and left alone to cope with critical situations arising from the old person's condition. Indeed, informal carers, especially in Greece, Spain and Italy, are often forced to act as coordinators of care provision by managing and arranging complicated schedules to avoid overlaps between health and social services, and by providing at the same time large amounts of practical care. This may also be the case in countries with more formal services, even if to a lesser extent (FR, UK, DE). From a formal carer's perspective, conflicting interests with informal carers may be perceived, for instance in Germany, as a feeling of being 'monitored' by family carers who interfere with their care activities and may even involve them in family conflicts.

All these barriers to cooperation and the inclusion of informal carers in integrated care are also referred to in the European Project CARMEN (Nies/Berman, 2004). Professional care providers do not always acknowledge the value of the contribution of informal carers, and they are seldom regarded as partners in the system (Peck et al, 2000: 27). Overall the stress generated by informal carers' attempts to fulfil the obligations of this coordinating roles for an unknown period of time, has well-documented negative repercussions on their physical, mental and social health status as well as on the well-being of the cared for older person (Andrieu/Aquino, 2002; Carretero et al, 2007). The Spanish report clearly documents the long-term consequences of failure to adequately address the causes of such stress by finding the right balance between formal and informal care provision. Thus finding 'collective solutions' to care

provision, through specific team support from formal carers towards their informal counterparts in order to work hand-in-hand, is a major goal still to be achieved.

In Germany, despite efforts towards improving links between formal and informal care provision, gaps still exist as illustrated in a survey among family caregivers, which revealed that the organisation of home care services is often considered not very user-friendly and deployment times are felt to be unsatisfactory. There is criticism of the lack of staff continuity in LTC situations and the lack of time on the part of formal care staff, together with an above-average frequency of inadequate social competencies, are issues of further complaints. Conversely, criticism from the perspective of the professional carers refer to the way in which informal carers fulfil their tasks, interfere in more or less awkward situations during their care activities and often try to draw them into internal family conflicts. As professional carers are not prepared to deal with these kinds of conflicts during their basic or continuous education, they can only develop coping strategies on the job (BMFSFJ, 2002: 205f).

6.5.6 Gaps in caregivers' social rights

As economic well-being, citizenship, social inclusion and rights mainly derive from labour market participation, the question of whether cash benefits should be considered as real wages attached to informal care work or whether they should be treated only as replacement income, is of paramount importance when comparing support policies targeting informal carers. Family culture embedded in society has proved to be a strong determinant explaining why, even in countries (DE, FR) that support informal carers through relatively generous cash benefits, they have not been fully recognized as being part of the 'working population' and thus entitled to the same level of social rights and revenues as most workers in the labour market. Paid family care is still not considered as real employment and/or incompatible with market employment. Also, since a low level of wages frequently correlates with inadequate social protection, informal carers are at risk of being considered as 'second class' workers and thus socially discriminated against. However, it must be acknowledged that this discrimination also correlates with the low status of professional home carers in the labour market hierarchy, which leads to difficulties in attracting and retaining them in this sector. Only in Nordic countries like Sweden and Finland, where this profession is better recognised, (informal) carers hired through public or private agencies have their wages set at a 'quasi equivalent' market level.

6.5.7 Gaps in the quality of services

In countries with a longer tradition of formal LTC services (SE, NL), also quality assurance in care provision seems to be further developed, due to strong public commitment, real control by local authorities, explicit employment contracts and accountability of expenses, while also informal carers are entitled to social benefits. In the context of increasingly market-driven governance of LTC, cash benefits for people in need of care and/or their carers, and the emergence of new types of providers, the issues of quality assurance and development have multiplied all over Europe. For instance, the new phenomenon of privately recruited and paid migrant care workers has triggered first attempts to regulate this grey market in Austria, Italy and Greece. Still, there is low control of migrant care workers' previous skills and knowledge in this field. Also the individualisation of choices by users creates increasing difficulties to assess and control the quality delivered by hired workers (DE, FR, NL). Again, an important factor is information and trust building on the part of the formal towards the informal carers. In the case of migrant care workers, support is needed in training and integration into mainstream services, with first attempts in this direction in IT and AT, but sometimes strong resistance from professionals (e.g. in EL), who perceive migrant carers as a threat to their own job security.

6.5.8 Gaps in fairness and equity

Choice between services in kind and benefits in cash is not ‘socially neutral’: in countries where people have the choice between cash and in kind services (e.g. DE), entitled persons are more inclined to choose cash, feeling they will be more autonomous with its use. Although this may be true in some countries where users can still buy more hours on the black market, as discussed earlier, this choice comes with a discounted purchasing level compared to what would have been achieved by buying in kind services (DE). However, choices are highly influenced by socio-economic factors, as evidenced by the fact that services in cash are more often chosen by low-income families. It can thus be argued that persons from middle- and upper-class families benefit more from in-kind services as they will be able to compensate for any potential remaining gaps from private assets – a mechanism which perpetuates and increases social care inequalities.

In summary

This section has shown wide country variations in both policies for informal carers and their implementation in terms of support measures. Contents, methods of assessment and issues arising in implementing a comprehensive policy for informal carers within LTC policies have been described, together with the main country approaches and the main gaps, both in policies and between political rhetoric and policy implementation in practice.

7 Examples of good practice addressing links and interfaces in long-term care

The following good practices have been identified with regard to the opportunities they contain for improving informal carer support and integration of informal and formal care at specific levels of the health and LTC systems in different European countries. The evaluation of some of these examples will be undertaken as part of the WP5 validation process in Phase 2 of INTERLINKS.

7.1 Linking health and social care at the systems level

Good practice 1

Legislation to overcome the fragmentation between health and social care provision (SK) (6.3; 7.4)

Specific legislation to overcome the fragmentation of services and promote modern elements of integrated LTC for older people with care needs was introduced by social legislation that came into force as of 1 January 2009. It refers to providing health care to the extent of nursing care directly in facilities of social care (Article 22 of the Act on Social Services), and vice versa, providing social services in health care facilities of the institutional health care (Article 70 of the Act on Social Services), after entering the provider in the register of social services providers (Slovakia – National Report WP5: 5).

Good practice 2

Reducing regional financial inequities in funding LTC services (SE) (4.1.4)

In Sweden, municipalities, county councils and regions are entitled to levy taxes in order to finance their activities. Taxes are levied as a percentage of the inhabitants' income. Municipalities, county councils and regions decide on their own tax rates. The average, overall local tax rate is 30 per cent. Approximately 20 per cent goes to the municipalities and 10 per cent to the county councils and regions. Tax revenues are the largest source of income for Swedish municipalities, county councils and regions. A fundamental part of the Swedish LTC financing system is the so called 'equalisation system' managed by the state. This system ensures geographical fairness of income distribution for LTC provision, by balancing out big differences among Sweden's municipalities, county councils and regions, due to the major regional variations in the average inhabitants' taxable income.

Good practice 3

A special fund for people with LTC needs (IT) (6.3)

This example, even if not directly targeting informal carers, shows how shaping fairness and equity into the financing of the LTC system may ultimately and indirectly benefit all informal carers.

The Fund for people with LTC needs was set up in 2006 as a response to public discussion on how to improve services, which essential service levels should be guaranteed and what specific economic contributions Italian citizens should offer. The Fund was opened with €300 million a year for three years (2007-2009). Under the last budget in 2008 a further amount of €200 million was introduced for 2008 and 2009, but in 2010 there is a risk that the Fund will be cut off, thus causing a huge problem in the sustainability of the social and health system. The Fund is proportionally shared out by the Regions, allowing them to improve initiatives of long-term assistance, outreach services, residential services and to support the network management. Some regions have used the Fund to carry out radical reforms of the system aimed at re-outlining and strengthening all services for older people (e.g. Emilia-Romagna, Lom-

bardia, Liguria). It also aims to ensure the same system of social protection and care for people with LTC needs throughout the country by means of: (a) providing and strengthening one-stop information services, (b) activating programmes of care for people with LTC needs through an individual action plan, which includes social and health care interventions, (c) activating and strengthening social and health care services with home care priority given to those who need LTC. There are no data on indicators or on the evaluation of the outcome of these interventions.

7.2 Empowering informal carers at the organisational level

Good practice 4

From 'should' to 'shall' in municipal LTC obligations to support informal carers (SE) (5.2.1)

In recent years in Sweden several programmes have been initiated by the government and managed by the National Board of Health and Welfare to improve the conditions for those who deliver informal care. Evidence for the shift in recognition of informal care is the recent change in the Social Services Act. Until the summer of 2009 one paragraph of the above-mentioned Act stated that municipalities 'should' offer support to relatives that provide care on a regular basis to their kin who have a chronic need of care. This paragraph has now been changed and states that municipalities 'shall' offer support to relatives that provide care on a regular basis to their kin.¹³ The main purpose of several of these programs have been to highlight the role of being an informal carer and develop direct and/or indirect support to reduce the burden for caregivers and also to develop quality in elderly care. Overall these programs have led to the result that virtually all municipalities have a variety of different forms of respite care and other support forms for informal carers. There is also a fairly wide range of different forms of personal support; support calls contacts and so-called family groups and the incentive funds have also enabled a wide variety of activities, provided by municipalities. Given these developments however almost all the municipalities express the opinion that there is a continuing need of further development (Kommuner- nas anhörigstöd slutrapport, 2009: 7).

These new obligations of municipalities in the LTC field do not disrupt mutual intra-family responsibilities such as married couples having responsibility, according to their own capability, to individually contribute to supply any means needed to meet their own and their family's needs. If informal carers decide to provide hands-on care, this is a free choice, as they are not considered as legally responsible for providing such care.

Good Practice 5

Regulating the conditions for migrant care workers (IT) (5.3.1)

In Italy, an increasing amount of general housekeeping work, and particularly care work in private households, is being carried out by foreign workers coming from outside the European Community (Ukraine, Russia, Moldavia, Bulgaria, Romania). According to the latest Italian official data, mainly due to regularisation in 2002 (Bossi-Fini Law), between 2000 and 2007 foreign private carers have more than doubled, rising from 134,000 to over 464,000. In 2007 more than 77% of migrant care workers were registered with the INPS (Italy's Social Security Insurance). This increasing number of private workers taking care of people in need of care and the fragile status of both involved subjects (the older person and the immigrant) stimulated many Italian authorities, particularly Regions and Local Authorities, to

¹³ <http://www.socialstyrelsen.se/NR/rdonlyres/04ADE553-7163-4ABF-8AF4-B9C7A10E3B37/14422/2009126194.pdf>

take action in support of private assistance in a home environment by matching demand with job supply, training initiatives, economic support, etc. From September 2009, the rising need for private assistance by Italian families led the Government to implement the regularisation of tax and social security contribution for those private carers working without a regular employment contract. Each household can now regularise up to two private assistants. Still, according to the figures of the Ministry of Interior, on 30th September (the deadline for submission of applications for regularisation) there were approximately 296,000 applications, despite predictions of a range from 300,000 to 500,000, thus indicating that many employers preferred to remain in the black market (see Di Santo/Ceruzzi, 2010).

7.3 Training of informal and professional carers

Good Practice 6

Guidance for organization on the content of courses aimed at caregivers and non-professional carers of older people in need of care (ES) (2.4, 5.4)

The Catalanian Department of Social Action and Citizenship has developed guidance for entities and organisations interested in developing courses aimed at informal carers of people with care needs. The guidance is available on the internet (Generalitat de Catalunya, 2010) and provides information addressed to entities and organisations that are willing to conduct training courses for carers according to the Catalanian Act 12/2007 of Social Services, which establishes the Catalanian System of Autonomy and Dependency Care. This guidance offers information about previous actions related to LTC in Catalonia, the objectives of training, legal framework, statistics, definitions, general recommendations, course structure, contents, and how to obtain the accreditation of the courses. Twenty organisations have obtained the accreditation of their training courses for informal carers in Catalonia.

Good practice 7

Project Pecujici (CZ) (2.2, 8.2.3)

The aim of the project Pecujici (www.pecujici.cz) is to train family carers of severely chronically ill older people and to promote their recognition. The information collected in this web-page aims to be helpful and to provide a tool to create self-help groups. It is addressed to carers, regardless of the type of disability of their family member (Holmerová, 2007).

7.4 Links at the interfaces between informal care and long-term care systems at the delivery level

Long-term care is increasingly being recognised as a relatively independent component of social protection in Europe and the essential links and interfaces to the health systems are only just developing. Although the strict division between health and social services concerning legislation and competencies is still strong in many countries, e.g. AT (Grilz-Wolf et al, 2004), it is increasingly recognised that a holistic approach to meeting the complex care needs of older people, especially within domestic/home care settings, requires multi-disciplinary teams to have access to a wide range of health and social care professionals and other supporting services (Vlantonì, 2009). The CARMEN project (Nies and Berman, 2004) advocated the provision of comprehensive patient/client centred care and the integrated care strategy involving integrated care pathways, individual case management and integrated care teams, recognising the value of informal carers and the unique role they play in the care process. Part of the integrated care

strategy involves cooperation and coordination between professionals and volunteers, with informal carers considered as both co-providers of care as well as clients themselves with their own needs and support requirements. The important role of NGOs in linking the two sectors, as well as in the delivery of specific services to older people and informal carers, also needs to be acknowledged and integrated into LTC systems.

The following national examples bring evidence regarding efforts of national, regional and local policy makers and legislators to enhance cooperative approaches to meeting both LTC needs of older people and their families. The fact that several examples are currently only in the process of becoming established in practice, confirms that the integration and coordination of formal and informal delivery of services is still a developing area.

Good practice 8

CLIC - Unique point of entry to the LTC system for older disabled people (FR) (3.2.2)

Local Centres for Gerontological Information and Coordination (CLIC) were created in 2000 as a common point where all professionals involved in the caring process could meet. Their first task was to provide information and guidance to the elderly population and at the same time deliver several types of support for their informal carers (Level 1). They were also conceived to be a place where workers of local public agencies would begin to assess individual's needs and follow the implementation of the care plan by coordinating corresponding services (Level 2) and undertaking some responsibility for the systematic follow-up of each individual situation (Level 3). They are now under the supervision of the general council and some of them are now embedded in a common organisation (MDPH) together with the disabled population under 60 years of age.

Good practice 9

Sendian program. Social Services Guipúzcoa (ES) (5.4)

The Sendian program was created to meet the needs of the families that have chosen to care for their elders, even if they have a severe problem of disability. To this end, the program develops various support resources for these families, by promoting a series of measures that will allow a comprehensive support program, combining technical, economic and material activities, as well as several initiatives performed by volunteers. These activities include family training, psychological support, self-help groups, 'Weekend' residential and day care, Relief services for three-four weeks a year, Technical assistance for improving the architectural restrictions at home, financial help, Volunteers for supporting the family unit and promotion of development of tax exemptions for these families (Diputación Foral de Gipuzkoa, 2010).

Good Practice 11

Single access point to health and social services networks (IT) (5.4.2)

"Punto Insieme" in the Tuscany Region is a reception and counselling service, where people can ask for assistance for their relatives in need of care, with a widespread distribution of nearly 300 reception points, distributed in the 34 'health and social care districts' of the Region (the local government level of the National Health System). The Emilia-Romagna Region has introduced the new position of a case manager (usually a social worker) in order to ensure continuing care, thus providing a single reference point for the cared person and his/her family members. A project for dementia care has enabled every local health agency to provide a counselling centre as a support to services, with tasks including guidance, monitoring, coordination between medical staff and family and between hospital departments and care services. Respite care for the support of families is ensured by every health district keeping a certain number of beds available for temporary hospitalization of people affected by dementia, and also

organizing training courses for family assistants, thus offering a deep knowledge of medical, psychological and behavioural aspects relating to the progression of the disease.

Good practice 12

Long-term care support centres (DE) (3.2.2)

The legislator in Germany attaches great importance to the development of productive cooperation between informal carers and home care services, with the aim of providing optimal care for older people. Their coordinated work should be set in motion and promoted especially by the social services of the hospitals and rehabilitation facilities, as well as by the LTC support centres with their case management advisory services, which are currently in the process of being established. Although as yet there is no formal evaluation of the contribution made by these institutional social services and the LTC support centres towards enhancing cooperation between informal carers and home care services, the following positive results have been noted: “Gaps in the provision of home care do not occur, or if they do, they can be successfully filled when the available potential support from family, neighbours and friends can be combined in the best possible way with the various professional and semi-professional support options available in the environment” (WP5 National Report Germany, 2009: 11).

Good practice 13

Community based development, work, rehabilitation and community based centres (SK) (6.4.6)

According to the new social services legislation in Slovakia there is an effort to encourage setting up mechanisms for community based cooperation between families with a member in need of care, municipalities, social services providers, training institutions, employment services providers and medical service providers. The aim is to support the abilities and skills of older people, to promote their social inclusion and to implement the philosophy of community-based rehabilitation through the recommended community-based centres.

Good practice 14

Care leave for informal carers (DE) (6.4.1)

According to the ‘Care Leave Act’ (FMJ 2008) employees can legally claim their (unpaid) leave or partial leave from work for a limited period of time in order to care for close relatives at home, without giving up their employment or fearing dismissal, which is protected against by the Act. The aim is to enhance the compatibility between employment and care, by providing the opportunity for either (a) a short leave up to ten days or (b) a longer ‘nursing period’ for one to six months (in companies with 16 or more employees).

Good Practice 15

Discharge management (most countries)

A crucial step in the LTC process is the transfer from acute hospital to home care. When a person with LTC needs is discharged from hospital, in most INTERLINKS countries (e.g. AT, SK, EL, FR, ES, CH) informal carers will get relevant information mainly from the hospital doctor, nurse or the hospital social work department. Hospitals usually contact families a few days before an older person’s discharge to provide them with some information about their relative’s health conditions/status (e.g. SK) and in some countries they inform family members about rights and procedures concerning available services or provide recommendations about possible caring solutions (e.g. ES, IT, FR, AT). In the UK or Denmark the assessment of an older person’s needs is a part of the hospital stay with important involvement of informal/family carers in planning of a future care arrangement. However, informal carers’ opinions and perspectives are not always considered as a major component of future care. In Germany, the social service of the hospital assumes a coordinating role in order to plan and prepare the next steps, together with

the person concerned and his or her relatives – who are often the subsequent informal carers. The discharge process is regulated by a specific ‘expert standard’ defining how quality in transition is practiced, including counselling and support structures for relatives.

The responsibility for managing the transfer of care varies: in some countries the hospital staff (doctor, nurse or social worker) is obliged to contact GPs and informal carers (e.g. SI, CH), whereas in other countries this responsibility lies with informal carers (e.g. SK).

Good Practice 16

The role of GPs

In Italy and Germany GPs are considered as case managers or consultants with responsibility for informing and tutoring older people and their families about appropriate social and other services. Some countries indicate that hospital doctors cannot play their role effectively because of lack of time and having too many patients. Another role of GPs can be seen in Spain or Slovakia where GPs’ primary responsibility is to establish a basic health programme and to cooperate with other health specialists (neurologist, gerontologist, psychiatrist) in its implementation.

Good Practice 17

The role of migrant Care Workers

The key role that migrant care workers can play in coordinating the complex activities of care work at home and the roles of the different professionals who are involved with the older person, is highlighted in the Italian Case Study. Migrant care workers often provide the vital link between the informal and formal sectors in the care of the older person (Di Santo/Ceruzzi, 2010).

Good Practice 18

Care planning and case management (ES) (6.4.3)

In Spain, the Dependency Law establishes the personal intervention plan. This means that the provision of services and funding is discussed between the family and a social worker. During this process the individual care needs must be assessed and a plan is set up to cover them. In some regions of Spain the case management system is being implemented. Case management has been identified as an effective care and service integration strategy, as well as an appropriate coordination method for practitioners and care providers delivering LTC to older adults (Rodenas et al, 2008):

- In Andalusia the regional government set up a case management program in 2002, in order to improve care for people with chronic illnesses, the disabled and the elderly. A law at regional level regulates the conditions and the remuneration for patient-oriented case management.
- In the Valencia Autonomous Region the government has used the case management method to achieve health care and social services continuum for older adults with social and health care problems, locating teams at primary health services to act as a gateway to the healthcare and social systems.

Good practice 19

Care and case management (SK)

Care and case management in LTC is a key role, which may be undertaken by nurses (preferably trained in gerontological practice). In Slovenia, home care is provided by community nurses, who also coordinate links with various experts in the health and social care sector intended for insured people in an individual region (MLFSA Slovenia, 2007: 17). Hence, it may be useful for nurses to enhance their psychosocial skills or develop close collaboration with social workers (Hallberg/Kristensson, 2004).

Good Practice 20**A single point of entry to multi-sector services in the municipality of TioHundra (SE) (6.4.7)**

In Sweden, following background dialogues with the citizens in Norrtälje, the joint organization for health, medical services and care was set up in TioHundra (Ten Hundred) – a name that is also the phone number for reaching all medical services in Norrtälje municipality. The short-term aim for citizens was the provision of a single point of entry into the health and care sector, whereas the longer-term aim was to create a long-term sustainable and secure structure for the health, medical services and care sectors in Norrtälje municipality. The new organisation focused on the following issues:

- better possibilities of finding one’s way in the care sector and to receive assistance;
- complete health care planning with the patient prior to discharge from the hospital;
- joint health and medical documentation for the hospital, medical services, and care;
- health and care efforts in the home to create continuity and security;
- all contacts ‘to be received kindly’ in order to assist and facilitate the customer throughout the chain in the health and care sector;
- better medical services and care for the seriously ill among the older population, through improved health care documentation and communication between the caregivers;
- a management development programme.

Results: The municipality implementing the project found it politically exciting, with agreement and political collaboration between the different parties through a common committee and a corporation jointly owned by the Association of Local Authorities and Regions.

Good practice 21**Alzheimer NGO support for informal carers (EL) (6.4.2)**

In Greece the only services to support informal family carers are those run by the Alzheimer organisations that provide extensive programmes of information, advice and counselling, respite and residential care, as well as training for carers. They also organise and run campaigns for greater public information on the disease and acknowledgement of its impact on carers, whilst lobbying for specific issues, e.g. the rights of Alzheimer patients to free drug treatment, which can improve the general and financial situation of carers. They also participate in EU level activities and research projects on the support of family carers.

In summary

These examples indicate that in all countries there are at least some attempts to link the informal and formal care sectors at the different levels of the LTC system, even if an over-arching LTC policy that addresses the specific needs of users, informal carers and service providers is missing.

8 Main findings, conclusions and recommendations

In this concluding section, based on the existing evidence presented in Sections 1 to 7 of the report, we summarise the main issues in the current development of informal care policies, their related support measures and their links with health and LTC systems.

We first describe main issues and factors regarding the way informal carers' policy can be envisaged in the realm of LTC policies (Section 1). At practice level, using our classification of support measures regarding informal carers (Sections 2, 3 and 4), we summarise how these factors have influenced the implementation of both informal and LTC policy and how countries can be broadly differentiated in this regard (Sections 5 and 6). Using examples of good practice (Section 7) we identify main issues in linking the informal and formal care sectors and suggest some research questions, which could help to answer identified dilemmas. Finally we give some 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.

8.1 Main findings and issues

1. There is evidence that in most European countries (with the exception of the Scandinavian countries), informal carers still provide most of the care delivered to older people in need of LTC, including hands-on care (Section 3). Their financial contribution is estimated to range from 50 to 90 % of the overall costs of LTC, thus surpassing the contribution of the formal care system. Also in this regard informal carers are thus to be considered as co-providers of care.

2. The length of time for which informal care is provided and the high risks for health and social status, as well as the ageing of informal carers, means that they should also be considered as service users with their own needs for support as clients of formal care providers. This is reflected in the obligations of the Swedish municipal policy to provide support measures to informal carers (7.2; Good Practice 4).

3. There is also evidence that, in the near future (Section 4), informal carers will not be as available as they are today. This prediction, linked to the fact that LTC financial sustainability is threatened by the growing needs of an ageing population, has led in most countries (again with the exception of Scandinavian countries) to the introduction of direct or indirect cash benefits as an important tool of LTC policies with various rationales:

- As care allowances, i.e. financial benefits paid directly to the informal carer, in recognition of their contribution to care and in order to secure their availability as care providers;
- As an attempt to reduce the higher costs of formal services that are subsidised by public authorities;
- As attendance allowances, i.e. financial benefits paid to the person in need of care to allow for more choice and autonomy in finding flexible care arrangements; in some countries these resources are used to pay for personal assistants – also on the grey or black market – who are most often 'migrant care workers'.

4. 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. The boundaries between informal and formal care are thus increasingly blurred (3.1).

5. The low status and low level of professional recognition of care workers in the field of LTC, although rarely explicitly acknowledged, is linked to a corresponding difficulty in the recognition of informal carers as a new type of worker. This in turn has strong implications for the way governments are acting to guarantee for a qualified LTC workforce, as it is not only informal carers' contributions to caregiving that are likely to be reduced in the future, but recruitment and retention of the formal workforce is already currently problematic, with gloomy future perspectives.

6. Gaps also exist in the way professional and informal carers work together and share responsibility for supervising and implementing the care process, which may result in conflicts between them (6.5.5). The dynamics of the 'triangle of care' consisting of the formal carer, the informal carer and the older person in need of care constitutes the central unit of analysis at the service delivery (micro) level (3.2), leading to the necessity for professional care providers to understand and assume responsibility for managing the care process.

7. There is also strong evidence at the service delivery (micro) level that there may be 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). This raises the issue of whose needs are being addressed when formulating an informal care policy and how to optimally link measures targeting informal carers with an overall LTC policy.

8. Training of both informal and formal care providers is a key issue in improving the status of care work and its recognition through better pay and working conditions (Section 7.3, Good Practices 6 and 7). In addition to their professional training, formal care staff need training in how to assess the needs of and provide support to informal carers. At the same time, also informal carers need training in caring techniques and how to look after their own physical and mental health.

9. There is clear evidence that intensive caring correlates negatively with being active in the labour market (Section 3.2.2), raising the dilemma of finding an appropriate balance between caring and working, while taking into account both informal carers' and older people's needs and choices. The SHARE survey provides substantial indications that providing an adequate level of formal services can promote both caring and working.

10. Finally, there is strong evidence (Section 5) that the division of responsibilities for the care of older persons between the family and the state is a crucial element in the formation of both general LTC policies and specific policies for informal carers. The extent to which responsibilities are shared and linked to practice, the different combinations of types of provision (in cash and in kind), the mix of specific and non-specific measures, as well as the critical issue of conditions for access to all measures and services are essential elements in assessing informal care policies (6.2).

8.2 A classification of LTC policies and measures

The following global synthesis of policies in INTERLINKS countries is based on the framework for assessing supportive measures and policies for informal carers (2.4) and their description (5.4).

8.2.1 In-kind services for older people (non-specific and indirect measures for informal carers)

In countries where formal in-kind services for older people are more developed, the Scandinavian and the Central European sub-groups can be differentiated. Both types of countries are characterised by a strong political obligation, to provide a relatively high level of LTC services, both nationally and locally. *However, it is the degree to which this commitment is more or less aligned with a consistent informal carers' policy that differentiates the two groups.*

In Scandinavian countries each citizen has a right based on citizenship to access services, irrespective of age or health status and the state is responsible for providing them. In contrast, in Central European countries (DE, FR, NL, UK), access for the older person is based on rights attached to employment and needs with different regulations. In this model of universal entitlement, in-kind services for older people are highly available and extensive in range, despite recent difficulties in funding (SE, FI). The main point regarding informal care policy is that this high access to LTC services has limited the need for specific measures directed to informal carers, as family members provide less 'hands-on' care (Section 4). As previously stated (Sections 3 and 6), data show that the frequency of visits by informal carers is higher but the type and intensity of provided care differs with less personal care. In parallel, if family members are willing or forced by circumstances to care, they are generally directly employed by the public agency (SE, FI), including a generous package of in-kind supportive measures and the same social rights as formal carers. It should also be acknowledged that these countries, following the dual bread-winner model, are among those which have achieved the highest levels of female and older workers' labour market participation (Section 4). Even if a large proportion of women is working part time in the public or non-profit sectors organising social support for children, handicapped and older people, these countries are promoting more equal opportunities and show less socio-economic inequality in access to services. Still, these positive outcomes are the result of an intensive public debate and they come at the price of a high taxation rate and relatively high public expenditures for LTC. This is why the 'Scandinavian model' may not be appealing for other countries with different fiscal policies, preferences for more private funding of LTC and more market-oriented solutions. Currently, important budget deficits and thus low margins for financial manoeuvre may impede governments to follow this model, while potential returns on investments (as shown by EL and ES) through a stronger economy with a higher level of employment are delayed (Section 3).

8.2.2 Cash benefits (specific or non-specific indirect measures for informal carers)

The introduction of cash benefits to compensate informal carers indirectly (attendance allowance) or directly (care allowance) for the tasks they are performing could be observed in all European countries, independently of their level of formal services. Most of these financial measures appear to have been put in place under a dual and contradictory logic: Firstly, an instrumental 'charity' approach, based on the moral feeling that carers' burden should be at least partially compensated in order to keep them available as care-providers. Secondly, a market-based approach, which assumes that giving more choices and opportunities to users will automatically have a positive impact on their carers, a position which seems to have a poor level of evidence (see Nies et al, 2010). Our analysis has consistently shown that, in most cases, the accessibility and the financial value of all types of cash benefits have been set at a level which is too low to guarantee a decent standard of living to informal carers, whether in or out of employment (even as retirees). Also the contribution of cash benefits for care to reach the Lisbon targets by increasing labour market participation rates of women and older workers has been minimal. Only in NL, where most women already worked part-time, cash benefits for care, together with other measures, have successfully contributed to keep carers working part-time or to accept part-time instead

of full-time work. In general, the low levels of cash benefits correlate with scarce possibilities to access care leave schemes. Rather than providing a decent opportunity to at least keep one's job, access to care leave is hampered by reduced social rights and very limited time periods granted. As already mentioned, cash benefits for care can only in rare cases, e.g. persons working under precarious work contracts, compensate for lost income on the labour market. As a consequence, providing cash benefits to carers can only be a part of the solution regarding an integrated policy for informal carers.

8.2.3 In-kind services to support informal carers (specific and non-specific, direct and indirect)

Regarding measures classified as *specific and direct*, such as health promotion and protection programs, information, counselling, training, psychological and social and peer support (2.4), even in the wealthiest countries where services are generally more developed, the basket of relevant services to empower carers by enhancing their caring skills and knowledge is not highly developed, albeit more numerous and accessible than in countries where overall service provision is poor.

This general paucity of in-kind services to support carers also holds true for *non-specific direct* services (e.g. respite care) and *indirect* services (e.g. home adaptations). This kind of support mechanisms, however, is not only supply-driven. Often it is lack of information, trust and/or quality perceived that prevent carers and/or their family members in need of care to use specific services, e.g. respite care.

At the micro level of care delivery, professionally mediated support (*specific, indirect*) for informal carers is at stake: support of informal carers by professionals is still underdeveloped, as the latter are usually not trained to improve carers' performance, to cooperate with carers or to respond to informal carers' individual needs. Efforts to actively recognise informal carers' contributions to the care process are still an exception, rather than a routine part of a team approach towards care at home. Such an approach would entail an explicit contractual agreement in which support of informal carers would be defined as a specific responsibility of professionals. This support would include the development of new training and education methods in caring professions focusing on when and how to identify and respond to informal carers' needs (see Kümpers et al, 2010).

In conclusion, in most countries informal carers will continue to play a major role in the provision of 'hands-on' care; however, considering the numerous gaps found in most of the studied countries, the mix of supportive measures is still insufficient to meet older people's and informal carers' basic needs and to allow real choices to be made in how care is provided.

8.3 Relevant research issues and the existing gaps at practice level

As informal carers will continue to provide a major contribution to caring, the main issues to be addressed are caring and working, the role of the family, and the impact of the social environment on the caring relationship, in order to both formulate and implement a realistic and targeted informal care policy with real choices for both the cared-for older persons and their informal carers.

- Firstly, *regarding the question of working and caring* (Section 3) transversal surveys have consistently demonstrated that in all studied countries, regardless of national variations and independently of gender, there exists a negative correlation between the level of employment and the intensity of care provided by informal carers: ‘non intensive helpers’ (caring less than 1 hour/day) are more frequently in the labour market than ‘intensive helpers’ (more than 1 hour/day), the difference being higher for women in Southern Europe. There is also preliminary evidence from countries providing more services that the causal negative effect of caring on employment in countries with a low level of services can be counter-balanced. Even if no general conclusion can yet be given regarding the modification of working status with the number of caring hours, or regarding a possible gender effect, or about differences within each of these two groups (high level/low level of formal services), we are beginning to gain evidence regarding the existence of causal links and their directions, namely that providing a certain level of in-kind services seems to have a positive effect on both the working and health status of informal carers. Still, we need more research using longitudinal panel data surveys with enhanced data volume and quality in order to make firmer conclusions.
- Secondly, *regarding the family’s role in informal care*, it has been elucidated that, with the traditional concept of the nuclear family vanishing, the family should no longer be considered as the only unit of analysis (Section 4). Instead, a new concept of what constitutes the core of family functioning is emerging, based on the predominant roles and interactions between its members, where each one acts as an individual with his/her own identity and preferences for self-determination. A better understanding of how decisions relating to care are taken inside the family and the logic and the determinants that explain its distribution, should be considered as an essential component of comparative research. This research should help not only in designing support packages better tailored to informal carers’ various needs, but also provide professionals with some insights regarding how to improve the coordination of their work with informal carers.
- Thirdly, *the social environment of family carers is also a crucial issue*, as it impacts on the quality of life of individual caregivers and the satisfaction they can gain from caring. In this area, civil society may play an important part in creating better structural conditions for carers, and various attempts are already being made to develop the role of volunteers, either individually or through advocacy groups, not only for direct and practical caring support measures, but also to ensure social integration of the carer in his/her local community (7.4, Good Practice 21). Thus, besides health and financial aspects, social cohesion issues could also play an important part for future policies directed at carers.

8.4 Caveats for designing a sound informal care policy

Policy should focus on the following three issues, which involve innovation in governance, organisation and practice management, rather than additional funding.

Firstly, at a collective level, decision makers should try to enhance public debate regarding LTC policies by giving more voice to informal carers (6.5.4).

The inclusion of advocacy groups as essential participants in the decision making process ensures that their expectations as stakeholders will be heard and dealt with, as experienced in Nordic countries and to a lesser extent in NL, UK, FR and DE. This means giving informal carers a strong political voice with an active role in the LTC policy building process, through the recognition and institutionalisation of advocacy groups and Carers Associations and using available and valid methods, such as the Open Method of Coordination¹⁴, to enable a real debate between all stakeholders. In this way informed decisions can be made, not only about levels of LTC funding and of formal services targeting the frail elderly population, but also regarding the relative importance of measures directed specifically to informal carers.

Secondly, at individual practice level, tools for assessment of the needs and choices of both older people and their informal carers should be promoted.

Most currently used assessment tools do not have a component directed specifically at informal carers as there is still a strong tendency for managers to view informal carers as useful contributors to the care process in order to ‘downsize’ the volume and content of formal services, rather than to set the care plan at an optimal level for both users and carers. Only with a few exceptions (Section 7) are informal carers’ opinions regarding how care should be organised within the care plan taken into account, while their specific needs are assessed jointly with those of the older people. This tailoring of assessment tools using a multidisciplinary approach should become a common goal for all countries.

Thirdly, the future provision of both informal and formal carers is at stake.

It is not only informal carers’ contributions to care giving that are likely to be reduced in the future, as recruitment of the formal workforce is currently problematic and future predictions are pessimistic, unless changes are implemented at professional level. Nordic countries are the only ones that have set the professional requisites and standards for formal caregivers at an appropriate level regarding the profession’s status and working conditions; simultaneously, an ‘equivalent level’ of wages and social rights are granted to informal carers providing ‘hands-on’ care, as well as specific support services. In contrast, in all other countries informal care is not recognised and considered as normal work as it takes place in the private sphere. Since the type of work undertaken by formal carers is largely similar to that delivered by informal carers (3.2), this in turn has led to a lower level of recognition of the profession of caregiving. Even in the wealthier countries, not only is the legal status and extent of social protection of professionals in old-age care set at a lower level than that of the average worker in the labour market, their status and wages are even lower than those for professionals working in child care.¹⁵ Perpetuating

¹⁴ For example through feedback to the sections on health and long-term care in the National Strategy Reports on Social Inclusion. http://www.age-platform.eu/images/stories/EN/pdf_AGE_Assessment_of_the_2008_NSR_FINAL-2.pdf.

¹⁵ Article No 33 “Family and professional life” of the Charter of Fundamental Rights (2000) stipulates a commitment for the reconciliation of family and professional life for people having a child, but not for other (older) family members in need of care.

the inferior working status of formal caregivers will lead to even more difficulties than at present in securing the future professional workforce in the LTC sector. Overall evidence shows, therefore, that enhancing the position of informal carers cannot succeed without enhancing the position of formal carers, through the latter's improved professional status and social and financial recognition.

8.5 Conclusions: Linking the informal and formal care sectors in an integrated model of long-term care

This report has provided a definition of the essential constituents of an informal carers' policy (6.1) within LTC policies, as well as a framework for the classification of all associated support measures (2.4). The framework has been used to describe the implementation of different support measures in the participating countries (5.4) which, together with the major country approaches to policy for informal carers (6.4), illustrates the large gaps in informal carer policies and their associated practical support measures (6.5).

However, the many links between the informal and formal care sectors, described in Section 7, provide evidence of some attempts in most countries to include informal carers within emerging LTC systems. The missing link is an overarching and comprehensive LTC policy, which specifically addresses all issues related to the support of informal carers.

During phase 2 of the project, these issues will influence the construction of the INTERLINKS model to describe, analyse and improve LTC systems, in particular by drawing on the identified good practices as important tools to bridge the gaps between formal and informal care.

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